MEANINGFUL PARTICIPATION AND SENSORY PROCESSING

EDITED BY: Antoine Bailliard, Batya Engel-Yeger, Winnie Dunn and Catana Brown

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MEANINGFUL PARTICIPATION AND SENSORY PROCESSING

Topic Editors:
Antoine Bailliard, Duke University, United States
Batya Engel-Yeger, University of Haifa, Israel
Winnie Dunn, University of Missouri, United States
Catana Brown, Midwestern University, United States

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Editorial: Meaningful participation and sensory processing

Antoine Bailliard[1]*, Winnie Dunn[2], Catana Brown[3] and Batya Engel-Yeger[4]

[1]Department of Orthopaedic Surgery, Duke University, Durham, NC, United States, [2]Department of Occupational Therapy, University of Missouri, Columbia, MO, United States, [3]Department of Occupational Therapy, Midwestern University, Glendale, AZ, United States, [4]Occupational Therapy Department, University of Haifa, Haifa, Israel

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EDITED AND REVIEWED BY
Rufin VanRullen,
Centre National de la Recherche Scientifique (CNRS), France

*CORRESPONDENCE
Antoine Bailliard
antoine.bailliard@duke.edu

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Editorial on the Research Topic
Meaningful participation and sensory processing

Sensory processing has been studied across many scientific disciplines using different epistemologies and ontologies. The diversity in philosophical and scientific approaches has yielded different sensory processing theories with varying assumptions and conceptualizations of what sensory processing is and how it relates to health, cognition, the environment, and doing activities. It has also yielded different interpretations of the wide range of sensory processing patterns that exist among humans and their naturally occurring biological conditions (e.g., autism spectrum disorders, schizophrenia, post-traumatic stress disorder, traumatic brain injury, developmental disorders, etc.). Studies have shown that the fit between a person's sensory capacities and their sensory environment is associated with mental health, physical health, emotional regulation, and a person's capacity to perform tasks and activities. However, many studies have embraced a biomechanical model of sensory processing which reduces sensory processing to a mechanistic transmission of sense data from the environment through sense organs and along the central nervous system to be represented, integrated, and processed by the brain. Studies using a biomechanical model often employ sophisticated neural imaging or occur in heavily controlled labs designed to isolate sensations in a manner that is a contextual, ahistorical and does not reflect the lived sensory experiences of humans.

Although there have been significant advances in research methods across disciplines (e.g., neuroimaging in the medical sciences, non-representational methods in the social sciences), there remains a gap in the literature exploring the relationship of human sensory processing with doing meaningful activities, community integration, and inclusion in society. Research addressing this gap in the literature is necessary to inform interventions, policies, and other initiatives that support the inclusion and quality of life of all individuals regardless of their sensory processing capacities.

The purpose of this Research Topic, *Meaningful participation and sensory processing*, is to expand holistic understandings of the relationship of human sensory processing with participation in meaningful activities, inclusion, and community integration. This of this Research Topic of 14 research articles is an important contribution toward this endeavor and demonstrates the central role of sensory processing to meaningful participation in everyday activities, health, and wellbeing.

Three articles advance knowledge on the relationship of interoception and participation. Interoception, the ability to identify and respond to internal bodily stimuli, is situated as a central factor in the lived experience of everyday activities. Schmitt and Schoen present a new conceptualization of interoception as a complex multidimensional system consisting of a bidirectional interplay between the brain and the body to maintain homeostasis with an everchanging internal and external environment. They argue interoception is a foundation for meaningful participation and highlight the importance of pursuing evidence-based practices to address interoception in practice. Kalingel-Levi et al. contribute to this growing area of sensory research with a qualitative design that explores the experience of pain among autistic adults. Their findings highlight the critical role of awareness and communication in participants' experiences of pain and the profound impact those experiences have on their coping strategies, function, and participation. To enhance research and practice, Dunn et al. developed the Sensory Profile Interoception (SPI) scale to identify patterns of participation in activities that are associated with high and low levels of interoception (i.e., Interoceptive Impact). To demonstrate construct validity, Dunn et al. correlated the SPI with the Adolescent/Adult Sensory Profile, the Perth Alexithymia Scale, the Body Awareness Scale, and the State-Trait Anxiety Inventory. Their scale is an important contribution to developing evidence-based research and practice on interoception and its relationship to participation.

Further evidence of the centrality of sensory processing to everyday participation is provided by Wallisch et al. who explored the extent to which sensory processing affects children's attention to food cues. Their study used eye-tracking and sensory profiles to examine the relationship between oral sensory sensitivity and attentional bias to food among children. Results showed that children with high oral sensory sensitivity oriented more quickly to and spent more time looking at non-food logos than food logos.

Two articles highlighted the centrality of sensory processing to sleep, an essential activity that significantly affects mental and physical health. Hartman et al. found that sensory processing patterns affect the sleep of all children. In their study, children with sensory sensitivities experience more negative sleep behaviors than their counterparts. Lane et al. performed a scoping review to explore the relationship between sleep and sensory processing in autism. They found studies often report a relationship between sleep concerns and sensory reactivity differences; however, conclude that relationship between sleep and sensory processing is multidimensional and requires additional research.

Another Research Topic of articles provided clear examples of the impact of sensory processing on participation in community, school, and family activities. Bagatell et al. analyzed sensory profiles, interviews, and GPS tracking data with autistic adults to explore how their sensory processing patterns affect their community participation. Participants with patterns of sensory sensitivity and sensory avoiding reported spending less time in the community and visited fewer places because places felt overwhelming and fatiguing. Agostine et al. used a postcritical ethnography in two middle school classrooms and found that the students with multiple disabilities had few opportunities for rich sensory experiences and that their days are often filled with periods of waiting passively. Little et al. used a mixed methods analysis to examine how children's sensory response patterns are associated with caregiver strategies. Study findings demonstrate that caregivers employ strategies that are specific to their child's sensory response patterns and not related to diagnosis, mental age, or chronological age. Their study demonstrates the impact of sensory responsivity on caregiver activities throughout the day. Recognizing this important relationship, Ben-Sasson et al. validated a new pediatric Family Accommodation Scale for Sensory Over-Responsivity (FASENS) to measure the daily changes families make to accommodate a child. They found that typical families often accommodate their activities for children; however, families of children with health conditions enact more accommodations as evidence by higher scores on the FASENS. Daly et al. embraced a strength-based approach to understanding sensory processing and participation by using a meta-ethnography to explore the successful occupational experiences of family participation among families with autistic children. The study demonstrated the centrality of sensory experiences to family life and highlighted the importance of living with unpredictability for successful participation in family life.

Sensory processing has an undeniable impact on participation in meaningful activities that affect health and quality of life. May-Benson et al. examined the relationship of childhood sensory processing and related motor performance patterns and later quality of life as an adult. Their study found that sensory discrimination and modulation accounted for one-quarter of the variance in quality of life in adults.

Despite the importance of sensory processing to participation and health, the variability in sensory processing patterns across people is a challenge to research and there is a need to develop innovative methods. Clément et al. demonstrate the importance of using participatory methods to highlight the experiential knowledge of autistic children, youth, and adults to understand participation from their perspective. Their findings demonstrate how the use of innovative methods that allow autistic persons to speak of their bodily-sensing experiences on their own terms can lead to new and authentic ways of understanding participation that should be considered to reconceptualize the International Classification of Functioning (ICF).

Indeed, sensory processing patterns vary significantly among humans. Dean et al. analyzed sensory patterns from the Sensory Profile 2 across a national sample of children to investigate whether variations in sensory processing represent a natural variability or a problematic aspect of disability. Their analyses demonstrated that children in all groups exhibited different rates of certain sensory patterns thereby suggesting sensory differences cannot be associated with problematic behaviors.

Together, this Research Topic represents an important advancement in knowledge drawing a specific connection between sensory processing patterns and participation in meaningful activities. This Research Topic demonstrates that sensory processing patterns differ across groups of individuals and these differences have an impact on their participation in meaningful activities. Together, these articles demonstrate that sensory processing patterns have a central impact on health, quality of life, and participation in meaningful activities. More research is needed to deepen understandings of how sensory health (i.e., whether sensory capacities match sensory environments and the sensory demands of activities) affects participation, inclusion, community integration, and belonging.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Sensory Experiences and Children With Severe Disabilities: Impacts on Learning

Susan Agostine*, Karen Erickson and Charna D'Ardenne

Center for Literacy and Disability Studies, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

The human sensory system is continuously engaged in experiencing and interpreting every interaction with other living beings, objects, and the environment. The purpose of this article is to describe the impact limited opportunities for rich sensory experiences have on students with severe disabilities in two middle school classrooms situated in a public separate school in the southeastern USA. The study employed a postcritical ethnographic approach and grounded theory thematic analysis of fieldnotes gathered over a two-year period. Three major themes supported by the data are presented and discussed in depth. They are: (a) students are afforded limited sensory rich experiences, (b) everyday routines make students passive recipients to school, and (c) instructional approaches result in little interaction with extended periods of waiting. The implications of the findings for improved sensory experiences and possible future directions are described.

Keywords: severe disabilties, grounded theory, post-critical design, sensory experiences, special education

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Edited by:
Catana Brown,
Midwestern University, United States

Reviewed by:
Evelyn Andersson,
Huntington University, United States
Susan M. Bruce,
Boston College, United States

****Correspondence:***
Susan Agostine
sagos@live.unc.edu

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INTRODUCTION

> "*Sensation is the common language by which we share the experience of being human; it provides a common ground for understanding*" (Dunn, 2001, p. 608).

Students with severe disabilities present with a variety of physical, sensory, cognitive, and communication needs that impact the ways they interact with and experience the world (Erickson and Geist, 2016). Though there are differences in the ways individual students with a range of abilities seek or avoid sensation (Dunn, 2001), and there are differences in the ways that various contexts place demands on sensation (Dunn, 2007), little is documented regarding the ways that students with severe disabilities experience and interpret their interactions with other humans, objects, and the environment. This study explored the sensory experiences of a group of students with severe disabilities in two middle school special education classrooms situated in a public separate school in the southeastern United States.

About Children With Severe Disabilities in United States Public Schools

In this manuscript, we discuss *children with severe disabilities*. By this we mean the group of children in United States public schools who receive special education services under the eligibility category of Multiple Disabilities as defined by the Individuals with Disabilities Education Act (2004). The group of children with severe disabilities also includes some children who receive services under the categories of autism, intellectual disability, or some other category (Erickson and Geist, 2016) and have a concurrent severe intellectual disability (American Association of Intellectual and Developmental Disabilities, 2017). In the United States, most children with severe disabilities are educated in special education classrooms or separate schools that exclusively serve children with disabilities (Morningstar et al., 2017; Burnes and Clark, 2021). Although they have diverse cognitive, motor, and sensory profiles (Towles-Reeves et al., 2012; Erickson and Geist, 2016), children with severe disabilities all consistently require: (a) instruction that is extensive, intensive, and individualized, (b) materials that are substantially adapted and modified, and (c) methods of accessing information that are individualized to help them acquire, maintain, generalize, and transfer skills across settings (Dynamic Learning Maps Consortium, 2016; Taub et al., 2017). Children with severe disabilities exhibit a broad range of expressive communication skills. Depending on the source (Towles-Reeves et al., 2012; Erickson and Geist, 2016; Burnes and Clark, 2021), approximately 7–10% percent communicate at a pre-symbolic level (e.g., gestures, vocalizations, facial expressions, and body language for highly contextualized purposes), 18%–31% at an emerging symbolic level (e.g., use of single words, signs, or graphic symbols for a restricted range of purposes), and 61%–69% at a symbolic level (e.g., combining two or more words, signs, or graphic symbols). All of the 25%–41% who communicate at pre-symbolic or emerging levels and 8%–10% who use augmentative and alternative communication to communicate at a symbolic level are said to have complex communication needs (CCN; Erickson and Geist, 2016).

The Challenge of Sensory Experience for Children With Severe Disabilities

There is a profound lack of literature regarding the sensory experiences of children with severe disabilities. A significant portion of the sensory literature addresses children with autism spectrum disorder or children without disabilities (Ayres and Tickle, 1980; Watling and Dietz, 2007; Engel-Yeger and Dunn, 2011; Pfeiffer et al., 2011; Lang et al., 2012; Mills et al., 2016; Roberts et al., 2018). However, the existing literature serves to inform understandings of the challenge of sensory experiences for children with severe disabilities.

Beginning in infancy, severe disabilities can profoundly delay or preclude the achievement of typical developmental milestones. The altering and delaying of this development affect a child's world view and sensory development. According to Pexman (2019), children's physical development is directly linked to how they interact with objects and the ways that conceptual understanding emerges from sensorimotor experience. As gross motor skills improve, infants have more opportunities to manipulate objects in space. Thus, they have new visual and tactile experiences that give them information and feedback about the world. Limited improvements in gross motor skills prevent children with severe disabilities from seeking and manipulating objects in space (Nilsson and Nyberg, 2003). These limitations have cascading effects on visual and tactile experiences and subsequent sensory development (Lima et al., 2013).

One adverse consequence of severe disabilities is limited opportunity to engage physically in play. As described by Parham and Fazio (2008), play facilitates learning and is one of the main occupations of early childhood. They define play as "any spontaneous or organized activity that provides enjoyment, entertainment, amusement or diversion" (p. 448). Play is intrinsically motivated, generally focused on process more than outcome, and integrally related to sensory processing skills among children without disabilities (Roberts et al., 2018). "Through play, children learn sensorimotor rules, rules of objects and of people, and rules of thinking" (Parham and Fazio, 2008, p. 12). Once children understand these initial rules, they build upon them to understand the more complex and interweaving rules of their culture. The importance of play cannot be overstated; however, there is a lack of evidence regarding play and its role in sensory processing and sensorimotor development in children with severe disabilities. What is known is that play has different forms for children with severe disabilities given the limits in their ability to physical interact with objects (Wenger et al., 2021), move their own bodies (Graham et al., 2019), and talk or otherwise interact with others (Clarke and Wilkinson, 2009). This in turn is likely to impact the sensory development that is promoted by typical play.

Whether in play or other interactions, children independently learn how the world works through *sense-making* and, when they have the benefit of interactions with other humans, *participatory sense-making* (Di Paolo and De Jaegher, 2012). As a general concept, sense-making is the creation of meaning through interactions with the world. Individuals use their past experiences to embody current experiences and make meaning. This gives the individual perspective that then shapes how they see the world. Sense-making is a constant and never-ending process that allows people to participate actively in the world. Participatory sense making goes beyond sense-making by emphasizing the ways that two or more people come together to make meaning from the world in a different way than they would do alone. Humans are driven to coordinate with each other in their sense-making in a fluid and dynamic way, and the coordination of two or more physical bodies helps to embody a different perspective on the world. As two or more people work together successfully coordinating their sense-making, they become more in tune with each other "swaying into and out of states that are close to stable, but not quite" (De Jaegher and Di Paolo, 2007, p. 491). Both sense-making and participatory sense-making are important tools in growth and development. When a child has severe disabilities, opportunities for sense-making may be diminished, which leaves them more dependent on participatory sense-making than other children. Thus, the opportunities adults provide for participatory sense-making are uniquely important for children with severe disabilities. While this has been reported anecdotally, no research could be located linking physical development, sensorimotor experience, and conceptual development in children with severe disabilities.

The Role of Sensory Experience in Learning and Development

How people process sensory information and what happens when they have impairments with sensory processing has been a topic of discussion since the early 1960's. Ayres (1973) first coined the term *sensory integration* to describe a theory created to "explain the relationship between deficits in interpreting sensation from the body and the environment and difficulties with academic or motor learning" (Bundy et al., 2002, p. 3). Later, Ayres and Robbins (1979) defined sensory integration as:

> the organization of sensory input for use. The 'use' may be perception of the body or the world, or an adaptive response, or a learning process, or the development of some neural function. Through sensory integration, the many parts of the nervous system work together so that a person can interact with the environment effectively and experience appropriate satisfaction (p. 184).

Since Ayres' early work, many occupational therapists have expanded upon and critiqued the theory of sensory integration (Wilbarger and Wilbarger, 1991; Dunn, 1997; Bundy et al., 2002; Dunn, 2007). The model of sensory processing by Dunn (1997), which depicts a relationship between the nervous system's thresholds and self-regulation strategies, informs the work reported in this manuscript. In this model, Dunn (2007) defined a neurological threshold as the point at which a nerve cell or a system has enough input to activate. Each individual's sensory systems can have different neurological thresholds. For example, an individual might have a high neurological threshold for auditory input (e.g., they can listen to very loud music) but have a very low neurological threshold for tactile input (e.g., light touch is experienced as noxious). Neurological thresholds are related to self-regulation, which is described as the central nervous system's ability to modulate and respond to the sensations received (Dunn, 1997, 2001). Self-regulation strategies are described on a continuum from passive to active. Passive strategies allow the sensory input to happen without trying to change the environment or the individual. Active strategies involve efforts to control the sensory input to support better self-regulation. These self-regulation strategies directly interact with an individual's neurological thresholds to create four basic sensory patterns.

As described by Dunn (2007), these patterns are: sensory seeking, sensation avoiding, sensory sensitivity, and low registration. Sensory seeking indicates a high neurological threshold and active self-regulation strategies, and it often results in children who engage in high levels of activity (e.g., never staying in their seats), have a limited of awareness of space (e.g., crashing into things), and high distractibility, which causes them to lose track of daily tasks. Sensory avoiding indicates a low neurological threshold and active self-regulation strategies. Sensory avoiding often results in children hiding and covering their ears when things get loud, crowded, and overwhelming. Sensory sensitivity indicates a low neurological threshold and passive self-regulation. Children with sensory sensitivity get overwhelmed like children who are sensory avoiding, but they have limited active self-regulation, which keeps them from hiding, covering their ears, or otherwise seeking to limit the sensory input, thereby a frequent response to sensory overload can be irritability, being short tempered, or demanding. The final pattern, low registration, indicates high neurological thresholds and passive self-regulation. Children with low registration often sit quietly, apparently unaffected by sensory input, often missing instructions, and doing nothing about it.

Children with low registration usually need adults to work hard to recruit their attention (e.g., calling their name multiple times or touching them). Children with low registration may seem oblivious to their environment and often appear unresponsive in situations that would typically elicit responses from children. Finally, children with low registration rarely yell or call out and are not thought of as having behavior issues that requires a lot of teacher attention. While Dunn (1997) originally described these patterns using data from children without disabilities, the patterns have since been utilized to understand the sensory processing patterns of at-risk children and children diagnosed with disabilities such as autism, ADHD, and Fragile X syndrome (Dunn, 2007).

Severe disabilities have a ripple effect on the development of sensory processing and the ability to enact active patterns in response to sensory input. Limited gross motor movement restricts opportunity to explore the environment, which leads to limited sensorimotor experience needed to make sense of the objects. This then delays fine motor skill development and restricts play, which further restricts sensory development. These motor impairments further restrict access to the active strategies required by some of the sensory seeking and sensation avoiding patterns by Dunn (2007). Participatory sense making is one means of supporting purposeful sensory experience and patterns of sensory processing, but it is vital to also support children with severe disabilities in independent play and sense making. Interacting with toys in whatever way they independently can and exploring their environment by touch, sound, mouth, or vision should be combined with learning through the process of engaging with others to support their efforts to pursue desired outcomes or complete tasks. These are just as important and meaningful for children with severe disabilities as they are for any child.

To date, there have been few studies that have analyzed interventions that focus on sensory experiences for children with severe disabilities. One study investigated children with a diagnosis of cerebral palsy who were able to walk and use speech to communicate (Jameel et al., 2019). The intervention focused on kinesthetic training that helped to significantly improve the participants' perceptual abilities. Specifically, the invention targeted kinesthetic sensitivity, which is needed to appropriately judge the amount of force needed to lift items, maneuver through the environment, and position one's body to be successful in everyday activities. Jameel and colleagues used body awareness activities with the children and found that after 36, 30-min sessions the children showed significant improvement in their tactile sense, pressure sense, and cognitive ability. Identifying this connection between sensory input and cognition is an important step towards understanding the lasting impacts of sensation, especially for children with severe disabilities.

In addition to impacting cognition, there is reason to believe that at least some sensory experiences provide opportunities to promote mental health. Sheehy and Nind (2005) discussed the limited literature regarding the mental health and emotional well-being of people with profound and multiple disabilities. They assert that the lack of attention to the mental health of people with multiple disabilities overlooks "their very humanness and their right to quality of life" (2005, p. 35). The authors point to the absence of symbolic communication as a primary reason that the sensory experience and mental health needs of people with multiple disabilities is overlooked, as the lack of conventional communication skills leaves them unheard and misunderstood.

Overall, it is evident that more research is needed to understand the impact of sensory experiences on children with severe disabilities. In the current study, sensory experiences emerged as an important theme during grounded theory thematic analysis that was conducted as part of a larger effort to understand thinking and learning among older children and young adolescents with severe disabilities.

MATERIALS AND METHODS

The current study was situated within a three-year postcritical ethnography designed to construct a theory of thinking and learning in students with severe disabilities including complex communication needs (CCN; Erickson et al., 2021). It was approved by the institutional review board at the university where the authors are employed and the school system where the research was conducted. Further, individual adult participants and the parents of the student participants provided written consent. The central question addressed was, *what was the nature and impact of the sensory experiences students with severe disabilities including CCN encountered in their classrooms?*

Postcritical ethnography requires researchers to intentionally reflect on untested assumptions (e.g., that students with severe disabilities must be educated in separate settings) and personal beliefs relative to the study at hand (Noblit et al., 2004). The interdisciplinary team of six researchers who conducted this study had backgrounds in literacy education, special education, early childhood education, augmentative and alternative communication, assistive technology, severe disabilities, occupational therapy, occupational science, and educational policy. The relevant, collective assumptions and beliefs of the research team include views of:

- disability as dis/ability, which challenges the view of disability as a binary concept and recognizes that disability is, in part, socially-constructed (Goodley, 2014);
- education as a path toward a more equitable world; and
- themselves as researchers who are learners-about-students.

Site and Participants

The school where we conducted this study is located in the southeastern United States and is representative of the separate educational placements of nine in 10 students with severe multiple disabilities across the country (Kleinert et al., 2015; Erickson and Geist, 2016). The school serves more than 50 school-aged students with a range of severe disabilities. The students are taught in multi-grade classrooms of six to eight students. Each classroom is led by a special education teacher who has the support of a full-time teaching assistant. Additional teaching assistants and nurses address students' personal care needs across multiple classrooms, and full-time speech-language pathologists, physical therapists, and occupational therapists work with the children and teachers. Other teachers (e.g., art, adapted physical education, media) and specialists (e.g., a teacher of children who are blind and visually impaired and a teacher of children who are deaf and hard of hearing) serve students in this school and others in the school system.

The data in this manuscript focus on two middle-school classes that participated in the larger postcritical ethnography across two school years. We selected these two classrooms because they offered groups of students of similar ages and abilities and teaching staff with similar backgrounds and experience. None of the students reported in this manuscript have known hearing or vision loss, but both are known to be underreported among students with complex needs (e.g., Erickson and Quick, 2016). We have intentionally chosen not to highlight or specifically name the individual teachers and teaching assistants. Instead, we forefront the experiences of the students and the systems that impact those experiences. Our goal is to emphasize the role of these systems rather than individual teachers. Throughout, we use pseudonyms for the students in order to emphasize their personhood rather than their diagnosis or perceived deficits.

Classroom 1

There were four or five consented students in Classroom 1 depending on the year of the study. All of the students had severe disabilities and used a range of idiosyncratic gestures, vocalizations, and behaviors to communicate. All of the students had CCN and were learning to use graphic symbols and voice output communication devices to communicate with others. The student featured in the data excerpts in this study is Jamie, who was 10 years old at the start of the study. Jamie, age 10 at the start of the study, was a Latino, male student who received special education services under the IDEA eligibility category, Multiple Disabilities. He was almost always in a wheelchair that he could maneuver himself, but teachers often pushed his wheelchair in the classrooms and when moving from one location in the school to another. He vocalized, sometimes touched graphic symbols from the 36 words from the Universal Core vocabulary to communicate, and sometimes reached out or used his eye gaze to communicate. Mostly he used facial expressions to express his joy, boredom, and outright disdain. Jamie loved music and would wave his arms, dancing, circling around in his wheelchair, laughing, grinning, and raising his eyebrows in response to music. By the second year of the study, Jamie was encouraged to be out of his wheelchair for periods of time, which allowed him to crawl on all fours to get to places he wanted to go.

Tom, just shy of 11 years old when we began the study, was a White, male student eligible for special education services under the IDEA category, Multiple Disabilities. He used a wheelchair for mobility, but he was unable to maneuver it himself. At the beginning of the study, he was working on establishing joint attention and participation. Over time, he began using graphic symbols on a laminated sheet. Then, he moved on to a communication notebook that offered about 25 or 30 pages filled with graphic symbols organized by category (e.g., activities, people, and places) that he accessed by pointing to a symbol representing one of the categories on the menu page. A partner then turned to the corresponding page and Tom selected. By the second year of the study, he was also using a voice output communication device that gave him access to 30 items that were represented by graphic symbols. These included words from the Universal Core vocabulary (e.g., WANT, LIKE, NOT, GO, MAKE; Erickson et al., 2021), the names of the teachers in his classroom, and a symbol representing COMMUNICATION NOTEBOOK that he used to request access to the book. Throughout the results, words produced by selecting these graphic symbols are written in all capital letters.

Sophie, age 16 at the start of the study, was a White female student who received special education services under the IDEA eligibility category, Intellectual Disability-Severe. She was alternatively in a stander or a chair with a lap belt, where she often rocked back and forth. Sophie almost always had a red switch in front of her that said, “Yes, that’s the one I want!” when pressed. She also commonly wore noise canceling headphones. Sophie could often be seen with her chin pulled toward her chest and with a furrowed brow. She often lifted one hand and used her long fingers to fiddle with her ear or her eye or her mouth. Sophie was always happy when music was playing.

Classroom 2

There were four or five consented students in Classroom 2 at various points in the study. All of the students had severe disabilities and all communicated using a variety of idiosyncratic gestures, vocalizations, and behaviors. All had CCN and access to some form of voice output communication device with graphic symbols to support their communication and occasionally selected one or two words at a time to communicate with others. The two students featured in data excerpts in this study were Cameron and Devan. Cameron, age 11 at the start of the study, was a White male who was eligible for special education in the category, Intellectual Disability-Severe. He had significant seizures, which impacted his attention and often left him fatigued. When he was not fatigued, he was vocal and worked actively to interact with peers in his vicinity. Marcus could walk with the support of an adult, used a therapeutic stroller to travel long distances, and sat in a therapeutic chair with a tray during instruction. Marcus primarily communicated using vocalizations, gestures, and facial expressions. He was learning to use a voice output communication device that displayed 32 words from the Universal Core vocabulary and a variety of cards and printed displays with graphic symbols representing words related to the topic of the lesson.

Devan, aged 10 at the start of the study, was a White, male student eligible for special education services under the IDEA category, Intellectual Disability-Severe. He used a wheelchair for mobility, but he was unable to maneuver the chair himself. He could walk with physical support from an adult and could move around on the floor through a combination of rolling and combat crawling. He had a voice output communication device with 32 graphic symbols representing words from the Universal Core vocabulary. He accessed it by touching the symbols. However, Devan communicated primarily through facial expressions, vocalizations, reaching, and other movements. Devan typically tore, crumpled, and dropped materials within his reach. A social person, he was often smiling broadly, reaching out, or moving toward classmates and others who entered into his immediate environment.

It is important to note that the teachers in this school were highly trained, and the school was well-regarded. The teachers were passionate, enthusiastic, and caring. They came to school each day eager to be with their students. Nonetheless, as detailed in the results, they sometimes failed to engage all of their students, especially when it came to offering rich sensory experiences that met the students’ sensory processing needs.

Data Collection Methods

The primary means of data collection for the study was participant observation. In addition, informal interview-style interactions occurred with teachers and other school staff seeking clarification and input regarding things that were observed and expectations regarding upcoming classroom and school activities. The content of these interactions was recorded in fieldnotes collected during the participant observations and were reflected upon in research memos. We were unable to interview the students because they did not have the symbolic communication skills required to participate in interviews or to otherwise provide first-person accounts of their perceptions or experiences in ways that we could record.

Fieldnotes were collected during classroom visits conducted from January 2018 to March 2020. Individual members of the research team visited the classrooms approximately once every 2 weeks. Members took detailed notes while observing, then clarified and added detail and commentary to the notes promptly after each observation. In addition, each researcher kept a personal researcher journal containing timely reflections that were shared and discussed in a weekly research team meeting. During these meetings, the team engaged reflexively in questioning their own and one another's representation of the data.

Observations and interviews were supplemented with artifacts gathered by members of the research team. These included work samples, instructional materials and products, and photographs of the classrooms. Documents such as student Individual Education Programs and school system policies regarding the use of prescribed curricula and assessments also contributed to the body of data informing this study.

Analysis Methods

Data in this study were analyzed using grounded theory methodology (Charmaz, 2006). This involved coding the data to distill, sort, and compare segments. Throughout this initial coding, memos were written whenever the first author felt it necessary to flesh out data points or thoughts and connections the data brought up. The memos varied in length and were shared with other team members during weekly meetings to get their perspective on emerging ideas and to develop emerging theory.

Once initial coding was done, focused coding began anew as the entire set of fieldnotes were analyzed to identify themes. In this stage, the goal was to start to group the initial coding together into more general themes (Charmaz, 2006). This focused coding then led to thematic coding, resulting in three major themes: (a) students are afforded limited rich sensory experiences, (b) everyday routines make students passive recipients to school, and (c) instructional approaches result in little interaction with extended periods of waiting.

As recommended by Charmaz (2006), all coding and thematic analysis was completed before the literature review in order to minimize the influence of the existing data around this population. As well as delaying the literature review, the first author worked to keep preconceptions that might influence the process in the forefront while tracking the way that they were influencing what was attended to and how it was understood. The authors acknowledge the fact that they approached this work from a western, White, middle or working class, and able-bodied standpoint. The first author is a pediatric occupational therapist, and the second and third authors are educators. All have previous experience working with children with severe disabilities.

RESULTS

Across the two classrooms, the students with severe disabilities who were the focus of the analysis exhibited a low registration sensory processing pattern (Dunn, 1997, 2007). This fact is relevant to each of the themes. What is unknown is whether these students were born with that pattern or if that pattern was a product of their abilities, environment, and experience. Due to their severe disabilities, these students had limited means of participating in or seeking out sensory experiences within the classroom context. Similarly, they had limited ability to evoke strategies to self-regulate and seek more or less sensory input. The restricted and highly controlled sensory experiences within the classroom contexts kept the students from meeting their neurological threshold, which could have helped them achieve the optimal zone for learning. As described in the following section, low registration sensory processing patterns, the instructional practices, and the environment resulted in long periods of waiting, which served to reinforce the low registration sensory processing patterns.

Students Were Afforded Limited Rich Sensory Experiences

Across the classrooms, the students were typically physically spread apart from one another in their wheelchairs or standers with few opportunities for independent exploration or independent work. The teachers moved from one student to the next, interacting briefly and moving on. The only purposeful, regularly occurring sensory experience for the students was music. Music was used to mark transitions, fill transition times, and facilitate lessons. Whenever music was used, there was a clear positive effect on the students. For example, when one teacher turned on the music, the result was:

> Jamie is in his chair… dancing by himself, smiling, looking upward, shaking his hands. He seems to be enjoying the music. He has a sublime smile. The teaching assistant comes back to dance with him again, and he has a look of utter JOY. He is smiling, laughing, and full of life in a way that I have not seen through the last 30+ minutes. He turns around in his chair to look at the teaching assistant who is moving his chair to dance with him.

Across observations, music was the one activity that resulted in this type of positive reaction from the students. Each one was observed to dance with whatever independent movement they had including arm waving, finger wagging, and tapping of their toes. They also had the highest levels of interaction with teachers when dancing to the music, and they were often observed requesting more music in various unconventional ways, such as vocalizations, eye contact and smiles. Unfortunately, the teachers controlled when the music was on or off, rather than the students. This was likely a result of the fact that music was used to fill time between activities or mark the introduction to a lesson.

Music wasn't itself viewed as a teaching tool or important sensory experience. Further, when music appeared to be used as an intentional part of a lesson, the connection was not always clear. For example, in one instance a teacher was teaching a lesson focused on the letter, W. While Whitney Houston's song "I Wanna Dance with Somebody" played in the background, the teacher moved around the room singing, dancing, and holding up a big piece of paper with the letter W written on it and a card with the word WANT and a graphic symbol representing the card. Though the teacher presented the W and word card close to the faces of each student, there was no clear expectation that the students would respond or interact with either the sign or the symbol. Some students reached out to touch them when they were presented, but other than responding to the physical act of touching, no meaning was assigned to the action or the song. Some students seemed to enjoy this lesson, but the goal of the lesson and connection to the music was unclear. The auditory input (i.e., music) along with the gross motor movement (i.e., dancing), appeared to hit the high neurological threshold of sensory input needed to 'wake' these students up and get them into the optimal zone for learning, but it was not clear what they were supposed to be learning beyond looking at or touching the printed W and the symbol representing WANT.

When potential opportunities for other forms of sensory experience were noted, they were typically adult-directed. For example, teacher 2 planned for the students to make Valentine's cards for their family members. The teacher gathered materials (e.g., stickers, glitter, glue) that typically offer students opportunity for sensory exploration with different textures, shapes, and colors while making cards. However, the students did not explore or interact with the materials. Instead, the teachers directed students step by step through making binary choices about materials and their placement on the card. The following exchange offers an example:

> The teacher presents a running string of questions in a rhetorical way, "Do you want glitter glue? Or googly eyes? Do you want colors? Help me put glue on the eyes--oh no, they are sticky back. Should we put a smirk down here? Do you want beads on your card? Do you want to put, 'I'm watching you?' If you don't answer, I will start putting stuff on. I'm putting 'I' and dotting 't's."
>
> Cameron responds with smiles, reaches, and shakes his head 'no'.
>
> The teacher states, "I think you should write, 'I love you and you better believe it'". The teaching assistant states, "Your mom will like that."
>
> Cameron smiles.
>
> The teacher asks, "What about 'You are the sparkle in my heart.'"
>
> Cameron responded, "Eh".
>
> The teacher concludes the lesson by saying," Ok, let's write that and then let it dry. We need to get ready for lunch".

Later the card was put in Cameron's backpack for him to bring it home for his mother. Throughout, Cameron's access to sensory experience was limited in ways that reflected the adult directed interactions and activities that dominated in both classrooms.

Students Were Afforded Limited Gross Motor Activity

Other missed opportunities for sensory experience resulted from limited gross motor movement in the classroom. All but one student in the two classrooms used a wheelchair for mobility, but only one was able to independently maneuver his manual wheelchair and one other had a motorized wheelchair. The remaining students were dependent on others to move them from one location to another when they were in their wheelchairs. Furthermore, the brakes on the manual wheelchairs were often on the back of the chair, presumably to maximize student safety, but eliminating any potential for the students to independently unlock their wheels to allow them to try to move around the classroom. A few students could independently move themselves on the floor by crawling and rolling, but perhaps because they were older children and adolescents, there were few observed opportunities for them to be on the floor. In fact, there was only one recorded instance where a student was noted to independently crawl across the room, with encouragement from the teacher. In this instance, the teacher provided Jamie with extended time and encouraged him to move to his wheelchair after he was taken out of the standing frame. Jamie moved across the room, and pulled himself up and into his wheelchair with minimal assistance. He was then observed wheeling himself back to his spot at the worktable for some free play. The researcher noted that this was the first time in more than a year of observations that Jamie was seen independently moving himself in or out of his wheelchair. As a rule, teachers moved students, transitioning them from one position to another, pushing their wheelchairs to the desired spots, and locking the brakes to when the chairs were in the positions the teachers selected.

Outside of the classroom, more gross motor movement was observed. During one instance, the researcher accompanied students to their adaptive PE class. The clear change in mood observed in the students was repeatedly noted. During the session, each student was given a chance to take a football down to a basket, drop it in, and ring a bell. The students each worked one-on-one with an adult. A researcher worked with Sophie and "she seems to come alive [during PE class] …with only a little encouragement [she] walks the length of the field several times." The researcher noted another student, who had been whining and crying as a means of complaining all morning, joined in on the fun. Although most students needed full support from teachers, they seemed to have no complaints about the effort it took to walk the length of the gymnasium and ring the bell. This gross motor movement seen in their adaptive PE class, as with music activities, appeared to meet the students' high neurological threshold, which then helped them engage and participate more actively.

Students Were Afforded Limited Touch Experiences

Touch was another sense that was rarely observed in the classroom. Touch was observed during care activities such as feeding, wiping a nose, or when a student needed to be changed or moved from one piece of equipment or another. Touch during those times served a specific purpose, rather than promoting connection. Importantly, students were sometimes observed trying to connect during these goal-directed interactions with teachers. Unfortunately, their efforts were not understood or acknowledged. For example, in one instance, a teaching assistant grabbed a tissue and said to

Tom, "Let me wipe your nose." In reply Tom used his communication device to say, "NO." When Tom appeared to note that the teaching assistant still had the tissue and looked ready, he added "GO, FINISHED." The teaching assistant repeated what Tom said but did not appear to make the connection that maybe he was saying he did not want his nose wiped; she then wiped his nose.

Touch is an important means of establishing connections and communicating with others. The students certainly seemed to understand this. At times, students were observed to reach out for other students or the teacher. Sometimes it was clear that the students were pinching or hitting others because they were frustrated, but at other times, they were using touch to connect in a positive way. For example, students reached out to hold hands with each other, and reached to pull themselves closer or gain attention from peers and teachers. Unfortunately, when teachers noticed this touching, they typically interrupted and redirected the students. Often, unlocking the brakes on their chairs and moving them further away. At other times, students were simply told to stop without explanation. This negative response to student sensory seeking patterns was noted to increase student frustration. It also served to reinforce a low registration sensory processing.

Everyday Routines Made Students Passive Recipients to School

Student passivity throughout the school day may have been a reflection of a general state of low registration sensory processing; however, there was recurring evidence that the students may have learned to be passive as a result of their everyday school experience. Students had very little control over what they did at school. The teachers posed questions, but rarely provided students with the time or means of responding to the questions. When they were offered a means of responding, the answer options were either highly restricted (as an array of 2 or 3 items) or they did not match the content of the question. For example,

> The teacher is scurrying around the room but stops long enough to look at Jamie's face. She says, "You are NOT happy, are you?" She holds up Jamie's communication board and points to LIKE NOT WANT GO as she says, "Do you LIKE it or NOT like it?" Jamie reaches with his right hand toward NOT, but she is distracted by one of the other students, puts down the communication board, and walks away before Jamie has a chance to reply. Jamie does not appear to be dejected and does not seem to react in any way to not getting his message delivered.

Teachers also talked to students when the students had no means of responding or initiating a different topic. For example, in one observation, a teacher displayed two cards close to Jamie's face, each presenting a word and graphic symbol. One card had the word and symbol representing GOOD and the other had the word and symbol representing NOT. In the interaction, the teacher said, "They said it was NOT GOOD," as she moved the cards for NOT and GOOD, respectively. Then she added, "They did NOT like it," as she moved NOT and then added, "It was NOT GOOD" as she moved the cards for NOT and GOOD again. Throughout this interaction, the teacher controlled the symbols and was just showing him each card and repeating lines that included the two words. Throughout the interaction, Jamie sat with eyes averted while the teacher talked to him.

When students did look in the expected direction or otherwise actively try to engage with the cards and symbols during these interactions, the teachers often reinforced the act of looking or touching rather than the potential meaning of the communication act. This focus on a behavioral response rather than building a communicative interaction may have systematically taught students to be passive recipients across the school day. Other evidence that teachers were not expecting active communication or participation was found in the words and symbols teachers selected to display during these everyday instructional routines. For example, during one language arts activity, the teacher selected cards with the words and graphic symbols representing WHEN and IT. The teacher held the cards up to match her words when she asked, "WHEN did IT start?" There was a clear question, but no way for the student to utilize the symbol cards to respond given the choice of WHEN and IT. On another occasion, a teacher selected the cards with the words and symbols representing WHAT and WEATHER. As she held up the cards she asked, "WHAT is WEATHER?" Sophie reached for the card representing WHAT. The teacher did not acknowledge her reach or the fact that Sophie said, "Ma ma ma." Instead, the teacher pulled out a single message voice output device programmed to say, "Yes, that's it." She put the device in front of Sophie who quickly responded by touching it. The teacher repeated, "Yes, that's it!" and moved on to the next student. Sophie responded as expected, but the response did not generate any meaning or ongoing interaction that may have helped her shift from a passive to an active role.

There were times when teachers asked yes/no questions or offered choices and worked with students to try to find a means of responding that led to mutual understanding and ongoing interaction. For example, during one observation, the teacher was trying to get Devan to make a choice between two books.

> The teacher holds up one book at a time in front of Devan and says, "Devan, do you want to read the ABC book? Use this arm (touching one of Devan's arms). Use your words. Do you want to *read The Cat in the Hat*?" Devan laughs and reaches out to the book. The teacher responds by continuing to hold up one book at a time saying, "Do you want *One Fish Two Fish Red Fish Blue Fish*?" Devan laughs and reaches out again … "or do you want *Green Eggs and Ham*?" The teacher taps Devan's arm with book, Devan reaches out to touch the

> book. The teacher still does not recognize the reaching behavior and says, "One more time, Devan." Then the teacher holds up the first book again saying, "ABC book?" Devan responds by laughing and putting his head down.

Throughout the day, students demonstrated a low registration sensory processing pattern. When they did respond to their teacher's direct requests or bids for attention, their efforts rarely resulted in ongoing interactions or active participation. Overall, there were few instances when the everyday routines encouraged or supported more active engagement or patterns of sensory processing.

Instructional Approaches Resulted in Little Interaction With Extended Periods of Waiting

The way teachers organized and controlled the classrooms resulted in students spending a great deal of time sitting and waiting throughout the day. They waited to be moved, to be touched, to be interacted with, to be talked to, and to be given something to do or attend to. Often, they waited while their peers had a turn. As one researcher observed, "the other kids have to sit and wait the whole time the teacher is cycling through with the other kids. It would be so easy [for the students] to check out." It appeared that these students did "check out" of the lesson, as the researcher noted, but they were regularly observed looking around the room at the teachers coming and going, chewing on their fingers, reaching out to touch a peer, rocking back and forth and more. The limited structures of interaction observed in the classroom lead the students to find other ways to engage themselves.

During one lesson, Cameron continually looked around the room and fidgeted. It appeared that he was unengaged in the lesson. He communicated his apparent boredom in a few ways, as illustrated by the following excerpt from the fieldnotes. His teacher was reading a book aloud to the class, and Cameron was seated in a therapeutic chair with a lap belt and an empty desk in front of him.

> Cameron looks up and watches as the teacher is reading. He looks to the right toward the teaching assistant, or maybe he is just looking down. He waves his left arm left toward another researcher and bangs on the table three times. Cameron looks left toward me and checks me out, watching me type. He waves his head side to side in a 'no' motion, then rubs his left arm on his tray. He puts his finger in his mouth then looks over at me. He looks up to the left…Cameron continues looking to his left and putting his hand in his mouth.

Many of Cameron's behaviors could be characterized as *stimming*, which is a self-stimulatory behavior that is marked by a repetitive action or movement of the body (Stimming, n.d.). However, the question here is whether he was engaging in "stimming" or was he just trying to fulfill his sensory needs given limited options. This type of behavior could easily be classified as sensory-seeking. Across multiple observations, the students were reported to rock back and forth, bite their fingers, look at the teachers moving around the room and in the hallway, and engage in other behaviors that could collectively be classified as sensory-seeking. In each of these instances, a lesson was going on, however, the lessons offered few opportunities for students to engage, interact, or otherwise meet their neurological thresholds. As a result, the students appeared to find other ways to meet them.

DISCUSSION

Understanding the impact of sensory experiences relative to sensory processing patterns is important. In the case of children with severe disabilities and CCN, sensory experiences and opportunities are especially important given their limited ability to self-regulate and either seek or reduce sensory input in a way that matches their neurological thresholds. As described in the current study, limited sensory experiences might contribute to what *presents* as a low register, passive sensory pattern among many children with severe disabilities and CCN; however, a closer look at what is often classified as stimming behavior may suggest that at least some of these children are seeking higher levels of sensory input to meet their needs.

Severe disabilities can interfere with the development of sensory processing and the ability to enact active patterns in response to sensory input. The student participants in this study had limited mobility, which made it difficult for them to engage actively in sense making. With these students and others with severe disabilities, intentional efforts to support participatory sense making (Di Paolo and De Jaegher, 2012) may offer much-needed sensory experience. Regular observations of the student participants "waking up" when there was music, dancing, and gross motor activity, suggest that the student participants in this study benefited when these efforts were made. Further the students' responses during these interactions supports the assertion that students who otherwise appeared to have high neurological thresholds for sensory input with passive self-regulation patterns may, in fact, have learned to be passive in the face of repeated, limited sensory experience. During these instances of more intensive sensory input, the student participants socially interacted with the teacher and teaching assistant. They vocalized, laughed, and appeared eager to exert effort and participate. The general mood changes that resulted from vestibular input were repeatedly documented in fieldnotes. For example, Jamie's affect, participation, and engagement all improved when dancing in his chair and with the teaching assistant. Although this did not change Jamie's low registration, the gross motor movement, one-on-one attention, and apparent interest in the music aroused Jamie and other students. Increasing the amount of movement and vestibular input children with severe disabilities receive throughout the day may lead to a shift in register in the long term.

Other sensory experiences included touch and vestibular input. The teachers would grab the students' hands, sometimes help them stand up, and sway them back and forth. This was one of the only times that touch was used for purely social interaction. Other than during dancing, touch focused on goal-directed duties required to meet the students' personal care needs. As in the example of the teaching assistant wiping Tom's nose, touch was used to address needs as perceived by the teachers, which eliminated students' bodily autonomy. Tom was a middle school student. It would have been reasonable to provide Tom with a choice regarding who touched him and how, especially since Tom very clearly used a communication device with efficiency and accuracy to express his desire not to be touched. Unfortunately, the teaching assistant either did not understand or respect Tom's communication efforts, as she simply repeated his words rather than responding to them meaningfully. The teaching assistant may have felt it was important to everyone's health and hygiene to wipe Tom's nose, but by not explaining this to him, she was reinforcing Tom's low registration sensory processing pattern.

Despite years of schooling and at least two years during the current study with restricted sensory experience, the student participants persisted in seeking sensory input, connection, and communication. There were numerous occasions when students attempted to interact with one another, when they danced in their locked wheelchairs, and when they quietly engaged in behaviors that could be interpreted as stimming that provided sensory experience. Unfortunately, these efforts were unnoticed, ignored, or interrupted by the teachers in the classrooms. There were many instances of missed opportunities of communication, interaction, lost bids for attention, and teachers physically directing, or controlling students rather than seeking to understand them. It is important that teachers work to understand all of their students' communication efforts while helping them develop the symbolic communication skills that Sheehy and Nind (2005) warn are critical to ensuring the mental health of people with severe disabilities.

Active engagement and interaction are central elements of effective symbolic communication development for children with severe disabilities and CCN (Erickson et al., 2021). Unfortunately, one of the most salient themes that appeared in the field notes was the amount of time the students spent sitting and waiting. Each of us spends time each day waiting—waiting for the toaster to pop, the light to change, or the lecture to get started. But in these classrooms, the student participants spent a disproportionate amount of time waiting. This waiting typically ensued without interruption given the students' apparent low registration processing pattern. Without the students actively seeking input through gross movement or loud vocalizations, there was no impetus for teachers to shorten the periods of waiting. Instead of working to improve student sensory processing and optimize the environment for student learning and engagement, teachers were being reinforced by students' low registration, which then led teachers to reinforce students' passive, low registration patterns.

It is unclear if the students' low registration sensory processing patterns were learned or innate, but the classrooms in this study definitely reinforced this low registration sensory processing pattern over a sensory seeking one. The students could not engage in many sensory seeking behaviors, as they sat in locked wheelchairs far enough away from one another to eliminate opportunities for physical interaction. However, there was evidence that they engaged in self-stimulatory behaviors, stimming, that provided sensory input when the environment did not. This suggests that perhaps they were innately driven to seek sensory input and that the low registration pattern had been learned and reinforced over time. It also points to the need for teachers to provide more opportunities for participatory sense-making.

IMPLICATIONS

Improving outcomes for students with severe disabilities requires that educational teams attend to their sensory needs. Though more research is needed to understand the impacts of sensory and play based learning in students with severe disabilities, the current study provides important initial evidence of the need to inform teachers of the impact of limited sensory input and different sensory processing patterns. Professional development courses could be a way to help teachers understand the senses and the impact of purposeful sensory experiences on learning, motivation, and self-regulation. This could also be accomplished by occupational therapists who provide direct and indirect services to students. These professionals could help teachers understand and apply the model of sensory processing by Dunn (1997). This would allow educational teams to identify patterns of individual students and offer specific strategies to manage sensory experiences to maximize student engagement and participation throughout the school day. Understanding the different types of sensory processing and how to help each type, especially low registration, get to the optimal zone could also significantly improve the experience, engagement and interactions between teachers and the students.

CONCLUSION

The limited rich sensory experiences observed in these two middle school classrooms have a profound impact on all students, but especially students with severe disabilities who may be unable to meet their own sensory input needs due to physical and environmental constraints. Without environments and other people to help them meet their sensory needs, the students are more likely to establish passive sensory processing patterns, which then reinforce increasingly long periods of waiting and more passivity. A low registration sensory processing pattern compounds the impacts of learning environments that offer few sensory experiences, and more research is needed to understand how to increase purposeful sensory experiences and the impact these experiences can have on students with severe disabilities.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, and further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Office of Human Research Ethics at UNC-CH. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

SA, KE, and CD'A contributed to the conception of the analysis for the current manuscript. KE was the PI and CD'A the project director of the larger project. KE and CD'A collected the data, contributed substantially to the methods, and revised all sections of the manuscript. SA analyzed the data with support from KA and CD'A and wrote the first draft of this manuscript. All authors contributed to the article and approved the submitted version.

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Construct Validity of the Sensory Profile Interoception Scale: Measuring Sensory Processing in Everyday Life

Winnie Dunn[1]*, Catana Brown[2], Angela Breitmeyer[3] and Ashley Salwei[3]

[1] Department of Occupational Therapy, College of Health Sciences, University of Missouri, Columbia, MO, United States,
[2] Department of Occupational Therapy, College of Health Sciences, Midwestern University, Glendale, AZ, United States,
[3] Department of Clinical Psychology, College of Health Sciences, Midwestern University, Glendale, AZ, United States

Scholars and providers are coming to realize that one's ability to notice and respond to internal body sensations (i.e., interoception) contributes to an overall sense of wellbeing. Research has demonstrated a relationship between interoceptive awareness and anxiety, for example. Currently, however, tools for evaluating one's interoception lack the conceptual foundation and clarity necessary to identify everyday behaviors that specifically reflect interoceptive awareness. Unlike existing interoceptive measures, the Sensory Profile Interoception (SPI) scale is participation-based and grounded in Dunn's Sensory Processing framework. In this study we investigated concurrent validity by correlating the SPI with the Adolescent/Adult Sensory Profile (A/ASP); we investigated construct validity by correlating the SPI with the Perth Alexithymia Scale (PAS), the Body Awareness Scale (BAS), and the State-Trait Anxiety Inventory (STAI). Using the REDCAP online platform, 74 college-aged participants completed the measures. Using Spearman rank order correlations there were statistically significant relationships between the corresponding sensory pattern subscales on SPI and A/ASP ($r = 0.277$ to $r = 0.582$). The PAS was only weakly related to the registration subscale of the SPI ($r = 0.260$). The BAS had significant relationships with seeking and avoiding on the SPI ($r = 0.496$ and $r = 0.385$). The STAI had significant relationships with sensitivity and registrations of the SPI ($r = 0.266$ and $r = 0.361$ for state; $r = 0.403$ and $r = 0.321$ for trait). Taken together, these findings provide evidence of construct validity of the SPI to identify participation patterns associated with both high and low interoception. With the more precise information the SPI provides, professionals can design tailored interventions to support everyday life goals and researchers can study interoception within authentic activities.

Keywords: interoception, measurement, construct validity, participation, sensory processing, occupational therapy, interoceptive impact

Edited by:
Emily R. Stern,
NYU Grossman School of Medicine,
United States

Reviewed by:
Eleanor R. Palser,
University of California,
San Francisco, United States
Cynthia Y. Y. Lai,
Hong Kong Polytechnic University,
Hong Kong SAR, China

***Correspondence:**
Winnie Dunn
dunnwi@health.missouri.edu

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INTRODUCTION

There are many bodily functions that we take for granted because they operate outside of our momentary awareness unless something is awry. Although neuroscientists have studied the internal body sensations systems (i.e., interoception) many decades ago (Kandel et al., 2013; Ceuhen et al., 2016), applied scientists have only more recently paid attention to the relationship between one's awareness of internal body sensations and various conditions like autism, anxiety, hypochondria, suicide attempts, and anorexia, to name a few (Engel-Yeger et al., 2013; Forrest et al., 2015; Longarzo et al., 2015; Critchley and Garfinkel, 2017; Fiene et al., 2018; Khoury et al., 2018; Abdulhamid et al., 2021).

An understanding of interoception and related conditions provides insight into how both interoceptive awareness and unawareness manifests as symptoms. Many studies have established that alexithymia (the inability to identify and describe one's emotions) is associated with lower levels of interoception, and there is also evidence that atypical interoceptive perception might result in compromised ability to regulate body functions such as breathing (Abdulhamid et al., 2021). Similarly, adults with autism have high rates of interoceptive confusion (74%), and this lack of awareness of bodily states is associated with alexithymia (Fiene et al., 2018). Anxiety is naturally associated with interoception as many of the symptoms include bodily reactions such as shortness of breath and racing heartbeat. One model suggests that people with anxiety have poor predictive ability at interpreting interoceptive input to determine if it signals a true threat (Paulus and Stein, 2010). This poor predictive ability brings about a constant state of uncertainty for the future. A review of interoception and anxiety highlights the role that body awareness plays in learning and the exertion of a behavioral response (Van Diest, 2019). In panic disorder, interoceptive awareness in the form of feelings of breathlessness results in a conditioned response of cardiorespiratory fear and arousal. In yet another example, eating disorders are associated with a mistrust of bodily sensations (Martini et al., 2021).

Existing interoceptive measures use both physiological and self-report approaches. Garfinkel et al. (2015) suggest there are three dimensions of interoception that must be distinguished. First "interoceptive accuracy" refers to one's ability to report about internal body sensations when compared to physiological measures. Secondly, "interoceptive sensibility" includes one's self-perceived ability to notice internally body sensations. Finally, "interoceptive awareness" describes one's metacognitive ability to recognize the synchrony of one's reporting with physiological readings of internal sensations. For example, physiological measures, such as heartbeat tasks, quantify how accurately a person can detect their own heartbeat at rest (Schandry, 1981). Other measures use self-report as a means of capturing an individual's self-perception of acuity or attention to interoception. Some self-report interoception measures focus on physiological observations (e.g., "I have an extra strong heartbeat" I feel when my bowels contract; e.g., Longarzo et al., 2015; Cabrera et al., 2018; Vlemincx et al., 2021). Others link attention to interoception as part of interoceptive sensibility (e.g., "When I'm short of breath, I focus on this"; Bogaerts et al., 2021; "I can return awareness to my body if I am distracted," Mehling et al., 2018). Desmedt et al. (2022) examined current interoception questionnaires to examine whether they were testing a common interoceptive construct. They found that the most frequently used assessments each tested a different aspect of interoceptive sensibility. They call for additional work on both conceptualization of interoception and on clearly articulating these conceptualizations within assessments.

Yet, interoception has an impact on the person that goes beyond physiological responses, awareness of internal sensations, emotions, cognition, and symptoms. The experience of bodily sensations influences participation in daily life. The International Classification of Functioning, Disability and Health (ICF) (World Health Organization [WHO], 2001) includes physiological responses and internal body awareness as "body functions and structures." The ICF also includes "participation" as a key factor in health; the ICF defines participation as "involvement in life situations." For example, if someone is feeling breathless at work, they may choose to step outside for some fresh air. If someone lacks an awareness of the need to empty their bladder, they may experience accidents that could affect the ways they socialize with others. A person who notices the effect of caffeine on their body, may choose to avoid coffee later in the day so that they can get to sleep at a reasonable time. For a comprehensive conceptualization to evolve, researchers must also consider the influence of interoception on everyday life (i.e., "interoceptive impact"). Perhaps this current study extends Garfinkel et al.'s (2015) model to include this fourth dimension.

A greater appreciation for the role of interoception and symptoms has led to the development of interventions targeting interoception. There is evidence suggesting that mindfulness-based interventions can lead to increased noticing of interoception input, resulting in decreased stress and increased wellbeing (Fazia et al., 2021). In another study, women in treatment for substance use disorder experienced improvements in interoceptive awareness, emotion regulation and days abstinent after participating in a mindfulness intervention centered on body-awareness (Price et al., 2019). A systematic review of cognitive-behavior therapy for panic disorder found that the most effective interventions were those that were administered face-to-face and included interoceptive exposure (Pompoli et al., 2018). However, many practitioners are also interested in interventions with outcomes related to activities of daily living, instrumental activities of daily living, work, leisure, and socialization. Targeting participation as an outcome is best when the assessment addresses the link between interoception and participation. For example, a participation-based interoceptive measure may alert the practitioner to potential leisure restrictions because the individual is concerned with getting hurt.

When using an interoception measure for intervention planning with outcomes focused on participation, it is important that the measure link internal awareness to activities people do in their daily lives. For example, if a person fails to notice hunger or thirst (low registration of interoceptive cues) which interferes with concentration, we can collaborate to design reminders throughout the day.

The Adolescent/Adult Sensory Profile (A/ASP; Brown and Dunn, 2002) is widely accepted as an important measure for assessing sensory processing in daily life. The assessment is used for both research and clinical practice (e.g., Pfeiffer et al., 2005; Rieke and Anderson, 2009; Chung and Song, 2016; Howe and Stagg, 2016; Bijlenga et al., 2017). The A/ASP is built on an evidence-based conceptual framework (Dunn, 2014) to characterize four sensory processing preferences:

sensitivity, avoiding, registration, and seeking. When the A/ASP was developed, seven senses were included: seeing, hearing, tasting, smelling, touching, moving (vestibular), and posturing (proprioception). The availability of an interoceptive measure based on Dunn (2014) provides a conceptual structure for intervention planning. Providers can obtain more details about interoceptive awareness from the four sensory processing preferences (seeking, avoiding, sensitivity, registration) to improve participation. Those who seek interoceptive input require interventions which facilitate more interoceptive activity (e.g., increasing the strenuousness of an activity), while those who are sensitive to interoceptive input require individualized plans that limit interoceptive input (e.g., planning controlled episodes of strenuousness).

In pilot studies focused on item development, researchers clarified wording, evaluated consistency with a conceptual framework (Dunn's Sensory Processing Framework) using item to scale correlations, internal consistency tests (Chronbach's alpha) and scale to scale correlations [A/ASP to Sensory Profile Interoception (SPI)], and edited the items based on feedback (Brown and Dunn, 2020). The current version of the SPI will benefit from further psychometric analysis that considers the relationship of the SPI with measures that capture related information already associated with interoception (anxiety, alexithymia, body awareness). If relationships are identified, this would support the construct validity of the SPI. Similarly, construct validity can be examined by determining the relationship between the SPI and Dunn (2014); the A/ASP contains subscales for the sensory patterns in DSPF, i.e., seeking, avoiding, sensitivity, and registration.

The purpose of this study was to evaluate the concurrent (A/ASP) and construct validity (other measures) of the Sensory Profile Interoception (SPI) scale, a participation-focused measure of internal body sensations. We expected that there would be positive correlations between low threshold sensory patterns (Sensitivity and Avoiding) and measures of body awareness and anxiety based on prior literature about interoception (Forrest et al., 2015; Longarzo et al., 2015; Critchley and Garfinkel, 2017; Fiene et al., 2018; Khoury et al., 2018; Abdulhamid et al., 2021). Similar to other researchers, we expected that alexithymia would be related to registration since both of these constructs reflect a failure to detect stimuli (Dunn, 2014; Fiene et al., 2018), and we hypothesized that the SPI sensory patterns would correlate most strongly with the corresponding sensory patterns of the A/ASP (Brown and Dunn, 2002) since we built items for the SPI using the same conceptual framework (DSPF; Dunn, 2014). Additionally, the SPI has the potential to expand the interoceptive framework of Desmedt et al. (2022) to include "interoceptive impact" based on the ICF model (World Health Organization [WHO], 2001) of function, disability and health.

MATERIALS AND METHODS

We conducted a correlational analysis to evaluate the construct validity of the SPI.

Participants

We recruited a convenience sample of students from occupational therapy programs at three universities and a behavioral science program at one of these universities. We sent emails to students inviting them to participate and provided a link to the secured server. We accepted all students who chose to participate because we believed this sample would have an adequate range of scores on the various measures.

Procedures

After obtaining IRB approval from each university and permission from chairs of each department, we sent emails to the students asking them to participate. The email included a description of what they would be doing and a link to a REDCAP survey, which held all the demographic and test items. We told participants that completing the REDCAP questions would serve as their permission to participate. Every participant received a code to track their answers; no personally identifiable information was collected.

Measures

Sensory Profile Interoception

The SPI is a newly developed scale to evaluate how interoception manifests itself in everyday life behaviors, particularly related to self-care (activities of daily living, ADL) (n = 29 items), eating (n = 25 items) and daily routines (instrumental activities of daily living, IADL) (n = 37 items). We designed the SPI for adolescents, young and older adults to align with the Adolescent/Adult Sensory Profile (A/ASP).

In pilot studies focused on item development, researchers clarified wording, evaluated consistency with a conceptual framework (Dunn, 2014), and edited the items based on feedback (Brown and Dunn, 2020). In the first study, we identified items from the literature, wrote items using the A/ASP as a guide to sensory pattern language, and solicited items from colleagues. We held focus groups with colleagues to obtain their feedback about clarity of items. Then we edited items and recruited a convenience sample of adults to take the SPI. We revised items to improve internal consistency. We used findings from this second pilot study to revise the SPI so that its structure reflects DSPF.

There are currently 91 items on the SPI, and respondents indicate the frequency with which they engage in the behaviors described in each item on a 5-point Likert scale (1 = almost never to 5 = almost always). The SPI is divided into four subscales, that mirror and are theoretically consistent with the sensory patterns of the Adolescent/Adult Sensory Profile described below. The sensitivity subscale (n-30 items) indicates a heightened awareness of interoception, the avoiding subscale (n = 25 items) is an assessment of active behaviors to avoid interoceptive sensations, the (low) registration subscale (n = 20 items) reveals a lack of awareness of interoceptive input, and the seeking subscale (n = 16 items) signals active behaviors to increase interoceptive input. These items have been tested in pilot studies (Brown and Dunn, 2020) to: a. clarify wording of items, and b. to evaluate consistency with DSPF using the Adolescent/Adult Sensory Profile. In the prior study we used item to subscale correlations, Chronbach's alpha within subscales to test for consistency and correlations between the SPI and the A/ASP to determine which items were strongest. There was good internal consistency (α = 0.63–0.88) and significant/moderate correlations with sensory patterns on the A/ASP (Seeking $r = 0.311$, $p = 0.032$; Registration $r = 0.378$, $p = 0.009$; Sensitive $r = 0.448$, $p = 0.002$, Avoiding $r = 0.323$, $p = 0.031$), suggesting both convergent and divergent validity of the scale. **Table 1** provides examples of the SPI items.

Adolescent/Adult Sensory Profile

The A/ASP (Brown and Dunn, 2002) is widely accepted within and outside of occupational therapy as an important participation-based measure for assessing sensory processing. The A/ASP uses Dunn's (2014) Sensory Processing Framework to characterize four sensory processing preferences: sensitivity, avoiding, registration, and seeking. In addition, the measure includes items representing seven different sensory modalities: vision, hearing, taste, smell, touch, vestibular (body movement), and proprioception (body position). Respondents record how frequently they engage in the behaviors described on 60 items using a 5-point Likert scale (1 = almost never to 5 = almost always). The A/ASP has good internal consistency (0.66–0.82), and validity has been established in the literature over the past two decades (e.g., Pfeiffer et al., 2005; Rieke and Anderson, 2009; Chung and Song, 2016; Gonthier et al., 2016; Howe and Stagg, 2016; Bijlenga et al., 2017; Mayer, 2017; Gándara-Gafo et al., 2019; Zaree et al., 2021).

Perth Alexithymia Questionnaire

The Perth Alexithymia Questionnaire measures difficulty attending to and assessing one's own feelings. This scale was chosen because many studies find alexithymia is associated with poor interoception (Abdulhamid et al., 2021). The PAQ is a 24-item questionnaire, and respondents mark on a 7-point scale (1 = not at all true of me to 7 = very true of me). The scale is divided into 5 scales: (1) negative and (2) positive difficulty identifying feelings, (3) negative, and (4) positive difficulty describing feelings, and (5) a general external oriented thinking scale. There is support for the measure's concurrent and discriminant validity and internal consistency, i.e., $\alpha \geq 0.80$ for all PAQ subscales (Preece et al., 2018, 2020), and it has an advantage over some other measures in that it assesses both positive and negative emotions (Preece et al., 2020).

State/Trait Anxiety Inventory

The State-Trait Anxiety Inventory for adults is a well-established and widely used assessment of anxiety symptoms (STAI; Spielberger et al., 1983). This scale was chosen because anxiety is considered by many to include a heightened sensitivity to interoception (Mallorquí-Bagué et al., 2016). There are 20 items related to anxiety and 20 items related to general state. Respondents mark on a 7-point scale (1 = strongly disagree, 4 = neither agree nor disagree, 7 = strongly agree). The measure has excellent test-retest reliability (average $r = 0.88$), excellent internal consistency (average $\alpha > 0.89$), and good discriminate validity (Metzger, 1976; Barnes et al., 2002).

Body Awareness Questionnaire

The Body Awareness Questionnaire (Shields et al., 1989) is an assessment of interoception that does not include emotional body processes. Although the scale is not divided into subscales, some of the items are more reflective of awareness of bodily reactions (consistent with sensitivity in the interoception scale), while others address the impact of habit or routine on body functions (consistent with avoiding on the interoception scale). There are 18 items, and respondents rate them on 7-point scale (1 = not at all true of me to 7 = very true of me). There is support for the measure's convergent and discriminant validity (Shields et al., 1989), test-retest reliability ($r = 0.80$), internal consistency (α range of 0.77–0.83; Shields et al., 1989), and concurrent validity (Unal et al., 2020).

Data Analysis

We conducted a set of descriptive analyses to describe our participants. We used correlations to examine the relationships among the SPI and other benchmark measures. Specifically, we completed Spearman Rank Order Correlations between summary scores on the SPI and summary scores on the other measures. We used Spearman Rank Order Correlations because this calculation does not assume linearity.

RESULTS

We describe our results based on our hypotheses. Seventy-four students participated in the study. Eighty-five percent ($n = 63$) were White, 1.5% ($n = 1$) was black or African American, 4% ($n = 3$) were Hispanic or Latinx, 4% ($n = 3$) were Pacific Islanders, and 5.4% ($n = 4$) reported "other"; 90% were female ($n = 67$).

TABLE 1 | Examples of items from the Sensory Profile Interoception scale.

	Eating	Activities of daily living	Instrumental activities of daily living
Seeking	"I eat whatever I want whenever I want."	"I like lots of blankets for sleeping."	"I enjoy activities that make my heartbeat faster (e.g., vigorous physical activity, amusement park rides, scary movies)."
Avoiding	"I stay away from new foods because I do not know how they will make me feel."	"Sleeping is elusive to me."	"I stay away from activities where I think I could get hurt."
Sensitivity	"I am careful about what I eat because only certain foods settle in my stomach."	"I have particular brands of hygiene products that are OK."	"My ears/face get hot during stressful meetings."
Registration	"I realize I need to drink something after it is too late (e.g., feel lightheaded, extremely thirsty)."	"I find a razor cut later in the day."	"I get bruises or other injuries and I do not remember how the injury happened."

They ranged in age from 21 to 45 years, with a mean of 26 years old and a standard deviation of 4.6 years. Eleven participants were 30 years of age or older. **Table 2** provides the means and standard deviations for the other measures in the study. There were no differences between age groups (21–23 years, *n* = 22, 24–29 years, *n* = 41, 30 years and older, *n* = 11) on the measures in the study based on an Analysis of Variance by age (Hotelling's Trace = 0.752, *F* = 1.128, significance = 0.338). We did not collect any additional information about the participant demographics.

Table 3 provides the correlations between the subscales of the A/ASP and the SPI. **Supplementary Appendix 1** contains scatterplots of significant correlations. The constructs of Dunn's Sensory Processing Framework (DSPF) were correlated across the A/ASP and the SPI. All of the SPI subscales correlated most strongly with their corresponding A/ASP subscale except for the avoiding subscale, with its highest correlation with the A/ASP sensitivity subscale (*r* = 0.366), but only a slightly lower correlation with the A/ASP avoiding subscale (*r* = 0.338). These findings support the SPI's concurrent validity in terms of the measure's consistency with its theoretical basis (the DSPF) (see **Table 1** for examples), and a participation-based sensory processing measure. As outlined in **Table 3**, seeking is only correlated with the corresponding subscale between the 2 scales (seeking = 0.523). Registration and sensitivity have their highest correlations with their corresponding subscales (registration = 0.552; sensitivity = 0.582), although these scales also have significant correlations with other subscales.

TABLE 2 | Means and standard deviations of the measures in the study.

	Mean	SD
State	38.70	11.39
Trait	43.38	10.06
Iavoid	66.89	8.41
Isens	83.20	13.27
Ireg	37.77	8.94
Iseek	40.56	8.61
ALEX	70.90	33.30
BAQ	80.90	15.32

State, State Anxiety Scale; Trait, Trait Anxiety Scale; Iavoid, Avoiding subscale of the SPI; Isens, Sensitivity subscale of the SPI; Ireg, Registration subscale of the SPI; Iseek, Seeking subscale of the SPI; ALEX, Alexithymia Scale total; BAQ, Body Awareness Questionnaire total.

TABLE 3 | Correlations between A/ASP and SPI subscales (*n*-74).

	SPI registration	SPI seeking	SPI sensitivity	SPI avoiding
A/ASP registration	0.552**	0.113	0.447**	0.009
A/ASP seeking	0.392**	0.523**	0.339**	0.187
A/ASP sensitivity	0.423**	0.093	0.582**	0.366**
A/ASP avoiding	0.277*	0.091	0.373**	0.338**

**p < 0.05, **p < 0.01 two tailed.*
*Significant correlations are plotted in **Supplementary Appendix 1**.*
A/ASP, Adolescent/Adult Sensory Profile; SPI, Sensory Profile Interoception.

Consistent with our hypotheses, we found that alexithymia had a small but significant correlation with the registration score on the SPI. Body awareness had moderate correlations with avoiding and seeking and a small but significant correlation with the sensitivity scores on the SPI. The State/Trait Anxiety measure had moderate correlations with sensitivity and registration on the SPI. **Table 4** provides the correlations. **Supplementary Appendix 1** provides scatterplots of significant correlations.

DISCUSSION

In this study, we examined the validity of the newly developed SPI in two ways. First, we examined the relationship between the SPI and the A/ASP to determine whether the SPI has a strong conceptual foundation, specifically Dunn's Sensory Processing Framework (DSPF), with an established participation-based measure of sensory processing (i.e., the A/ASP) (concurrent validity). Secondly, we examined the relationship between the SPI and related mental health measures to determine whether the SPI reflects known relationships between interoception and psychological factors (construct validity). We provide examples of the SPI items in **Table 1**.

Knowing more precisely how interoceptive awareness will affect every day routines provides knowledge for effective intervention planning at the participation level. The State Anxiety scale includes "I feel tense" and "I feel upset"; the Trait Anxiety scale includes "I feel nervous and restless." The SPI provides more detail about how "tense," "nervous," and "upset" might affect one's daily routine, such as "I worry about stomach/digestive processes" and "I select hobbies that are orderly and predictable so I can stay calm" which indicate possible focus for intervention planning (e.g., in these examples, eating, or hobbies). Additionally, by also reflecting the four sensory patterns from DSPF, more precision is possible. For example, "I stay away from activities where I think I could get hurt" (avoiding), "I get bruises or other injuries, and I do not remember how the injury happened" (registration), "I enjoy activities that make my heart beat faster (e.g., vigorous physical activity, amusement park rides, scary movies)" (seeking), and "I try to control my heartbeat when it becomes too fast (e.g., by slowing

TABLE 4 | Correlations between alexithymia, body awareness, and anxiety to the Sensory Profile Interoception scale (*n* = 74).

	SPI Avoiding	SPI Sensitivity	SPI registration	SPI seeking
Perth alexithymia scale	−0.047	0.138	0.260*	−0.000
Body awareness questionnaire	0.385**	0.256*	0.002	0.496**
State anxiety	0.143	0.266*	0.361**	−0.016
Trait anxiety	0.142	0.403**	0.321**	−0.035

**p < 0.05, **p < 0.01 two tailed.*
SPI, Sensory Profile Interoception; PAS, Perth Alexithymia Scale; BAS, Body Awareness Scale; State and Trait are parts of the State/Trait Anxiety Scale.
*Significant correlations are plotted in **Supplementary Appendix 1**.*

down, meditating)" (sensitivity) suggest different approaches to supporting participation.

Concurrent Validity With the Conceptual Foundation and Participation-Focused Framework of the Sensory Profile Interoception

The SPI seems to reflect DSPF. All corresponding sensory pattern subscales (i.e., seeking, avoiding, sensitivity, registration) had significant correlations between the SPI and the A/ASP, and, in all cases but avoiding, these subscales correlated most strongly with their corresponding subscale (for example, the A/ASP seeking subscale and the SPI seeking subscale). As an illustration, "I find a razor cut later in the day" from the SPI is significantly correlated with several low registration items on the A/ASP: "I trip or bump into things," "I am unsure of footing when walking on stairs," and "I miss the street, building or room signs when trying to go somewhere new," while being unrelated to A/ASP items reflecting other sensory patterns. Additionally, the correlations were moderate, suggesting the SPI is assessing some additional information not covered by the A/ASP. The SPI seems to reflect the strong conceptual base of DSPF seen across many studies of the Child and Adult Sensory Profiles (e.g., Little et al., 2018; Nesayan et al., 2018; Tomchek et al., 2018; Zaree et al., 2021). This foundation gives providers and researchers a clear structure for discussing findings about interoception and linking to other systems that might be relevant to a specific research question or intervention planning.

The seeking subscales only correlated with each other, suggesting that seeking has some distinct characteristics that are present on both the SPI and the A/ASP. As reported in prior literature, the low threshold sensory patterns (avoiding and sensitivity) correlate with their corresponding pattern (i.e., avoiding with avoiding, sensitivity with sensitivity), and with each other. This trend is also consistent with prior literature, which suggests there is a continuum of high responsiveness to sensory input (low sensory thresholds). Finally, registration, which reveals missing cues in the environment, is most highly correlated with its counterpart as well.

Construct Validity of Sensory Profile Interoception as Related to Psychological Factors

We examined construct validity with psychological factors by correlating the SPI with alexithymia, body awareness and anxiety measures. The SPI differs from other interoception measures because the quadrants allow for consideration of level of awareness of interoception (sensitivity and registration) as well as active efforts to regulate interoceptive input (avoiding and seeking quadrants).

As anticipated, the Perth Alexithymia Scale was correlated with the registration score on the SPI, which was the only significant correlation. Alexithymia is an inability to detect and describe one's emotions; registration scores (as it is tested on the SPI and the A/ASP) indicate the amount that a person misses cues in the environment. This finding is consistent with other studies indicating a relationship between poor interoception and alexithymia (e.g., Abdulhamid et al., 2021).

The Body Awareness Questionnaire related to all the subscales except registration. As expected, the Body Awareness Questionnaire was associated with the SPI sensitivity scale, which assesses interoceptive awareness. However, the highest correlations were with the seeking and avoiding scales. Both seeking and avoiding are measuring active self-regulation patterns; perhaps active self-regulation patterns contribute to knowing about one's body. Since registration on the SPI evaluates how frequently people miss cues in their everyday lives, it is not surprising that with our sample from a general population, registration on the SPI would not be correlated to body awareness as tested on the BAQ.

State and trait anxiety were related to sensitivity and registration. Patterns of both noticing and missing input is consistent with other studies examining anxiety and sensory processing. In the second edition of the Toddler Sensory Profile (Dunn, 2014) and in other studies with adults (Engel-Yeger and Dunn, 2011; Engel-Yeger et al., 2016, 2018; Brown et al., 2020), there is a small but significant relationship between registration and conditions such as anxiety, hypochondria, anorexia, and pain catastrophizing (Forrest et al., 2015; Longarzo et al., 2015; Critchley and Garfinkel, 2017; Fiene et al., 2018; Khoury et al., 2018; Abdulhamid et al., 2021). We believe that people with registration tendencies do miss cues as we originally believed. However, at some point, bystanders (people with low registration) do notice a possible catastrophe, but it is so late in the situation that a big response is necessary (Little et al., 2016). This big response looks remarkably like a sensor's responses; it is the timing that is different. In addition, Clark et al. (2018) found high sensitivity and registration from the A/ASP and high trait anxiety in people with chronic low back pain. However, they also found high sensation avoiding. They hypothesize that premorbid trait anxiety and sensory processing patterns contribute to pain experiences.

It is unclear as to why avoiding on the SPI was not correlated with trait or state anxiety, but it may be that this relationship is more detectable in a clinical population. Alternatively, the regulation through avoiding may be different for interoceptive input. People with avoiding tendencies are more likely to anticipate difficult situations and stop them, for instance not attending a party or turning down an invitation to a public event. However, with the SPI, avoiding is characterized as an active behavioral response that can be adaptive in terms of managing unpleasant sensations. Anxiety is associated with passive coping strategies, which can include a general lack of engagement in life (LeDoux and Gorman, 2001). People with sensitivity try to participate and then find themselves overwhelmed, which is consistent with anxiety laden behaviors and thoughts (Dunn et al., 2016a,b).

Limitations of This Study

We recruited a convenience sample of students for this study, which introduces sampling bias. It is possible that students in occupational therapy and behavioral sciences would be more aware of interoception and behavior, although participants had not completed their professional education at the time of participation. We also had a majority of white female participants, which could also bias our outcomes. Future studies must expand the demographics to learn how these data fit into the bigger picture.

CONCLUSION

The concurrent validity of the four-quadrant model of the SPI was supported by the correlation of the SPI with the Adolescent/Adult Sensory Profile. The low to moderate correlations with the psychological factors (construct validity) already related to interoception suggest that the SPI reflects related concepts while being a distinct assessment of interoception. As the first participation-based interoception assessment, the SPI may be particularly useful for clinical use when intervention goals focus on participation-oriented outcomes.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because the measure described by the authors is under development and we would want to approve of any use of the data before offering it to others. Requests to access the datasets should be directed to cbrown2@midwestern.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Midwestern University Institutional Review Board. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

WD and CB contributed to the conceptualization and design of the study, data analysis, and writing and editing of the manuscript. AB contributed by assisting with the selection of relevant assessment and editing of the manuscript. AS contributed by assisting with data collection and editing of the manuscript. All authors contributed to the article and approved the submitted version.

SUPPLEMENTARY MATERIAL

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Conflict of Interest: WD and CB were authors of the Adolescent/Adult Sensory Profile, a measure that was used in this study. We receive royalties for the assessment.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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ORIGINAL RESEARCH
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Family Accommodation Scale for Sensory Over-Responsivity: A Measure Development Study

Ayelet Ben-Sasson[1], Tamar Yonit Podoly[2,3] and Eli Lebowitz[4]*

[1] Department of Occupational Therapy, Faculty of Social Welfare and Health Sciences, University of Haifa, Haifa, Israel,
[2] Association for Children at Risk, Kfar Saba, Israel, [3] Department of Psychology, Bar-Ilan University, Ramat Gan, Israel,
[4] Child Study Center, Yale University School of Medicine, New Haven, CT, United States

Family accommodation refers to the attempt of family members (most often parents) to prevent their child's distress related to psychopathology. Family accommodation can limit meaningful participation in personal and social routines and activities. Accommodation has been studied extensively in the context of childhood anxiety and has been linked to greater impairment, and poor intervention outcomes. Like anxiety, sensory over-responsivity (SOR) symptoms are associated with heightened distress and thus, may also be accommodated by family members. The current study describes the validation of a new pediatric family accommodation scale for SOR. Parents of 301 children ages 3–13 years completed an online survey, of which 48 had medical or developmental conditions. The survey included the Child Sensory Profile 2 and the newly developed family accommodation scale for sensory over-responsivity (FASENS). Three Sensory Profile 2 scores were analyzed: SOR, sensory under-responsivity and sensory seeking. The FASENS consists of 18 items; 12 describing the frequency of accommodation behaviors and 6 describing the impact of the accommodation on the wellbeing of the family and the child. Results indicated that the FASENS has high internal consistency ($\alpha = 0.94$) as well as a significant 3-factor confirmatory model fit: (1) accommodations (i.e., avoidance and changes), (2) family impact, and (3) child impact. FASENS scores significantly correlated with SOR symptoms ($r = 0.52$–0.60, $p < 0.001$). However, they also correlated with under-responsivity and seeking ($r = 0.33$–0.42, $p < 0.001$). Parents of children with health conditions reported significantly higher FASENS scores ($p < 0.002$), which corresponded with their child's significantly higher sensory scores ($p < 0.001$). Family accommodations for SOR occur to some extent in the general population, but their prevalence and impact are significantly greater when the child has a health condition, in addition to SOR. Additional research is needed to explore whether these accommodations are adaptive and whether families and children would benefit from learning to reduce them, as with anxiety.

Keywords: sensory over-responsivity, family accommodations, children, measure development, sensory modulation

Edited by:
Catana Brown,
Midwestern University, United States

Reviewed by:
Beth Pfeiffer,
Temple University, United States
Sean Roush,
Pacific University, United States

****Correspondence:***
Ayelet Ben-Sasson
asasson@univ.haifa.ac.il

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INTRODUCTION

The development of sensory modulation, the ability to execute an adapted behavior in response to the sensory environment, is a complex process which relates to several factors. These include developmental age, temperament, innate regulation ability, and the degree of previous exposure to stimuli (Williamson and Anzalone, 2001). Typically developing children differ in their level of sensory over-responsivity (SOR) and in the degree to which it interferes with their participation in daily activities (Bar-Shalita et al., 2008; Ben-Sasson et al., 2010). Despite the weight of personal characteristics in the ability to regulate and adapt to the sensory environment, the importance of the family environment and reactions should not be underestimated. Families define opportunities for sensory exposure, as well as affective modeling of coping in stressful situations. Families vary in the way they respond to their child's sensory sensitivities. The current study aimed to develop a tool for quantifying how families accommodate to their child's sensory sensitivities, and the distress caused to the child and/or family because of these interactions.

Family accommodation describes attempts of family members to reduce their child's distress by avoiding the source of fear, taking part in rituals, reassuring, and changing their routines and activities. It is important to identify family accommodations as while they may provide immediate relief, they predict greater symptom severity (i.e., higher anxiety levels, more rituals, and compulsions), lower levels of functioning (more avoidant behaviors), and poor intervention outcomes (Storch et al., 2007; Peris et al., 2008; Lebowitz et al., 2012, 2013; Strauss et al., 2015; Feldman et al., 2019; Shimshoni et al., 2019). Family accommodations have primarily been studied among children with OCD and anxiety disorders (Storch et al., 2007; Lebowitz et al., 2013) and to some degree in ASD (Feldman et al., 2019). Research shows that although the types of accommodations among different fear-based disorders may differ, the frequency of accommodations remains the same. These conditions share repetitive, catastrophic thoughts, experiences of fear, avoidance, and seeking a secure state (Reuman and Abramowitz, 2018). Since SOR is associated with heightened anxiety (Ben-Sasson et al., 2009; Conelea et al., 2014), we hypothesized that family members would accommodate some sensory symptoms, even when it comes to families with typically developing children.

Although family accommodations reflect the parents' intention to reduce their child's distress, paradoxically these strategies tend to reinforce the child's distress and avoidance and inhibit the child's ability to self-regulate (Norman et al., 2015). Many parents report distress when performing accommodations, while when they do not accommodate their child's anger, distress and worry increases (Reuman and Abramowitz, 2018). Some children cannot complete certain tasks without accommodations, which pressures parents to construct them (Lebowitz et al., 2014). Therefore, understanding the types of family accommodations and their effects on the child and parents is important for understanding the delicate child-family dynamics surrounding a disorder and for facilitating healthier child-family interactions.

Sensory modulation reflects the individual's ability to respond adaptively to interoceptive and exteroceptive stimuli. This ability reflects continuous information processing of the intensity, duration and frequency of stimulation enabling attention to relevant stimuli while filtering out background stimuli (Brown et al., 2018). Sensory modulation also involves maintaining an arousal level adjusted to the environment and activity (Hong, 2015). Sensory modulation disorder (SMD) is diagnosed when a difficulty in the process of sensory modulation impairs daily functioning. According to Miller et al. (2007), there are three types of SMD: SOR which is an intense and over-sensitive response to mundane stimulation; Sensory Under-responsivity, a lack of responsiveness and inattention to every day sensory stimulation; or Sensory Seeking, a constant sensory search and craving. Sensory modulation traits follow the same classification. The current study focuses on the design of a tool for quantifying the family's response to the child's SOR symptoms by studying its distribution in a non-clinical sample.

Children with elevated SOR experience many everyday stimuli at home and in the community as bothersome, unbearable, and overwhelming. This is manifested in behavioral avoidance, elevated distress, anxiety, and/or active resistance of the sensory exposure. Consequently, those with SOR find it difficult to participate in some activities and feel anxious before and during the encounter with stimuli (Parham and Mailloux, 2005). Evidence shows that a child's SOR is associated with limited participation in leisure activities and requires changes and restrictions in family activities and routines (DeGrace, 2004; Bar-Shalita et al., 2008; Epstein et al., 2008; Bagby et al., 2012). Studies dealing with the implications of SOR on quality of life and family well-being demonstrate the challenges and stress associated with having a child with SOR. Parents of these children report increased restrictions in their personal and social activities (Carter et al., 2011), they experience more burden and challenges, especially when the mothers have sensory difficulties of their own (Turner et al., 2012; Gafni-Lachter et al., 2021).

The increased irritability and distress associated with SOR can lead some parents to try to minimize their child's distress. To meet the child's sensory needs, parents build strategies and routines which enable participation in activities within the home (Spagnola and Fiese, 2007). These efforts include changing schedules and finding resources to meet their child's needs, which can disrupt family cohesion (Spagnola and Fiese, 2007). Parents of children with ASD, described the difficulty that arises from trying to balance responding to the child's sensory difficulties, while maintaining flexibility in daily routines (Schaaf et al., 2011). The family's restrictions, adjustments, and adaptations around the child's SOR, help reduce the child's exposure to the bothersome sensations and avoid outbursts. Changes in family life due to SOR have not been evaluated from a family accommodation perspective and it is not known whether family accommodations maintain or exacerbate sensory avoidance. Developing a tool to characterize family accommodations for SOR is a first step in enabling such an assessment.

Existing family accommodation scales originated from tools developed for adults with OCD (Calvocoressi et al., 1999). Later, scales were developed for children with OCD (Peris et al., 2008), anxiety disorders (Lebowitz et al., 2013; Benito et al., 2015) and ASD (Feldman et al., 2019). These scales share the assessment of (1) the frequency of accommodations (e.g., enabling child's avoidance of feared situation). And (2) severity of consequences of not providing the accommodations for child and family wellbeing (e.g., level of distress when accommodation is not delivered). Therefore, the sensory family accommodation tool designed quantified these two aspects.

To summarize, the literature reviewed indicates that having SOR is a cause of child anxiety and avoidance as well as family distress; thus, we predict that it is likely to evoke accommodations. Identifying the specific accommodations associated with sensory symptoms can reveal precipitating, perpetuating, and protective environmental factors. The current research sought to establish the reliability and validity of a new tool, the Family Accommodations Scale for Sensory Over-Responsivity (FASENS), by investigating the:

1. internal reliability and structure validity of the tool,
2. frequency and impact of sensory-related family accommodations in the general population,
3. discrimination of the FASENS scores between children with and without health conditions associated with elevated SOR,
4. convergent validity of the FASENS scores with the child's sensory profile scores.

MATERIALS AND METHODS

Procedure

The study was approved by the Ethics Committee of University of Haifa. Parents were recruited through social media and other social networks by the research team and by undergraduate students in a research course at University of Haifa. Using a link, parents entered a Qualtrics survey in which they signed consent to participate in the study and completed the questionnaires for up to 30 min. If a family had more than one qualifying child, parents were asked to report on one child only.

Participants

Included were children ages of 3–13 years living in a two-parent household, to avoid a potential effect of single parenting on family interactions (Chapple, 2009). Parents were proficient in Hebrew. A total of 301 parents completed the survey intended for the general population. Children were an average of 8.2 years old (SD = 2.7) and 161 (53.5%) were males. See **Table 1** for background information. Of the 301 parents, 48 (15.95%) reported a significant medical or developmental condition. This subgroup will be referred to from here on as the "Conditions" group. Excluded from this group were children with corrected issues such as vision, chronic ear infections, or who attended a few sessions of therapy in the past.

TABLE 1 | Background characteristics.

Variable	Result
Position in family N (%)[ab]	
Only child	16 (5.40%)
First of several[b]	118 (40.0%)
Middle[b]	75 (25.40%)
Last[b]	86 (29.20%)
Mother's age, M (SD)	38.28 (5.67)
Father's age, M (SD)	41.14 (5.82)
Mother's years of education, M (SD)	16.21 (3.70)
Father's years of education, M (SD)	15.40 (3.96)
Mother full time employment, N (%)[a]	173 (57.50%)
Father full time employment, N (%)[a]	248 (82.40%)
Developmental and medical issues N (%)*	48 (15.95%)
ADHD	15
Allergies (e.g., skin, food)	8
Growth (e.g., FTT, Obesity)	5
Developmental coordination disorder	2
Sensory modulation problems	6
Mental health difficulties	6
Developmental delays (e.g., general, language)	7
Chronic medical condition (e.g., epilepsy, heart condition)	6
Pervasive developmental condition (e.g., ASD)	2

Note: ADHD, attention deficit hyperactivity disorder; FTT, failure to thrive; and ASD, autism spectrum disorder.

**The categories are not mutually exclusive.*

[a] *These variables were missing for some of the sample.*

[b] *Of 2–7 children, with 73.4% 2–3 children in family.*

Measures

Family Accommodations Scale for Sensory Over-Responsivity

The FASENS[1] was designed as a caregiver questionnaire to assess family accommodations related to children's SOR symptoms. The questionnaire starts with explaining SOR symptoms, listing examples of behaviors in auditory, visual, tactile, movement, smell and taste modalities. Next, are 18 items to rate relative to these symptoms (see **Supplementary Table 1**). Twelve items describing family accommodation behaviors of avoidance and changes implemented by family members in the past month, on a 5-point Likert scale from 1 "Never" to 5 "Daily." Four items describe the severity of impact of the accommodation on the child's function and well-being and 2 describe the impact on the family's well-being on a 5-point Likert scale from 1 "None" to 5 "Extremely." Separate mean scores were computed for accommodation frequency, for child impact, and for family impact.

The content of the scale was developed based on the Family Accommodation Scale Anxiety (FASA) in terms of item phrasing, domains, and Likert scales. FASENS items were designed to reflect family challenges related to SOR as reported in the literature and based on the clinical expertise of the first two authors. The content validity of the first draft of the questionnaire was tested. Three clinical pediatric experts and three parents of elementary school-age children were asked to review the measure for the degree to which items measure family accommodations,

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[1] Ben-Sasson, A., Podoly, T. Y., and Leibowitz, E. (2020). *Family Accommodations Scale for Sensory Over-Responsivity. Unpublished manual.*

clarity, and missing items. Based on this feedback, the authors revised the scale. The final measure was used in this study.

Sensory Profile 2

This caregiver questionnaire evaluates a child's pattern of sensory processing across six modalities (e.g., auditory, visual, tactile, taste/smell, vestibular, and proprioceptive) involved in daily life activities (Dunn, 2014). Parents rate 86 items on a 5-point Likert scale from 1 "Almost never" to 5 "Almost Always." The sensory profile items are classified and scored into four quadrant summary scores: Sensitivity, Avoidance, Seeking and Registration (termed under-responsivity in this paper), as well as a SOR composite which is a sum of the Sensitivity and Avoidance scores. The analysis of this study focused on SOR given the high correlation between Avoidance and Sensitivity scores ($r = 0.81$), a method supported by previous research (e.g., Ben-Sasson et al., 2009; Little et al., 2017).

This questionnaire has good internal consistency, 0.71–0.90. Test-retest reliability ranged from 0.83 to 0.97. Inter-rater reliability was 0.70–0.80. Content validity was established through a panel of experts of occupational therapists with expertise in sensory processing. Convergent validity was high between the Sensory Profile 2 and previous Sensory Profile version (Little et al., 2017; Brown et al., 2019). The Hebrew version has been validated and showed strong psychometric properties (Dunn, 2014). This tool has been used to characterize sensory modulation traits in several general population studies (Kientz and Dunn, 1997; Ermer and Dunn, 1998).

Demographic Questionnaire

This questionnaire asked for background information, such as child and parents' ages, gender, birth order in family, parents' level of education, and child's medical or developmental status.

Data Analysis

Internal consistency was tested with Cronbach Alpha. AMOS 27 was used to conduct confirmatory factor analysis of the FASENS items. Three FASENS mean scores were derived: (1) accommodations, (2) family impact, and (3) child impact. Kolmogorov-Smirnov tests of normality indicated that all FASENS mean scores were not normally distributed ($p > 0.05$). Hence, non-parametric tests were applied for testing correlations and group comparisons related to these scores. Discriminant validity of the scale was examined by comparing FASENS scores between typical and conditions groups. FASENS items were compared between groups using Mann–Whitney tests. The associations between FASENS scores and background variables were tested using Spearman correlations for continuous variables, and Mann–Whitney *U* or Kruskal–Wallis tests for comparing 2- or 3-category variables.

RESULTS

Internal Consistency

The FASENS items showed a high internal consistency ($\alpha = 0.94$), with none of the items reducing reliability. Item descriptives are presented in **Supplementary Table 1**.

Factor Analysis

Confirmatory factor analysis was conducted in AMOS 27 (see model **Figure 1**). The very high correlation between FASENS avoidance and changes scores ($r = 0.79$, $p < 0.001$) led us to the analysis of a 3-factor solution with 12 accommodation items in factor 1, 4 child impact items in factor 2 and 2 family impact items in factor 3. The shared variance between four item estimates was accounted for in the model. The model fit was high, as indicated by the ratio between chi and *p*-values = 2.91 under the threshold of 3, CFI = 0.929, IFI = 0.930, and RMSEA = 0.08. All standardized estimates were significant ($p < 0.001$).

Discriminative Validity

Table 2 presents FASENS and Sensory Profile scores for the total sample and by group. Mann–Whitney *U* tests showed that FASENS scores for parents of typically developing children were significantly lower than for parents of children in the conditions group (see **Table 2**). This corresponded with MANOVA results indicating the significantly higher Sensory Profile scores, Wilk's Lambda = 0.90, $F(3,297) = 11.19$, $p < 0.001$, and $\eta^2 = 0.10$ (see **Table 2**). Mann–Whitney *U* tests comparing FASENS items between typical and conditions groups showed significantly higher scores in five items ($p < 0.003$; see **Supplementary Table 1**).

Convergent Validity

All three FASENS scores were significantly and moderately correlated with Sensory Profile SOR, Seeking, and Under-responsivity scores (see **Table 3**).

Background Correlates of FASENS

Spearman correlations indicated that child age was mildly negatively correlated with accommodations and child impact scores ($r = -0.19$, $p = 0.001$, $r = -0.13$, $p = 0.03$, respectively). In other words, parents of younger children had higher accommodative behaviors and reported higher child impact score when these accommodations were prevented. Mother's age was mildly negatively correlated with all three scores ($r = -0.23$, $p < 0.001$, $r = -0.13$, $p = 0.03$, $r = -0.16$, $p = 0.008$, respectively). That is younger mothers tended to report more accommodations, higher family impact and child impact. Father's age correlated with accommodations and child impact ($r = -0.19$, $p = 0.001$, $r = -0.14$, $p = 0.02$, respectively).

DISCUSSION

The idea that a child's living environment can be changed or reorganized with the help of the family in a way that either maintains difficulties or encourages functioning is reflected both in research and clinically (Salloum et al., 2018). Sensory modulation difficulties and specifically SOR, may provoke family accommodations in the same way that anxiety disorders do. Over-responsivity to certain stimuli, can cause the child to avoid these stimuli, and to express severe distress. In response, the parents can accommodate the avoidance by reducing the exposure to the distressing stimulus and by that

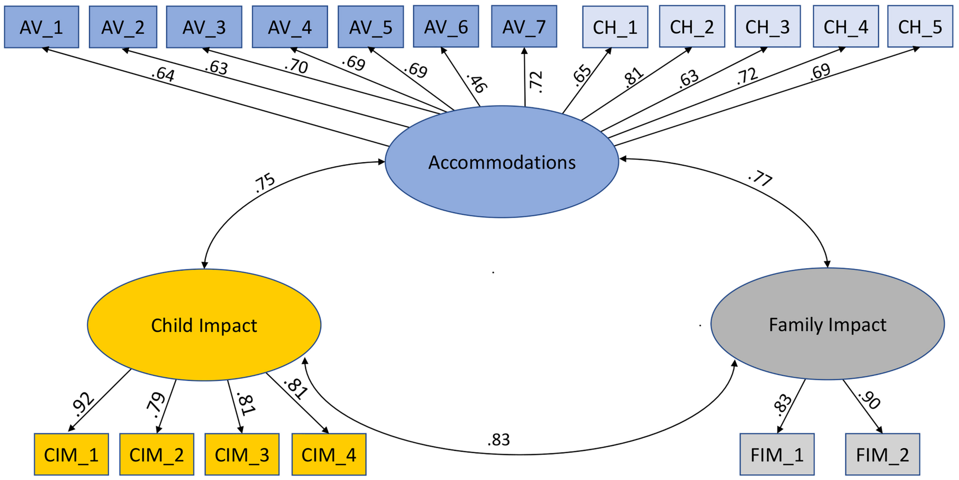

FIGURE 1 | Confirmatory factor analysis model.

TABLE 2 | Sensory profile and FASENS scores with group comparisons.

	Mean, median (SD), Min-Max			
	Total sample ***N* = 301**	**Typical** ***N* = 253**	**Conditions** ***N* = 48**	**Statistics***
FASENS				
Accommodations	0.62, 0.42 (0.71), 0–3.83	0.56, 0.42 (0.68), 0–3.83	0.90, 0.75 (0.79), 0–3.17	$U = 4339$, $p = 0.002$
Family impact	0.45, 0 (0.74), 0–4	0.38, 0 (0.69), 0–4	0.79, 0.75 (0.86), 0–3	$U = 4354.50$, $p < 0.001$
Child impact	0.72, 0.25 (0.88), 0–4	0.65, 0.25 (0.86), 0–4	1.06, 0.88 (0.91), 0–3	$U = 4333.50$, $p = 0.001$
Sensory profile				
SOR	74.48, 72 (28.61), 0–163	70.53, 69 (26.76), 0–159	95.29, 92 (29.3), 26–163	$F(1) = 3.49$, $p < 0.001$, $\eta^2 = 0.10$
Seeking	34.17, 33 (15.115), 0–88	32.59, 31 (14.22), 0–81	42.52, 42.5 (17.02), 5–88	$F(1) = 18.43$, $p < 0.001$, $\eta^2 = 0.06$
Under-responsivity	33.2, 31 (15.58), 0–92	31.59, 31 (15.1) 0–92	41.69, 41 (15.51), 7–81	$F(1) = 17.88$, $p < 0.001$, $\eta^2 = 0.06$

*Note: * Mann–Whitney U test was applied for comparisons of FASENS scores and MANOVA for comparisons Sensory Profile patterns scores.*

increasing the avoidance patterns leading to further restriction of child and family meaningful participation. The current study validated a tool designed for assessing family accommodation in the context of SOR.

The FASENS had excellent psychometric properties: it showed high internal consistency and good convergent validity with the Sensory Profile 2 scores. Family accommodation, as measured by the FASENS accommodation score, was significantly correlated with the severity of all sensory patterns, as measured by Sensory Profile 2. Nonetheless, the relation with SOR was the strongest. The relation between accommodation and children's severity of the psychopathology (i.e., anxiety and OCD) which the accommodation relates to was also shown with previous family accommodation scales (Lebowitz et al., 2013; Flessner et al., 2017). When scrutinizing the FASENS correlations in our study, the magnitude of difference between groups was greatest for the SOR pattern. Given the association with all three sensory profile scores, it should be noted that families are accommodating children who are dysregulated. Since the tool primarily asks parents to think of their child's sensitivities and highlights the SOR pattern, it is not possible to determine how much of the accommodation is associated with each sensory pattern. As previously mentioned, SOR symptoms can cause children significant distress and anxiety (Carpenter et al., 2019). The child's anxiety may cause distress and lead to accommodation behaviors of the family, so it is no wonder that the strongest correlation we found was between the SOR pattern and FASENS scores.

TABLE 3 | Spearman rho correlations between FASENS scores and sensory profile scores.

	Sensory profile		
	SOR	**Seeking**	**Under-responsivity**
FASENS			
Accommodations	0.53**	0.42**	0.38**
Child impact	0.60**	0.39**	0.39**
Family impact	0.52**	0.33**	0.42**

*Note: **$p < 0.001$.*

Factor analysis confirmed that the FASENS comprises 3 factors: frequency of accommodations, child impact, and family impact. Previous family accommodation scales differed in their number of factors and subscales loaded. The FAS factors were Avoidance of Triggers and Involvement in Compulsions (Flessner et al., 2011) and the FASA factors were Participation and Modification (Lebowitz et al., 2013). Our results indicated that avoidance/participation versus modification/changes items are distributed on one factor rather than two. Overall, the current results underscore the need to evaluate the presence of accommodations separately from their impact on child and family well-being and participation. Replicating this factor analysis in a clinical sample with higher and variable scores is warranted.

Furthermore, we found that the child impact factor was higher than the family impact across groups but most dramatic for the conditions group. This reflects the higher distress levels of children when family accommodation is not performed. It is important to keep in mind that this distress occurs to some extent in typically developing children. For example, our sample included 10 parents who reported child impact (child impact scores between 0.25 and 0.75) but no accommodations (mean = 0). This may represent parents who are not cooperating with their child's demands for avoidance or are not taking part in their rituals and thus, stress is higher for the child. The even higher levels of child impact scores in the conditions group may relate to the higher frequency of family accommodations, and the children's greater difficulty in self-regulating under such conditions of negative emotionality. In this group, the rate of moderate-extreme ratings for family impact was 22–27%, while the rate of child impact items was 30–44%. Similar findings were reported in a pediatric anxiety sample (Lebowitz et al., 2013): lower levels of family distress/impact (70.7%) and higher scores for the consequences of accommodations upon the child (85.3%). This supports the common nature of family accommodations, in which lack of accommodating leads to increased child distress, regardless of the type of disorder.

This study provides a unique opportunity to examine and compare family accommodations in typical and atypical populations. Prevalence of accommodations in families raising typically developing children can serve as a baseline for assessing disability/impairment. As we expected, we found a very low prevalence of accommodation in the typical group; prevalence rating of daily and 3–6 times a week across items ranged from 3.2 to 12.2%. For the conditions group, the prevalence rating of daily and 3–6 times a week across items ranged from 4.2% (avoid places/change schedule or recreation) to 23% (enable child not to perform self-care). Family adjustments and changes in the environment and in routines are part of the normal behavior of a functioning family. Typical accommodations in this sample were providing items to reduce sensitivity and help in avoiding irritating discomfort. Among the conditions group, avoidance was much more common than changes in routines. Performing activities instead of the child was also observed more often among this group. Typical levels and types of accommodation are rarely discussed in the family accommodation literature. This study highlights the notion that family accommodation occurs to some extent in the general population and is not merely an indicator of abnormality. Further research into thresholds for impairing accommodations can enhance the clinical utility of family accommodation scales.

The higher FASENS scores reported in families with children with developmental and medical needs could be due to several reasons:

1. Increased caregiver burden: Family accommodation was previously associated with deficits in emotional regulation (Helbig-Lang et al., 2015; Reuman and Abramowitz, 2018). The burden of raising a child with a medical condition or special needs may also lead to a decrease in emotional regulation among caregivers and as a result to increased cooperation with their children's non-adaptive behaviors.
2. Increased caregiver's worry and protectiveness: This may occur particularly when there is inherent uncertainty in the health condition (e.g., epilepsy, Tourettes syndrome, and asthma). In some of these conditions, the family aims to avoid the child's outburst as with respect to fear-based disorders (Reuman and Abramowitz, 2018). Parents of children with developmental and medical needs may express too much empathic concern with their child's difficulties, and thus, cooperate with them and not expect them to self-manage these difficulties (Reuman and Abramowitz, 2018).
3. Evidence for elevated anxiety/distress and SOR in some of these conditions: The conditions group included children with conditions which often involve SOR comorbidity, for example: ADHD (Lane and Reynolds, 2019), ASD (Lane et al., 2012), allergies (Engel-Yeger et al., 2007), and general developmental delay (Rogers et al., 2003). It is expected that higher rates of SOR would lead to higher rates of accommodation. In addition, children with the developmental difficulties noted above (i.e., ADHD, ASD, allergies, etc.) present lower capacity to regulate distress (e.g., Mazefsky, 2015; Sullivan et al., 2015) and experience higher levels of distress. This is consistent with evidence showing that severity of anxiety in the child is associated with more parental accommodations (Storch et al., 2010).

Accommodation in the current sample tended to occur for younger parents of younger children, consistent with previous family accommodation evidence (Jones et al., 2015). Accommodation was also more likely to occur in families with an older sibling (potentially implying higher burden). It is noteworthy that the current sample represents larger families relative to the world[2]; with 2–7 children per family. In addition,

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[2] https://data.oecd.org/pop/fertility-rates.htm

the average age of children who were the eldest in our sample was about 5 years. This might explain the significant need for family accommodations, especially with several young children in the house.

Limitations and Future Research

The conditions group was heterogeneous in terms of the child's disability, with very different family burden and child anxiety levels. It is unclear whether families of children with health conditions report overall higher family accommodations or are responding specifically to the sensory symptoms of their children. In addition, we found no literature concerning family accommodations for children with a chronic medical condition. Further research can examine whether there are distinct sensory accommodations for specific clinical groups. There is also a need to determine family accommodations that stem from the child's SOR versus anxiety or obsessions that develop in addition to the SOR. In this study, we did not measure the child's or mother's anxiety levels, which are important to characterize, to understand the mechanisms involved in the emergence of family sensory accommodations. Future research assessing potential factors contributing to family accommodation is needed. These include medical condition and special needs of family members, interventions, and other services that the family consumed, and demographic data that could influence family accommodation. Anxiety of both children and parents should be monitored considering previous findings (Kerns et al., 2017) about child and parents' emotional dysregulation and the tendency of the family to accommodate. As our sample included only families of two-parent household, we suggest conducting a study with a larger and more representative sample that will allow to compare the effect of family structure on the tendency to accommodate SOR. The utility of the FASENS as an outcome measure requires examination of test-retest reliability.

Clinical Implications

The FASENS adds important implications to practice by highlighting: (1) that mapping parental accommodations is critical for understanding SOR symptoms as parental behavior plays a significant role in both maintaining and exacerbating certain symptoms such as rituals, avoidance, tantrums. (2) Often children do not cooperate with interventions and the way to treat them is by including their parents in the process. The FASENS questionnaire can help parents understand their child's difficulties and how they are retained within the family unit. (3) This tool can be used in occupational therapy applying a Family-Centered Care approach to encourage the involvement of parents in therapy.

This preliminary study examined family accommodations related to sensory sensitivity as part of the effort to study family accommodations for conditions other than anxiety and OCD (Shimshoni et al., 2019). These conditions include developmental populations like ADHD, ASD and of course, SOR. To date there are targeted interventions that address family accommodations, in cases of anxiety disorders and other psychopathologies (e.g., Peris et al., 2017; Lebowitz et al., 2020). Considering sensory family accommodation may open new opportunities for developing family oriented sensory interventions.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by The Ethics Committee of the Faculty of Social Welfare and Health Sciences, University of Haifa, Israel. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

AB-S was involved in the research design and management, data collection and analysis, and manuscript writing. TP contributed to the measure design and manuscript writing. EL contributed to the measure design and manuscript preparation. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.867508/full#supplementary-material

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REVIEW
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Sleep, Sensory Integration/Processing, and Autism: A Scoping Review

Shelly J. Lane[1]*, Marco A. Leão[1] and Virginia Spielmann[2]

[1] *Sensory Integration, Play, and Occupational Therapy Research Lab, Department of Occupational Therapy, Colorado State University, Fort Collins, CO, United States,* [2] *STAR Institute for Sensory Processing, Centennial, CO, United States*

The prevalence of sleep dysfunction is considerably higher in the autistic population than in the non-autistic. Similarly, the incidence of sensory reactivity differences in autism exceeds that in the neurotypical population. The basis of sleep disorders in autism is multifactorial, but sensory integration/processing concerns may play a role. Research that investigates this interplay for autistic individuals is limited but vital. In this scoping review, we examined literature addressing the following research question: *What is the relationship between sleep and sensory integration/processing in autism?* We included articles if they were peer-reviewed, English or Spanish, purposefully addressed sensory integration/processing differences, were sleep focused and included autism as the primary diagnosis or population. Articles were excluded if the language was not English or Spanish, research was conducted with animals, they were non-peer-reviewed, the primary population was not autistic, the sensory focus reflected a specific sensorineural loss (e.g., blindness, or deafness), there was not a clear inclusion of sensory integration/processing or sleep. We searched six databases and included all citations from the inception of each database through June 2021. The search strategy identified 397 documents that were reduced to 24 included articles after exclusion criteria were applied. The majority of studies we identified characterized the relation between sleep and sensory integration/processing differences in autism. Investigators found multiple sleep concerns such as bedtime resistance, sleep anxiety, delayed sleep onset, night awaking, and short sleep duration in autistic individuals. Identified sensory concerns focused on reactivity, finding hyper- and hypo-reactivity as well as sensory seeking across sensory domains. Co-existence of sleep concerns and sensory integration/processing differences was frequently reported. Few intervention studies showed a clear sensory focus; those that did emphasized pressure, movement, touch, and individual sensory preferences/needs. Swimming programs and massage showed promising results. No studies were of high quality. At a minimum, there is a co-existence of sensory reactivity differences and sleep concerns in autistic children, and possibly autistic adults. The relationship between poor sleep and sensory integration/processing differences is complex and multi-faceted, requiring additional research. Interventions

Edited by:
Catana Brown,
Midwestern University, United States

Reviewed by:
Angeles F. Estévez,
University of Almería, Spain
Enrico Giora,
Vita-Salute San Raffaele University, Italy

****Correspondence:***
Shelly J. Lane
shelly.lane@colostate.edu

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that purposefully include a central sensory component have not been well studied in autistic children or adults. Overall studies with greater rigor and purposeful use of sensation and sensorimotor supports as a component of intervention are needed. This study was not funded.

Keywords: autism spectrum disorder, sleep disturbances, sensory processing/integration, sensory reactivity, children, adults, insomnia

INTRODUCTION

Sleep is a critical occupation for adequate neural function and maturation. Inadequate sleep has been linked to disruptions in attention, memory, mood, and behavior (cf. Souders et al., 2017; Tester and Foss, 2018), all of which influence participation across occupations. While many neurotypical children experience sleep difficulties, the incidence in autistic children[1] is reported to be substantially higher; sleep disorders have been identified in as many as 50% of autistic adults and 80% of autistic children (Hirata et al., 2016; Souders et al., 2017; Deliens and Peigneux, 2019; Hohn et al., 2019). Reported sleep difficulties vary and may differ across the life span. However, the most often reported sleep concerns include reduced total sleep time, prolonged sleep latency, poor sleep efficiency, and wake after sleep onset; the literature is highly variable in both incidence and characteristics of sleep concerns (Malow et al., 2006; Miano et al., 2007; Goldman et al., 2012; Morgan et al., 2020).

Sensory reactivity differences are ubiquitous in autism and include sensory hyper-reactivity, sensory hypo-reactivity, and unusual sensory interests (Tomchek and Dunn, 2007; Crane et al., 2009; Marco et al., 2011; Puts et al., 2014; Tavassoli et al., 2014b; Taylor et al., 2020). Unusual sensory interests may be expressed as sensory seeking or craving (such as extensive smelling or touching of objects) and, along with reactivity differences, may be seen across the range of sensory domains (Schaaf and Lane, 2015). Importantly, investigators have indicated that sensory differences can negatively impact participation in autistic children (Little et al., 2015) and adults (Tavassoli et al., 2014b; Robertson and Simmons, 2015; Clince et al., 2016; Syu and Lin, 2018). More specifically, sensory integration/processing differences in autistic children have been associated with participation differences during mealtimes (Zobel-Lachiusa et al., 2015), in the classroom (Ashburner et al., 2008), during sleep (Reynolds et al., 2011), and with social participation (Watson et al., 2011). In addition, researchers such as Hochhauser and Engel-Yeger (2010) indicate that the choice of and setting for engagement in leisure is influenced by sensory seeking and sensory sensitivity. In autistic adults, sensory integration/processing differences have been shown to impact participation in higher education, and at least indirectly, social interactions (Robertson and Simmons, 2015; Syu and Lin, 2018), and other daily life activities (Tavassoli et al., 2014b). While there has been a great deal of research conducted on many of these associated occupational divergences, particularly in autistic children, the relationship between sensory integration/processing differences and the occupation of sleep has received only limited attention.

Importantly, both sensory reactivity differences and sleep concerns interfere with occupation and participation in activities of daily life (Roley et al., 2015; Dunn et al., 2016; Medic et al., 2017; Silverman and Tyszka, 2017; Berkley, 2021; Neufield et al., 2021). Clinically, understanding the range of these differences, as well as their inter-relatedness, has the potential to support more focused intervention. Deliens and Peigneux (2019) suggested that sensory reactivity and unusual sensory interests might play a role in sleep disturbances in autistic individuals. Drawing from the literature on neurotypical children (Tzchishinsky et al., 2008; Shochat et al., 2009), Deliens and Peigneux (2019) suggested that difficulty in the ability to filter out environmental sensation could interfere with sleep. Consistent with this suggestion, Hollway et al. (2013) indicated that to fall asleep and stay asleep individuals must be able to filter out sensation from the environment; as sensory reactivity differences are core to autism, this ability is heavily implicated.

Endeavoring to explain the link between historically perceived *core characteristics*[2] associated with autism (e.g., differences in social communication challenges, insistence on sameness, and resistance to change) and sleep difficulties, Hollway et al. (2013) suggested that autistic children may interpret external cues around bedtime to be stressors, leading to sleep difficulties. These bedtime challenges may result in hyperarousal and difficulty falling asleep (Deliens and Peigneux, 2019). Hollway and colleagues also indicate that the relationship between sleep challenges and autism may be bidirectional such that poor sleep exacerbates *features of autism*, which in turn leads to sleep challenges. Other investigators (Schreck et al., 2004; Hundley et al., 2016; Cohen et al., 2018) have also indicated that poor sleepers have more significant *autism features*. However, the bidirectional relationship between sleep and *features of autism* is not universally accepted (Deliens and Peigneux, 2019). For instance, and admittedly with some inconsistency, investigators have found that sleep problems in individuals with a range of *autism features* correlate with IQ (Gabriels et al., 2005; Bruni et al., 2007; Giannotti et al., 2008), and *challenging behaviors* in both children and adults (Limoges et al., 2005; Allik et al., 2006;

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[1] We have chosen to use identity first language throughout this manuscript, in keeping with current trends in understanding autism.

[2] What have historically been considered as *features, core features, core characteristics,* and *challenging behaviors* associated with autism are feasibly symptoms of autistic distress, vs. stable and perceptible differences (Lafrance and McKenzie-Mohr, 2013). We recognize that attributes such as *autistic features, core characteristics,* and *DSM-V diagnostic criteria for autism,* are hotly debated, particularly in context of recent participatory research (Sweet and Decoteau, 2017; O'Reilly et al., 2020). To honor current trends in understanding autism and in respecting autistic individuals, in this paper we italicize attributed terms and use identity first language.

Bruni et al., 2007). In addition, Hundley et al. (2016) indicated that sleep challenges do not correlate universally with what are considered *challenging behaviors*. Instead, they found that poor sleep correlates with high rates of repetitive sensory-motor behaviors but not insistence-on-sameness. These investigators indicated that intervention for the myriad sleep challenges needs to be multifaceted and should consider sensory aspects of the environment (Hundley et al., 2016).

We are faced with challenges. First, there is inconsistency in research relative to the relationship between sleep difficulties and sensory integration/processing differences. Second, there remains some uncertainty about the impact of poor sleep and sensory integration/processing differences on occupation and participation in autistic individuals. Together these factors make for challenges in appreciating this interplay and lead to difficulties in providing appropriate intervention services. Further, investigations looking at this interconnectedness focus primarily on children with very limited information available for autistic adults. In this review, we examined how this relationship is characterized and defined by current research and looked at the interventions that have been used. Due to the broad nature of this aim, we determined that a scoping review was the most appropriate approach.

In conducting our review we considered both the National Institute of Mental Health Research Domain Criteria (RDoC) framework[3] and the Diagnostic and Statistics Manual V (DSM-V; American Psychiatric Association [APA], 2013) to examine the interplay between the dimensions of sleep and sensory integration/processing. The RDoC is a framework designed to guide understanding of mental health as well as illness, in psychological and biological systems. The RDoC addresses the construct of Sleep/Wakefulness within the domain of Arousal and Regulatory Systems. Sensory reactivity, of interest in this review, is arguably also included under arousal in the domain of Arousal and Regulatory Systems: "sensitivity of the organism to stimuli, both external and internal."[4] Sensorimotor systems are represented as a separate domain and include constructs of motor actions, agency and ownership, habit–sensorimotor, and innate motor patterns. In addition, sensory systems are embedded within the Cognitive Systems domain under the construct of perception (visual, auditory, olfactory, somatosensory, and multimodal). While the inclusion of both sleep and sensory reactivity within the Arousal and Regulatory system domain supports our examination of this interaction, the multiple representations of sensory integration/processing across other domains present challenges for examining the interaction of these constructs. In addition, there have been notable calls to include sensory processing as a unique domain in the RDoC (Harrison et al., 2019), and leading theorists are recognizing the importance of sensory integration/processing across disciplines (Bogdashina, 2016; Robertson and Baron-Cohen, 2017; Sinclair et al., 2017; Mueller and Tronick, 2020). These positions closely support our perspective on the centrality of sensory integration/processing to the development of health, wellness, occupation, and participation, providing support for this review. Within the DSM-V the foundational importance of sensory integration/processing to wellbeing finds some additional support, although it comes from the perspective of dysfunction. Within this framework, sensory reactivity differences are associated with autistic *core characteristics* and included under the "restricted, repetitive patterns of behaviors, interests, or activities" diagnostic feature. While no direct link is made to sleep concerns, they are considered either a reflection of underlying anxiety or depression, or a concomitant *feature of autism*.

METHODS

This scoping review was structured based on the framework developed by Arksey and O'Malley (2005) and guidelines from the Joanna Briggs Institute (Peters et al., 2020), and utilized the PRISMA-ScR checklist (Tricco et al., 2018). This project was registered with Prospero, CRD42020209872.

Identifying the Research Question

Our intention in this review was to examine literature that investigated the relations between sensory integration/processing differences and sleep challenges in autistic individuals, across the life span. Our research question was: *What is the relationship between sleep and sensory integration/processing in autism?*

Identifying and Locating Relevant Studies

We conducted an initial search in CINAHL, Pubmed, PsychINFO, Academic Search Premier, Web of Science, and Embase databases, and included all citations from the inception of each database through November 2020. A sample search strategy comprised the terms: [sleep OR "sleep-wake disorders" OR "sleep dysfunction" OR "sleep disorder" OR "sleep problems" for Sleep; ["sensory processing" OR "sensory processing disorder*" OR "sensory integration" OR "sensory integration dysfunction*" OR "sensory integration dysfunction" OR "sensory processing disorder" OR "sensation disorder" OR "sensory over responsivity" OR "sensory reactivity" OR vestibular OR propriocept* OR interocept* OR tactile OR touch OR somatosensory OR "somatosensory" OR Postur* OR "multi sensory" OR multisensory OR sensorimotor] for sensory integration/processing; and ["autism spectrum disorder" OR "autistic disorder" OR asperger OR autism OR autistic] for autism. The search terms were entered into the databases with an "AND" term between each of them.

In June 2021, we conducted a follow-up search in the same databases to check for newer articles. We hand searched the reference lists from included articles (August 2021) to ensure that all appropriate articles were comprised.

Study Selection

Based on our research question, we set the inclusion criteria to be as follows: (1) peer-reviewed articles (qualitative or quantitative research papers), written in English or Spanish; (2)

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[3] National Institute of Mental Health, Research Domain Criteria Initiative (NIMH RDoC). https://www.nimh.nih.gov/research/research-funded-by-nimh/rdoc.

[4] NIMH RDoC.

TABLE 1 | Results per database.

		Results
Pubmed		85
EBSCO Host	CINAHL	33
	PsychINFO	52
	Academic search premier	32
Web of science		87
Embase		108
Hand search		2
Total		399

sensory integration/processing differences purposefully included (3); sleep focused and (4) autism as the primary diagnosis or population. We detailed the exclusion criteria in the following hierarchical order: (1) articles written in a language other than English or Spanish; (2) articles conducted with animals; (3) presentations, conference proceedings, non–peer-reviewed research literature, dissertations, and theses; (4) primary focus on populations other than autism; (5) sensory focus on a specific sensorineural loss (e.g., blindness, or deafness); (6) no clear inclusion of sensory integration/processing or sleep.

Initial and follow-up searches resulted in a total of 397 references. Of these, 114 duplicate articles were removed. A total of 283 abstracts were screened by title and abstract by two reviewers; conflicts were resolved by a third reviewer or through discussion and 179 articles were excluded. Two reviewers conducted full-text reviews of the remaining 104 potential articles; 82 additional articles were excluded for the following reasons: one study was conducted with animals rather than humans; 32 articles were not peer reviewed, seven articles collected data from populations other than autism; 40 studies did not include a clear definition of sensory integration/processing or sleep; one article was an additional duplicate and one full text was not available. Per hand search of reference lists in all included articles, we identified and added two additional articles (**Table 1**). **Figure 1** shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-ScR; Tricco et al., 2018) flow diagram of the search strategy.

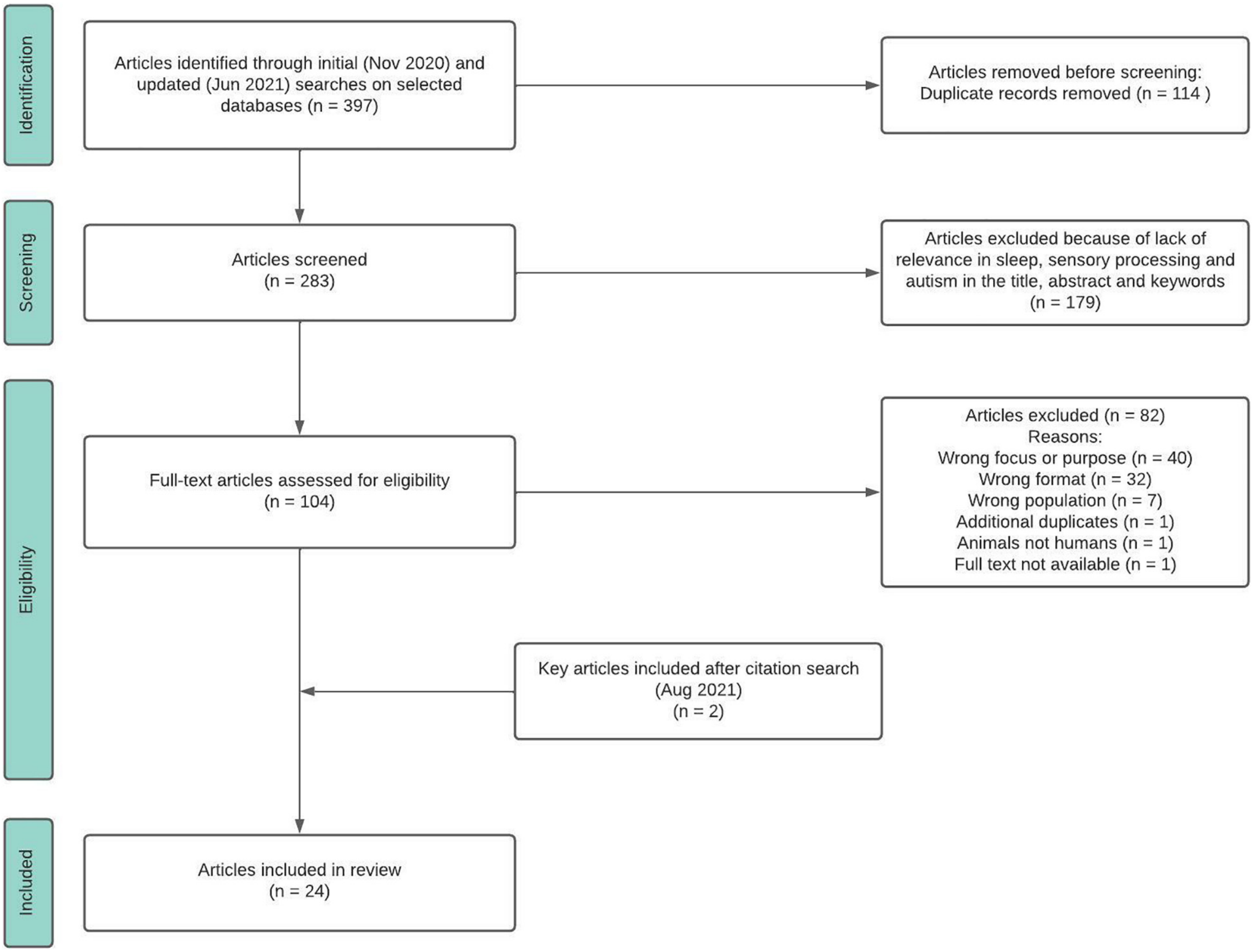

FIGURE 1 | Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA- ScR).

The search strategy used for Web of Science is available as a Supplementary Table.

Charting the Data

A total of 24 articles met the inclusion criteria and were included in the final review (**Figure 1**). Data extraction was conducted using these fields: title, authors, year, journal, source country, study design, research question, sample size, and characteristics, inclusion and exclusion criteria, diagnostic tools, measures of sensory integration/processing, sleep and other characteristics, intervention, quantitative and qualitative findings, identified relationships between sensory integration/processing and sleep, and authors conclusions.

Collating, Summarizing, Reporting

We collated and summarized the data from the extraction table and determined there were two broad categories into which studies fell: characterization and intervention. We present results based on these categories.

RESULTS

A total of 24 articles were included in the data extraction. Of these, 17 articles offered information characterizing a relation between sleep concerns and sensory integration/processing differences (**Table 2**), and seven articles were intervention studies using approaches with a clear sensory focus (**Table 3**). We considered these interventions *sensory-based* if consideration of the sensory components was a focal point, or *sensory incidental* when the intervention provided sensory input, but the inclusion of sensation was not the primary focus.

Measures of Sleep and Identified Concerns

The most commonly reported tool used to reflect sleep concerns was the *Children's Sleep Habits Questionnaire* (CSHQ; Owens et al., 2000). This screening tool asks parents to reflect on their child's sleep characteristics over a typical recent week. Subscales include bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, sleep disorder breathing, parasomnias, and daytime sleepiness. A total sleep score is also generated (Owens et al., 2000). The original version of this tool had 45 questions [CSHQ (45)]; the authors created a 33-item revised version to reduce redundancy and ambiguity [CSHQ (33)]. The CSHQ, or a version of it, was used to define sleep concerns in seven of the 17 articles that characterized a relationship between poor sleep and sensory reactivity differences (**Table 2**, studies #2, #9,#14, #15, #16,#23,#24) and one of the seven articles that utilized sensory-based interventions (**Table 3**, study #13). A variety of other means of determining sleep concerns, including both published tools and those purpose-built for individual studies, were used by other authors (**Tables 2**, **3**). In some studies, sleep concerns were identified using both subjective measures based on parent report, and more objective measures such as actigraph (**Table 2**, study #12; **Table 3**, study #7). Sleep concerns of autistic children were multifaceted and included concerns in all domains tapped by the CSHQ, along with wake after sleep onset. Hohn et al. (2019), the only study found addressing adults, reported that autistic adults experienced an elevated incidence of insomnia.

Measures of Sensory Integration/Processing and Identified Concerns

Sensory integration/processing was assessed using a variety of tools, although some form of the *Sensory Profile* ([SP]; Dunn, 1999) or *Short Sensory Profile* ([SSP]; McIntosh et al., 1999) were used most commonly (**Table 2**, studies #6, #9, #12, #14, #15, #16, #19, #23, #24; **Table 3**, studies #7, #13, #22). In the SP and the SSP the authors consider the interface between neurological threshold and self-regulation in response to sensation, defining sensory processing patterns across four quadrants: poor sensory registration, sensory seeking, sensory avoiding, and sensory sensitivity. With the SP, Dunn also identifies reactivity differences within each sensory domain (sensory section scores) along a continuum from hyper- to hypo-reactivity, and within behavioral domains (behavioral section scores); this finer delineation is not available to users of the SSP. Thus, in these identified studies, the focus of sensory integration/processing differences was on sensory reactivity rather than perception or discrimination. There was variability in examining and reporting sensory differences across the studies. However, overall findings can be generalized to reflect sensory hyper-reactivity (which includes both sensory avoiding and sensory sensitivity), hypo-reactivity, and sensory seeking. Often a combination of these sensory processing differences was identified. While some investigators reported differences within specific sensory domains, we did not find consistency across studies; investigators variously reported sensory processing differences within visual, tactile, auditory, taste-smell, and vestibular sensory domains.

Characterizing the Relation Between Sleep Disturbances and Sensory Integration/Processing Differences

Most investigators agreed that there was, at minimum, a co-existence of sensory reactivity differences and sleep concerns. This finding was clearly stated by Silva and Schalock (2012): sleep and sensory processing differences co-exist in autism, and disordered sensory processing has a negative impact on sleep. In a family-based study, Nieminen-von Wendt et al. (2005) set out to examine familial traits of Asperger Syndrome not included in specific diagnostic criteria (DSM-IV or ICD-10). While they did not delineate a specific relationship between sleep concerns and sensory differences, they did find that these concerns and differences co-existed in their participants. These investigators suggested that sensory processing differences might be considered in the diagnostic criteria for Asperger Syndrome. Other investigators indicated that the combination of sleep concerns and sensory reactivity differences in autistic children exceeded that found in neurotypical children (Nieminen-von Wendt et al., 2005; Reynolds et al., 2012; Tzischinsky et al.,

TABLE 2 | Characterizing sleep/sensory processing relations.

References, table, ID#	Study design and aim	Participants, N, Age range, M_{age}, % Males	Sensory processing tool; areas of sensory difference	Sleep tool and areas of difference	Other measures related to aims	Findings related to sleep and sensory processing	Country	Quant	Qual
Eyuboglu and Eyuboglu, 2020, #2	Cross-sectional, descriptive, correlational Aim: Examine incidence of sleep problems in autistic vs NT children; examine the relationship between maternal anxiety and child sensory reactivity and sleep problems.	ASC $N = 48$, age 18-60 months $M_{age} = 33.3 + 9.6$ 83% male; NT $N = 51$, 18-60 months**	Sensory reactivity scale (purpose built): autistic children had higher scores in SOR, SUR, SS	CSHQ: autistic children had higher frequency of BR; TST; Parasomnias; amount of sleep	Hospital anxiety depression scale (mother); AuBC; CARS	Sleep concerns and sensory reactivity differences more prevalent in autistic children; autism severity correlated with sensory reactivity and sleep concerns; maternal depression and anxiety correlated with sleep problems and sensory reactivity; parasomnia predicted maternal depression	Turkey	X	X
Ghanbari and Rezaei, 2016, #6	Cross-sectional description, correlational Aim: Determine relationship between sensory processing disorder and sleep disturbance in autistic children	ASC $N = 35$, age 3-12 years $M_{age} = 9 \pm 2.30$ 80% male	SSP: 95.3% showed some degree of sensory processing disorder	SDSC: 68.6% showed sleep disturbances	Demographic form	No significant relationship between sensory processing disorders and sleep disturbances	Iran	X	
Hohn et al., 2019, #8	Cross-sectional, descriptive, correlational Aim: Examine link between sensory responsiveness, social skills, and insomnia in autistic adults	ASC $N = 631$ 18-65 years $M_{age} = 42.62 \pm 12.21$ 48% male	SPQ, Short Form: outcome not specified	ISI: Subthreshold insomnia, higher than reported in general population; influenced by sex, IQ	Autism Spectrum Quotient-28 Social Skills Subscale	Insomnia extends into adulthood for autistics; severity of insomnia symptoms predicted by high levels of sensory reactivity and lower social skills. Sensory reactivity impact seems driven by visual system	Netherlands	X	
Hollway et al., 2013, #9	Cross-sectional retrospective, correlational chart analysis Aim: Explore variables related to sleep in autistic children to replicate prior findings; provide foundation for evidence-based interventions.	ASC $N = 1583$ 2-17 years $M_{age} = 6.34 \pm 3.5$ 84% male	SSP: Domain findings not presented	CSHQ: Domain findings not presented	VABS, MSEL, SB5, CBCL	Greater taste/smell impairment associated with more sleep anxiety; greater SUR, SS, and auditory filtering contributed to a prediction of CSHQ 23-item total score***	United States	X	
Jamioł-Milc et al., 2021, #10	Cross-sectional, descriptive, correlational Aim: Determine whether Tactile Stimilation Modulation disorders are linked to insomnia in autistic children.	ASC $N = 27$ $M_{age} = 6.8 \pm 2.9$ years** 81.5% male	Identification of TSM disorder via parent interview; observation of tactile responsivity according to behaviors identified by Miller, et al: Tactile SOR 74.1%; tactile SUR 25.9%	AIS (difficulty falling asleep, night and early morning awakenings, TST, and wellbeing during the next day): 40.7% children showed insomnia	Purpose built parent questionnaire (pregnancy, childbirth, perinatal circumstances, school history, sensitivity towards tactile stimuli at home)	Trend toward higher prevalence of insomnia in autistic children with tactile SUR; lack of significance related to small sample size	Poland	X	

(Continued)

TABLE 2 | (Continued)

References, table, ID#	Study design and aim	Participants, N, Age Range, M_{age}, % Males	Sensory processing tool; areas of sensory difference	Sleep tool and areas of difference	Other measures related to aims	Findings related to sleep and sensory processing	Country	Quant	Qual
Klintwall et al., 2011, #11	Cross-sectional, descriptive, correlational with ASC subgroups Aim: Describe sensory differences in preschool autistic children; compare autism across autism subgroups; relate findings to other clinically relevant symptom domains	ASC *N* = 208 <4.5 years** 84.6% male	PARIS schedule interview (SOR,SUR): > 1 major sensory difference found for 76% children: SOR: 44% sound, 19% touch, 5% smell; 19% visual stimuli; SUR: 40% pain, 22% cold, 7% heat. Number of sensory differences varied across autistic subgroups	None specified	AuBC; VABS; cognition; expressive language	Greater number of sensory differences found in autistic children with sleep problems	Sweden	X	
Kosaka et al., 2021, #12	Two-group comparison, cross-sectional, descriptive, correlational Aim: Validate relationship between sensory characteristics and sleep dynamics among autistic children	ASC *N* = 20, 3-6 years $M_{age} = 5.1 \pm 1.3$ 85% male; NT *N* = 20 3-6 years $M_{age} = 5.1 \pm 0.9$ years 60% male	SP-J; all sensory subscales differed between groups for both high and low threshold items	JSQP: autistic children showed higher scores RLS, SOSA; CRD; DS, SE, WASO, TST parasomnias, insomnia Actiwatch Spectrum Plus: significant group difference in activity during sleep, activity per minute during sleep	NA	Activity per minute during sleep in autistic group correlated with vestibular and oral sensory sensitivity	Japan	X	
Manelis-Baram et al., 2021, #14	Longitudinal, descriptive, correlational Aim: Further examine the longitudinal relationship between sleep disturbances and sensory sensitivities	ASC *N* = 103 $M_{age} = 3 \pm 1.12$ years [at baseline, T1]**, $M_{age} = 4.5 \pm 1.19$ years [at follow-up, T2]** 75.7% male	Infant/ Child SP: All children showed SOR (avoiding and sensitivity), SUR, SS above expected levels at baseline	Hebrew CSHQ autistic children showed BR, SOD, SD, SA, NW, SDB, DS, parasomnias, children sleeping 1-2hr 35min less than NT peers	BSID WPPSI	Changes T1 to T2: 35% children had worse sleep, 34% were stable; 28% had greater sensory sensitivity, 55% stable; 34% had more sensory avoiding, 43% stable; 34% had more SS, 49% stable; 23% had worse sensory registration, 52% stable. Changes in sleep paralleled sensory changes, except for sensory seeking. Significant total sleep disturbance correlated with sensory sensitivity, sensory avoiding, and sensory registration, not with SS. Changes in sleep disturbances correlated with sensory sensitivity only. Regression showed sleep T1 predicted sleepT2, and sensory sensitivity was only sensory quadrant that improved prediction.	Israel	X	

(Continued)

TABLE 2 | (Continued)

References, table, ID#	Study design and aim	Participants, N, Age Range, M_{age}, % Males	Sensory processing tool; areas of sensory difference	Sleep tool and areas of difference	Other measures related to aims	Findings related to sleep and sensory processing	Country	Quant	Qual
Mazurek and Petroski, 2015, #15	Cross-sectional, descriptive, correlational Aim: Determine the relationships among sleep problems, sensory problems, and anxiety in autistic children.	ASC *N* = 1547 2-17.6 years; M_{age} = 7.9±3.4 younger group 2-5 years** 82.9% male; older group 6-18 years** 85.9% male	Subset of SSP reflecting SOR in touch, taste/smell, movement, visual and auditory domain; Domain findings not presented	CSHQ: Domain findings not presented	CBCL DSM-oriented Anxiety Problems scale	For both age groups, SOR correlated with all subscales of CSHQ using bivariate model Multivariate model: younger children showed SOR associated with SOD, SD, NW, but no other sleep challenges; older children showed links between SOR and all sleep challenges other than NW. Anxiety showed bivariate and multivariate relationship with all sleep challenges for both groups	United States	X	
Mazurek et al., 2019, #16	Descriptive, correlational, longitudinal Aim: Examine chronicity of sleep disturbance in autistic children; determine longitudinal relations among sleep problems and co-occurring symptoms	ASC *N* = 437 younger group 2-3 years [at T1] M_{age} = 2.98 ±.58 84% male; older group 4-10 years [at T1]; M_{age} = 6.35 ±1.7 81.5% male	Subset of SSP reflecting SOR in touch, taste/smell, movement, visual and auditory domain: SOR	CSHQ: BR; SOD; NW; SDB; SD; SA;DS; TST	CBCL scales: Aggressive Behavior Syndrome Scale; Attention Deficit/Hyperactivity DSM-Oriented Scale; Anxiety Problems DSM-Oriented Scale; Somatic Complaints Syndrome Scale; ABC; AuBC	Significant relationship between sleep difficulties and SOR in both younger and older participants; SOR predicted later sleep problems in younger children, and sleep disturbance longitudinally predicts hyperactivity and attention challenges	United States	X	
Nieminen-von Wendt et al., 2005, #17	Cross-sectional, descriptive, correlational Aim: Determine if a set of clinical features not included in the DSM-IV or ICD-10 for AS, are associated with AS or a familial trait that is not related to AS.	*N* = 10 families (138 individuals), 58 ASC 4.5-78.2 years M_{age} = 32.8	Purpose built questionnaire (face recognition difficulties, presence of aberrant sensibilities, aberrant eating habits): Face recognition differences and aberrant sensibilities (touch, light, sound, smell) high in family members with AS; aberrant eating habits higher in AS	Purpose built questionnaire (sleeping disturbances): Sleep disturbances in AS, 48.3%; NT 23.2% Risk of sleep problems slightly higher in AS	VABS	No clear links examined; both differences in sensory processing and greater sleep disturbances are important to consider in AS.	Finland	X	
Ornitz et al., 1973, #18	Cross-sectional, descriptive, correlational Aim: Examine sleep characteristics of autistic and NT children under 3 sensory conditions during sleep: no stimulation; mild continuous sinusoidal vestibular stimulation; auditory click stimulation	ASC *N* = 6 39.3-94.5 months M_{age} = 57.57 100% male; NT *N* = 8 43-128 months M_{age} = 65.44 75% male	NA	REM activity during REM sleep; # REM periods, duration of REM burst within each REM period, duration of REM period, % time in REM, # night wakings; proportion of time awake.	EEG to determine sleep stage; eye movements to reflect REM bursts	Autistic children showed fewer REM burst eye movements with vestibular stimulation, suggesting under-responsivity	United States	X	

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TABLE 2 | (Continued)

References, table, ID#	Study design and aim	Participants, N, Age Range, M_{age}, % Males	Sensory processing tool; areas of sensory difference	Sleep tool and areas of difference	Other measures related to aims	Findings related to sleep and sensory processing	Country	Quant	Qual
Reynolds et al., 2012, #19	Cross-sectional, descriptive, correlational Aim: Examine relationship between physiologic responses to sensation and sleep in autistic and NT children; determine variables distinguishing good from poor sleepers	ASC *N* = 27 6-12 years M_{age} = 104.85 ± 21.9 85% male; NT *N* = 29 6-12 years M_{age} = 105.04 ± 22.9 50% male	SP: ASC children had higher percentage of definite difference scores for all SP quadrants, significantly greater dysfunction relative to NT children; 81% scored definite difference for at least one quadrant	Sleep questions from CBCL formed sleep index (nightmares, overtired, sleeps less than most kids, sleeps more than most kids, talks or walks in sleep, trouble sleeping): autistic children had higher frequency of problem sleep behaviors; sleep index in autistic children higher	EDA, EDR, cortisol response to sensory challenge	Autistic children have more sleep disturbances and sensory modulation differences than NT; sensation avoiding highly correlated with sleep problems; poor sleepers together had have high afternoon cortisol, greater EDR response to sensory challenge, trend toward higher cortisol 25-30 minutes post sensory challenge; auditory stimulus most salient in distinguishing good vs poor sleepers; poor sleepers also had higher magnitude responses to smell and visual stimuli	United States	X	
Sacco et al., 2010, #20	Cross-sectional, descriptive, correlational Aim: Delineate medical components of autism; assess association with biological endophenotypes	ASC *N* = 245 2-30 years M_{age} = 8.82 ± 5.62 88.2% male	Purpose built questionnaire (pain sensitivity, presence of muscle hypotonia at intake): Decreased pain sensitivity, 36.7% Hypotonia, 10.2%	Purpose built questionnaire (sleep disorder at intake): Not specified	VABS, Griffith Mental Developmental Scales; Colored Raven Matrices; Bayley Developmental Scales; Leiter International Performance Scale	Identified four medical components of autism, one termed 'circadian and sensory dysfunction'	Italy	X	
Silva and Schalock, 2012, #21	Cross-sectional, descriptive, measure validation Aim: Validation of Sense and Self-regulation Checklist (SSC).	ASC *N* = 99 M_{age} 3.9 ± 1.2** 81.8% male DD *N* = 28 M_{age} = 2.26 ± 1.4** 60.7% males NT *N* = 138 M_{age} = 3.9 ±.89** 50.7% male	SSC: SOR and SUR in 4 sensory domains (touch–pain auditory, visual, taste–smell) broken into body part areas: 96% prevalence of ≥ 1 SOR or SUR response; more SOR than SUR	SSC, self-regulatory items re sleep: Significant differences for autistic children relative to others for TST, and total sensory + TST; all self-regulatory domains differentiated autistic children from others	PDDBI	Self regulatory and sensory differences co-exist significantly; sleep is negatively impacted	United States	X	X

(Continued)

TABLE 2 | (Continued)

References, table, ID#	Study design and aim	Participants, N, Age Range, M_{age}, % Males	Sensory processing tool; areas of sensory difference	Sleep tool and areas of difference	Other measures related to aims	Findings related to sleep and sensory processing	Country	Quant	Qual
Tzischinsky et al., 2018, #23	Two-group comparison; correlational Aim: Perform more in depth study of sleep disturbances and sensory differences in children with autism	ASC *N* = 69 3-7 years M_{age} = 4.94+1.23 81% male NT *N* = 62 3-7 years M_{age} = 4.84 + 1.15 66% male	SP: significant between group differences in all 5 sensory modalities; autism group significantly lower scores compared to norms and controls. Autism group had lower scores for both high and low threshold items.	CSHQ: Autism group had greater disturbance for total score and all subscales except sleep DB, NW, DS		Autism group showed significant negative correlation between touch + oral sensitivity and total sleep disturbance; control group between touch + vestibular sensitivity and total sleep disturbance. Both groups showed same pattern of scores for low threshold items. Touch sensitivity predicted 29% of variance in total sleep disturbance score in autism group, 16% in control; 20% of variance in controls explained by vestibular sensitivity. Touch low threshold items alone predicted 24% variance in total sleep disturbance in autism group.	Israel	X	
Wang et al., 2019, #24	One-group, cohort, cross-sectional Aim: Evaluate association between sensory processing problems and sleep disturbances, emotional and behavioral problems and abnormal mealtime behaviors in autistic children	ASC *N* = 81 3-6 years M_{age} = 5.18 ±.92 82.7% male NT *N* = 153 3-6 years M_{age} = 5.34 ± 1.14 73.2% male	SSP: ASC significantly more SUR, SS, auditory filtering, low energy/ weak, and total	C-SHQ: Greater BR, SOD, SA, DS, total sleep score	SCQ, SDQ, Mealtime Behavior Questionnaire; Peabody Picture Vocabulary Test	In autism group, significant relationship between CSHQ total and SOR for tactile and movement, SUR, SS, low energy/weak, total SSP; SUR and SS explain 8% variance in total CSHQ scores; SSP total explained 18.7% variance in sleep disturbance	China	X	

Descriptive terms: AS: Asperger Syndrome; DD: developmental disability; NT: neurotypical; LD: learning disability.

Assessment tools: ABC: Aberrant Behavior Checklist; AIS: Athens Insomnia Scale AuBC: Autism Behavior Checklist; BSID: Bayley Scales Of Infant and Toddler Development; CARS: Childhood Autism Rating Scale; CBCL: Child Behavior Checklist; CSHQ: Children's Sleep Habits Questionnaire; C-SHQ: Chinese Sleep Habits Questionnaire; EDA: electrodermal activity EDR: electrodermal response; ISI: Insomnia Severity Index; JSQP: Japanese Sleep Questionnaire for Preschoolers; MSEL: Mullen Scales of Early Learning; PDDBI: Pervasive Developmental Disorders Behavior Inventory; SB5: Standford Binet 5th edition; SCQ: Social Communicatoin Questionnaire; SDQ: Strengths and Difficulties Questionnaire; SDSC: Sleep Disturbance Scale for Children; SP: Sensory Profile; SP-J: Japanese Sensory Profile; SPQ: Sensory Perception Quotient; SSP: Short Sensory Profile; TMS: Tactile Stimulation Modulation; VABS: Vineland Adaptive Behavior Scale; WPPSI: Wechsler Preschool and Primary Scale of Intelligence.

Sleep parameters: BR: bedtime resistance; CRD: circadian rhythm disorder; DS: daytime sleepiness; RLS: restless leg syndrome; SA: sleep anxiety; SD: sleep duration; SDB: sleep disordered breathing; SE: sleep efficiency; SOD: sleep onset delay; SOSA: sensory obstructive sleep apnea; NW: Night Wakings; TST: total sleep time; WASO: wake after sleep onset.

Sensory domains: SOR: sensory over- reactivity or responsivity; SS: sensory seeking; SUR: sensory under-reactivity or responsivity.

* *Other details on age not provided.*

***These articles appear to be duplicates in terms of participants, design, and outcomes; different authors and journal. Only one was fully reported?in the current review.*

****CSHQ Total Score was based only on items listed in insomnia subscale.*

TABLE 3 | Interventions addressing sleep and sensory processing.

References, table 3 ID#	Study aim(s) and design	Participants, age range, % male	Sensory processing tool; areas of sensory difference	Sleep tool and areas of difference	Other measures	Intervention	Findings	Country	Quant	Qual
Cullen et al., 2005, #1	One-group cohort, exploratory Aim: Explore experience of parent/child touch before and after touch therapy training program; develop model of touch therapy process	ASC *N* = 14 2-13 years** 87% male	Parent report of tactile defensiveness, food aversion related to texture and temperature	Parent report of poor sleep patterns	Parent interview and Home Record Sheet		Improved sleep patterns in 6/7 children with sleep difficulties; more relaxed and calmer child; improved tolerance of touch, increased sense of closeness between parent and child	UK		X
Gee et al., 2021a, #3* (Gee et al., 2021b, #4*)	Single subject, pre-post test ABA Aim: Assess effectiveness of weighted blanket use on sleep quality in autistic children with sleep disturbances and SOR	*N* = 2 P1: 4 years 5 months, male; P2: 4 years 1 month, female	SPM-P: P1: definite difference for tactile, auditory, visual SOR P2: definite difference for tactile, auditory, visual SOR	CHSQ; Sens Sleep App P1: poor sleep quality; difficulty falling asleep (seven days a week), WASO (seven days a week), wakes up too early (five days a week), experiences a poor morning mood (five days a week) P2: difficulty staying asleep (wakes > x1, five days a week), wakes up too early (seven days a week), experiences a poor morning mood (five days a week).	Daily online survey re sleep parameters	A(1): 9 dy baseline; B: 14 consecutive days weighted blanket (10% body weight) use; A(2): 7 days, no blanket. Data collected for time to fall asleep, number of wakings, hours of sleep, morning mood	Weighted blanket had little influence re improving sleep quality through the objective and subjective measures	United States	X	
Gee et al., 2016, #5	Single subject with repetition; ABA design Aim: Explore effectiveness of weighted blankets with autistic children ages 3-6, and SOR (touch and/or auditory)	*N* = 2, P1: 4 years, 2 month, male; P2: 5years, 1 month, male	SPM: P1: definite difference in social participation, visual, auditory, tactile processing, body awareness, balance and motion, planning and ideas P2: definite difference in social participation, visual, auditory, tactile processing, body awareness, balance and motion, planning and ideas	CHSQ; P1: falling asleep on his own, NW, staying in bed at bedtime, SD P2: WASO, fear of the dark, breathing difficulties (chronic congestion, history of ear infections) at night, awakening in negative mood	Daily online survey re sleep parameters	A(1): 9 days, baseline; B: 14 consecutive days weighted blanket (10% body weight); A(2): 7 days, no blanket. Data collected for time to fall asleep, number NW, hours of sleep, morning mood	Minimal improvement (slight increase in TST/night and decrease in time to fall asleep).	United States	X	
Gringras et al., 2014, #7	RCT, multicenter, controlled, crossover Aim: Determine if weighted blankets increase TST and improve other sleep parameters for autistic children	*N* = 73; 6 discontinued 5-16 years $M_{age} = 8.7 \pm 3.3$ 88% male [in intervention first], $M_{age} = 9.9 \pm 2.8$ 74% male [in control first]	SSP: domain scores not provided	Baseline parent report: Failing to fall asleep within 1 hr of "lights off", 3/5 and/or failing to achieve 7 hrs continuous sleep, 3/5 nights. Study measures: actigraph and sleep diary for TST, SOL, CHSQ: SOD, poor sleep maintenance, poor sleep onset and maintenance	CSDI, ABC, SBQ, SCQ	Baseline: 7-21 dys; Weighted blanket vs non-weighted blanket, 12-16 dys	No difference in TST, SE, WASO, sleep latency between blankets in actigraph or sleep diary. CSDI showed slight improved sleep with control blanket. Children "really liked" weighted blanket more than control; parents indicated sleep was much better, child calmer with weighted blanket.	UK	X	X

(Continued)

TABLE 3 | Interventions addressing sleep and sensory processing.

References, table 3 ID#	Study aim(s) and design	Participants, age range, % male	Sensory processing tool; areas of sensory difference	Sleep tool and areas of difference	Other measures	Intervention	Findings	Country	Quant	Qual
Lawson and Little, 2017, #13	One-group, cohort, cross-sectional, pre-post test Aim: Understand effects of swimming on sleep in ASC children Examine feasibility of swimming program Define features of children showing decreased sleep disturbance	ASC *N* = 10 5-12.3 years M_{age} = 7.5 ± 2.4 years	SP: Definite or probable difference for all quadrants for both responders and non-responders	CSHQ: Elevated sleep disturbance scores at baseline	Demographic form SRS Parent satisfaction questionnaire	8 wkly 30-minute swim lessons; 1:1 with social opportunities (e.g., songs and games) at the start/end each lesson. Lessons individualized based on learning and sensory preferences, emphasized both skill development and water safety	All families completed; high parent satisfaction; intervention feasible. Variable changes in sleep (4/10 improved, 1/10 remained the same; 5/10 increased sleep disturbance). Responders were older, had decreased ASC severity, attended more sessions and had sensory characteristics reflecting high sensory sensitivity and avoidance, with low SS	United States	X	X
Silva et al., 2007, #22	One-group, cohort, cross-sectional, pre-post test Aim: Replicate earlier study with small controlled sample and blinded examiners	ASC *N* = 15 [intervention] *N* = 7 [control] 3-6 years M_{age} = 3.9 ± 1.2 81.8% male At 5 months control group also received treatment; *N* = 5	SP; All five senses were involved, although different children had different combinations of involvement Response to massage tool; scoring number of areas of aversion and duration of tolerance to touch. Video of first visit:	Parent questionnaire sleep items	BDI: Cognitive Domain Screening Test VABS: Daily Living Skills, Socialization, Communication, Motor domains Parent Questionnaire addressing bowel patterns Study designed Scoring Tool for Cignolini Method	The Cignolini Qigong methodology: 11 different Qigong massage movements from head to foot along acupuncture channels; duration of 15 min. Delivered for 5 months total, alternating practitioner administration twice daily for 5 weeks with parent administration at least once daily for 5 weeks.	SP scores improved overall (total SP) and within each sensory domain in intervention group; decrease in number of body areas showing adverse responses to gentle touch; improved sleep and bowel concerns. Improvements in daily living skills and social learning	United States	X	

Descriptive terms: NT: neurotypical; STS: sleep to sound mattress.

Assessment tools: ABC: Aberrant Behavior Checklist; BDI: Batelle Developmental Inventory; CCC: Children's Communication checklist; CFQL: Child and Family Quality of Life questionnaire; CSDI: Composite Sleep Disturbance Index; CSHQ: Children's Sleep Habits Questionnaire; FISH: Family Inventory of Sleep Habits; PDDBI: Pervasive Developmental Disorders Behavior Inventory; SBQ: Sensory Behavior Questionnaire; P: Sensory Profile; SCQ: Social Communication Questionnaire; SRS: Social Responsiveness Scale; SSP: Short Sensory Profile; VABS: Vineland Adaptive Behavior Scale.

Sleep parameters: DS: daytime sleepiness; SD: sleep duration; SOD: sleep onset delay; SOL: sleep onset latency; NW: Night Wakings; TST: total sleep time; WASO: wake after sleep onset.

Sensory domains: SOR: sensory over- reactivity or responsivity; SS: sensory seeking; SUR: sensory under-reactivity or responsivity.

**These articles appear to be duplicates in terms of participants, design, and outcomes; different authors and journal. Only one was fully reported in the current paper.*

*** Other details on age not provided.*

2018; Wang et al., 2019; Eyuboglu and Eyuboglu, 2020) and that a greater number of sensory integration/processing differences could be seen in autistic children with sleep concerns (Klintwall et al., 2011). Jamioł-Milc et al. (2021), investigating tactile modulation differences in autistic children through parent interview and observation, identified a potential relationship between tactile hypo-responsivity and insomnia but no relation between tactile hyper-responsivity or sensory seeking and insomnia. Interestingly, Ghanbari and Rezaei (2016) found no relationship between sensory processing differences and sleep concerns.

Using a Hebrew version of the CSHQ (45) (Tzchishinsky et al., 2008) and a version of the Infant-Child Sensory Profile (Neuman et al., 2004; Dunn, 2014) that had been validated in Israel, Manelis-Baram et al. (2021) examined the relationship between sleep and sensory reactivity at ages 3 (time 1) and 4.47 (time 2) years. Looking first at time 1, investigators indicated that sensory sensitivity was the only reliable indicator of sleep disturbance when controlling for scores in other sensory quadrants on the SP. Sensory sensitivity showed a strong relationship with both nighttime and total sleep time (including naps). Looking at change over time, these investigators found that more than 50% of their participants showed considerable changes (positive or negative) in either sleep severity or sensory reactivity. Hierarchical regression modeling, using age at time 1, time between assessments, time 1 sleep score, and the change in sensory sensitivity between times 1 and 2, investigators strongly predicted sleep disturbance at time 2; no other measure of sensory reactivity contributed to this prediction. They concluded that sleep disturbance and sensory reactivity severity were coupled and possibly rooted in a common physiological mechanism.

With a somewhat different focus, Mazurek and Petroski (2015) and Mazurek et al. (2019) drew items from the SP that reflected only sensory hyper-reactivity. Mazurek and Petroski (2015) grouped children with autism into younger (2–5 yrs.) and older (6–18 yrs.) subsets and found sensory hyper-reactivity to significantly correlate with all CSHQ (45) subscales. Applying a path analysis, they found sensory hyper-reactivity to be associated only with sleep onset delay, sleep duration, and night waking for the younger group. In contrast, sensory hyper-reactivity was related to all CSHQ (45) subscales except night waking for the older children. In a later study, Mazurek et al. (2019) identified a relationship between sensory hyper-reactivity and all subscales of the CSHQ (45) in both preschool and school-aged children. These investigators further indicated that sensory hyper-reactivity in preschoolers predicted sleep challenges at school age.

Looking within specific sensory systems, Tzischinsky et al. (2018) used the Hebrew version of the SP (Neuman et al., 2004) and found that while tactile and oral sensitivity differences were related to total sleep disturbances [Hebrew CSHQ (45)], tactile hyper-reactivity explained 24% of the variance in total sleep disturbance scores in autistic children. Jamioł-Milc et al. (2021) investigated tactile modulation disorders (either hyper- or hypo-reactivity) and poor-quality sleep in autistic children using their own tools. While they did not find significant relationships because of small sample size, they suggested that insomnia in autistic children could be related to tactile hypo-reactivity. Ornitz et al. (1973) investigated auditory and vestibular input and the relationship to aspects of REM sleep. These investigators found fewer REM burst eye movements in the autistic children who slept on a custom-made mattress that delivered continuous sinusoidal vestibular input, compared to the non-autistic group. One suggested conclusion from this study was that the vestibular system might be hypo-responsive during sleep in young autistic children.

Hohn et al. (2019) examined the relationship between sleep concerns, measured using the Insomnia Severity Index (ISI; Morin, 1993), and sensory processing differences, using the Sensory Perception Quotient (SPQ; Tavassoli et al., 2014a) in autistic adults, along with a link to social skills. They predicted that findings would parallel those in autistic children, and might vary relative to the sensory domain addressed. Overall, they found subthreshold insomnia in their population, although it was higher than that in a neurotypical population. The severity of insomnia was predicted, and potentially driven by, high levels of visual reactivity (neither proprioception nor vestibular modulation were assessed), but also related to increased difficulty engaging in neurotypical social skills as measured by the Autism Spectrum Quotient short form (ASQ; Hoekstra et al., 2011). Sacco et al. (2010) included adults and children in their study, seeking to define factors that contribute to *autistic traits* using statistical methods. Using a purpose-built survey based on clinical *features of autism*, participant and family features, and supporting assessments, these investigators completed a complex principal components analysis resulting in the identification of four components that they hypothesized may allow for categorization of autistic endophenotype subgroups with some homogeneity. One such component was, "circadian and sensory dysfunction" which was linked to sleep disorders, self-injurious behavior, hyperactivity, decreased pain sensitivity, and differences and delays in language development. Authors suggest that sleep challenges and sensory differences could be connected in a complex manner.

Effect of Sensory-Based Interventions on Sleep

We found relatively few studies we considered *sensory-based,* having a primary sensory intervention focus. Gee and colleagues (Gee et al., 2016, 2021a,b[5]), as well as Gringras et al. (2014), investigated the use of weighted blankets in improving sleep for autistic children. Based on existing theory, they reasoned that the provision of deep touch pressure might release endorphins and serotonin, leading to a sense of calm. In each of the investigative reports by Gee et al. (2021a,b) a single subject ABA design with replication was used (N = 2 in each study). These investigators collected data across a 9-day baseline, 14-day intervention, and 7-day intervention withdrawal period in all studies. Outcomes reflected no meaningful improvement in CSHQ (33) sleep quality either subjectively or objectively. Gringras et al. (2014) conducted a more rigorous randomized control study with crossover, and a

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[5] Gee et al., 2021a,b appear to use the same population and have the same aims. They have been treated as a single manuscript for reporting purposes.

much larger sample size ($N = 73$). Based on the actigraph sleep measure used, the weighted blanket (used for 12–16 days) failed to lead to improved quantitative sleep scores, although parents perceived their child slept better and was calmer after using the weighted blanket. In addition, parents reported that their child liked sleeping under the weighted blanket.

Lawson and Little (2017) investigated a sensory-enhanced swim program for autistic children. In this pre/post single group study autistic children with sensory integration/processing concerns identified using the SP, participated in 8 weekly 1:1 swim lessons, each 30 min in length. There was also the opportunity for social interaction. The sensory enhancements to swimming were based on sensory strengths and needs, as identified on the sensory profile, along with visual schedules, communication strategies, physical supports, and modeling. They found the intervention to be feasible, with high parent satisfaction. Looking at sleep outcomes reflected on the CSHQ (33), 40% of the children showed reduced sleep disturbance, and 50% showed increased sleep disturbance. Of the 40% showing improvements in sleep, children were older, *autism severity scores* were lower, the children attended more swim sessions, and baseline sensory differences reflected sensory hyper-reactivity but low sensory seeking. Investigators concluded that children with sensory hyper-reactivity may be the best candidates for this intervention; they hypothesized that engagement in the intervention provided proprioceptive and tactile inputs that helped the children regulate their arousal. Johnson et al. (2021) also utilized a swimming intervention, provided in 12-sessions over a 3-week timeframe. Although the focus of this study was on child *challenging behavior* and parent wellbeing, parent report indicated improved sleep on the days of swim lessons.

Cullen et al. (2005) trained parents to implement a touch therapy (massage) program, titled "Training and Support Programme" (TSP). Parents received 8 weekly training sessions with the therapist and their child. In addition, they received written information which included instructions, diagrams, and photographs to guide the touch interactions with their child. Parents completed home record sheets and engaged in an interview 16 weeks from baseline. The home record sheets indicated that touch therapy sessions lead to calm, relaxation, and sleepiness in five of seven children, and improved sleep patterns for six of the seven children reported to have sleep difficulties. Other benefits were also noted, including an increased feeling of closeness between parent and child.

Silva et al. (2007) examined the effect of providing Cignolini Qigong massage to autistic children, determining if they could replicate outcomes from an earlier case series (Silva and Cignolini, 2005). Using a two-group design (treatment and control), trained practitioners initially provided massage (11 massage movements delivered in approximately 15 min) twice weekly for 5 weeks. Parents were given written and verbal instruction during initial sessions and demonstrated their ability to provide intervention during later sessions. For the next 5 weeks, the parent provided the massage at least once daily. Practitioner and parent interventions then alternated in 5-week blocks for the 5-month intervention. At the 5-month time, investigators offered intervention to the control group, based on improvements in the intervention group. Silva et al. (2007) reported global improvement in sensory processing scores on the *Sensory Profile* following the intervention, and a worsening of sensory concerns in the control group prior to being switched to intervention. Sleep improvements were reported by parents in areas including going to sleep at a typical time, faster sleep onset time and sleeping through the night.

DISCUSSION

While there is a body of literature addressing the sensory differences experienced by autistic individuals (cf. Crane et al., 2009; Elwin et al., 2017; Feldman et al., 2020) and another addressing sleep concerns (cf. Malow et al., 2006; Goldman et al., 2012; Morgan et al., 2020), the interplay between these constructs has not received the same degree of consideration. We report evidence indicating, at minimum, a co-existence of sensory integration/processing differences and sleep concerns in autistic children, and to some extent, autistic adults (Nieminen-von Wendt et al., 2005; Klintwall et al., 2011; Reynolds et al., 2012; Silva and Schalock, 2012; Tzischinsky et al., 2018; Wang et al., 2019; Eyuboglu and Eyuboglu, 2020; Kosaka et al., 2021). In some instances the relationship was predictive (Hohn et al., 2019; Mazurek et al., 2019). Some narrative reviews, however, have suggested a causal relationship between sensory sensitivity and difficulties with sleep in autism (cf. Cortesi et al., 2010; Reynolds and Malow, 2011). A handful of investigators have begun to examine interventions that are sensory-based or sensory incidental in nature, with some having a positive, or partially positive, impact on sleep (Cullen et al., 2005; Silva and Schalock, 2012; Lawson and Little, 2017). However, there are few intervention studies, and they are hampered by small sample sizes and often no comparison groups.

Of note, the vast majority of literature we identified was on children and teens; only Hohn et al. (2019) focused on adults, and results indicated that insomnia in autistic adults was predicted by high levels of sensory reactivity differences, along with decreased social skills as defined in neurotypical individuals, as measured by the ASQ. Approaching this data dimensionally—per the RDoC framework—Hohn and colleagues suggest that these relations indicate a cyclical influence between quality of sleep, sensory responsivity and the resources autistic adults have available to navigate neurotypical social interactions.

While Sacco et al. (2010) included adults in their sample, the mean age in this study was 8.82 ± 5.62 years. They did identify a component of autism characterized by circadian and sensory integration/processing differences, linking sensory integration/processing differences and sleep concerns across several life stages. Thus, while we have some insight into the relationship between sleep concerns and sensory integration/processing differences in autistic adults, this connection requires further investigation.

Sleep concerns in autistics run the full gamut; bedtime resistance, sleep onset delay, short sleep duration, sleep anxiety, night wakings, sleep disorder breathing, parasomnias, daytime sleepiness; and shortened total sleep have all been reported.

Investigators have variably found that sleep in autistics may or may not be influenced by age (Tzischinsky et al., 2018), *autism severity* (Hollway and Aman, 2011), behavioral differences (Hollway and Aman, 2011), medications, (Hollway et al., 2013; Tzischinsky et al., 2018) and intellectual ability (Hollway et al., 2013). Similarly, sensory integration/processing differences encompass a range of findings, including hyper- and hypo-reactivity and sensory seeking, with investigators also reporting a variety of specific sensory domain differences. The outcomes related to specific sensory domains are somewhat conflicting. Hohn et al. (2019) suggested that visual sensory sensitivity is a driver for insomnia in autistic adults. In children, investigators report poor auditory filtering and taste/smell differences (Hollway et al., 2013), tactile hypo-reactivity (Wang et al., 2019; Jamioł-Milc et al., 2021), vestibular and oral hyper-reactivity (Kosaka et al., 2021), vestibular hypo-reactivity (Ornitz et al., 1973; Wang et al., 2019), and touch and oral hyper-reactivity (Tzischinsky et al., 2018).

As might be expected, the relationship between poor sleep and sensory integration/processing differences is often described as complex and multi-faceted. The inconsistencies noted by these investigators are likely related, in part, to the assessment and outcome tools used. As noted, investigators often used the CSHQ or a version of it. Other investigators used sleep diaries, or purpose-built tools, all relying on parent report. While literature reports consistency between parent report and objective measures of some domains of sleep (Malow et al., 2006), other sleep concerns may be under-estimated (e.g., night wakings) or over-estimated (e.g., total sleep duration) (Goodwin et al., 2007) by parents. The intervention study conducted by Gringras et al. (2014), and the characterization study by Kosaka et al. (2021) coupled parent report tools with an objective measure of sleep such as actigraphy. To optimally measure sleep challenges many investigators recommended the use of actigraphy, polysomnography or activity trackers to enhance accuracy.

A variety of frameworks and models have been proposed to describe sensory reactivity differences, and, while there is some overlap between the models, there is no current consensus regarding typology. Most of the studies examined in this review relied on the model derived from the Sensory Profile (SP; Dunn, 1999), the Short Sensory Profile (SSP; McIntosh et al., 1999), and the Sensory Profile 2 (Dunn, 2014). As noted earlier, in this model Dunn considers the interface between neurological threshold and self-regulation in response to sensation, and identifies patterns across four quadrants (poor sensory registration, sensory seeking, sensory avoiding, and sensory sensitivity). Reactivity differences within each sensory domain (sensory section scores) can be identified along a continuum from hyper- to hypo-reactivity, and within behavioral domains (behavioral section scores). Other models of sensory processing differences have also been developed, but few were used in the studies included in our review. Thus, our review findings regarding sensory processing differences are informed more by the SP, or a derivative of it, than any other model or tool. Furthermore, the selection of these tools emphasizes differences in sensory modulation and omits sensory discrimination and the sensory-based motor differences of posture and motor planning defined in a recent model of sensory integration (Bundy and Lane, 2020). Expansion of research to include these dimensions would enable investigators to explore the dynamic interactions among constructs that contribute to health and illness.

Sleep is a universal and core occupation throughout the lifespan. Inadequate sleep can interfere with synaptic development and brain maturation, attention, memory, mood regulation, behavior, and other aspects of daytime function (Killgore, 2010; Beebe, 2011), leading to restrictions in occupation and participation. While sleep difficulties are not uncommon in the neurotypical population, sleep disorders have been reported in up to 80% of autistic individuals (Richdale and Schreck, 2009; Souders et al., 2009; Cortesi et al., 2010; Morgan et al., 2020). Souders and colleagues suggested that autism alone may predispose individuals to sleep problems. Alternatively, being autistic in a neurotypical world may itself predispose individuals to sleep problems.

Differences in neural synaptic pruning and neural organization, circadian function, and melatonin production, and arousal and sensory processing have been identified in autistic individuals, and are putative causes of insomnia. The potential connection with sensory integration/processing and establishing supportive circadian rhythm cannot be overlooked. Verhoeff et al. (2018) suggest that sleep concerns are part of the overall picture of autism. They indicate that sleep problems in autistics increase as children age, and contrast this with the decrease in sleep problems across ages seen in the neurotypical population. The effect of sleep deprivation, the high incidence of sleep concerns in autistics, and the possibility that sleep concerns may worsen during childhood, make it critical to consider effective interventions. In addition, and importantly, sleep challenges for autistic children also have a negative impact on the sleep of their parents (Lopez-Wagner et al., 2008).

Therapeutic supports have been suggested. A recent review and meta-synthesis of sleep interventions for autistic children indicated that intervention fell into five broad approaches: pharmacological, melatonin (which is sometimes included in the pharmacological category), behavioral, parent education, and alternative therapies (Cuomo et al., 2017). In terms of pharmacological interventions, melatonin appears to have the strongest level of support, especially for sleep duration and latency to sleep onset. A major drawback relative to melatonin is that it may stop working after its initial success (Bruni et al., 2007). In addition, Esposito et al. (2020) indicated that parents of autistic children often prefer non-pharmacological interventions.

There is some evidence suggesting that behavioral interventions, which include a wide array of approaches ranging from extinction, to developing sleep hygiene, may have positive effects. Practice Guidelines from the American Academy of Neurology (Buckley et al., 2020) support trying behavioral interventions initially, and offering melatonin as a second line of defense. Esposito et al. (2020) suggested that behavioral interventions will not be a good fit for all families; such interventions should be guided by a knowledgeable clinician and utilized by motivated caregivers. They further indicated that approaches such as sleep hygiene and behavioral interventions are not well utilized or understood by parents, and are not well researched.

Parent education programs show some effectiveness, although it appears to be relatively weak (Cuomo et al., 2017). The Autism Treatment Network[6] provides a parent guide and sleep tool kit for parents that addresses sleep setting and aspects of sleep hygiene; it also includes a supplemental calming module, addressing internal factors including sensory and arousal dysregulation that threaten sleep. However, Adkins et al. (2012) have suggested that written material alone is not sufficient support for parents. Both Cullen et al. (2005) and Silva et al. (2007) provided written materials and one-to-one training in their investigations of different forms of massage. Cullen and colleagues noted that, while some of the child participants initially found touch therapy (massage) unsettling, the majority accommodated over the course of the program. Cullen et al. (2005) indicated that parents reported positive changes in many behaviors; of the seven children with sleep concerns, six showed improvements in sleep. This investigation did not include a comparison group. Silva and colleagues also report improved sleep following a Cignolini Qigong intervention, along with positive changes in sensory processing, adaptive and social skills. While still a relatively small study (total $n = 15$), a comparison group was included, adding some rigor.

Alternative interventions, including types of massage described above, have been noted to have some positive outcomes. In conducting this review we identified studies that we interpreted as *sensory incidental,* delivering sensation as an important component of the intervention. Two were yoga-based interventions, which would have incorporated proprioception and vestibular inputs as well as addressing sensorimotor differences like posture and bilateral coordination. In a pilot and follow-up study Narasingharao et al. (2017a,b) provided yoga to autistic children, delivered by a trained yoga teacher; parents were encouraged to practice asanas at home with their child. Investigators documented changes in all aspects of sleep measured by a purpose-built questionnaire in both studies; parent report indicated uninterrupted and longer duration nighttime sleep, and a reduction in daytime sleeping. Sleep disordered breathing also improved. Sensory changes noted included better body balance and body awareness, although there was no clear measure of sensory differences. Frazier et al. (2017) examined the effectiveness and tolerability of the "Sleep-to-Sound" mattress. This mattress technology allows users to hear any audio file, feel vibration, or have both stimuli coming through the mattress; the intensity of both sensations could be set by the user. In this study, a baseline period was followed by a 2-week intervention (mattress either on or off) with immediate crossover. Findings indicated overall tolerability, and improvement in sleep parameters including sleep duration and efficiency, as determined by actigraphy. In addition, parent-completed sleep diaries indicated improved sleep quality and ease of falling asleep. Unfortunately, because neither of these studies included a measure of sensory integration/processing they were not included in our review. Further, Cuomo et al. (2017) point out that the available studies using alternative interventions are of low quality. The guidelines from the American Academy of Neurology (Buckley et al., 2020) indicate that there is no evidence for the efficacy of interventions such as weighted blankets or specialized mattresses, much as we reported in this review.

Overall, the range of potential interventions coupled with limited research to support most described interventions points to a large gap in existing literature. In fact, Cuomo and colleagues concluded that of the available interventions, no single approach was effective across all domains of sleep concerns. Further, noted interventions failed to adequately address pre-sleep concerns (e.g., sleep anxiety). Given the clear relation between sleep concerns and sensory integration/processing differences (including modulation, discrimination and sensorimotor dimensions) identified in this review, we suggest that future investigations consider the inclusion of tools to address sensory differences within sleep focused interventions may provide a missing piece to the sleep intervention puzzle. This is supported in a case report by Souders et al. (2017), in which pre-sleep calming was based on sensory needs, along with anxiety, interests, and preferences, with positive outcomes for both sleep and anxiety.

LIMITATIONS

We limited our search to articles published in English and Spanish. As such we may have missed pertinent articles. In addition, there is considerable variability in terminology around sensory integration/processing; we may have missed some articles due to variability in keyword use. We did not restrict our review to studies with high rigor, thus some of the reported findings require replication. Some studies lacked detail, and this along with the variability in assessment tools and terminology made it challenging to summarize across studies.

CONCLUSION

There is an established relationship between sleep concerns and sensory integration/processing differences in autistic children. In contrast, there is insufficient evidence to make this determination for autistic adults. Overall, research examining sensory and sleep differences in autistic individuals warrants future investigation. While the number of studies examining characteristics of this relationship exceeded those examining intervention, there is still much that is unclear. Intervention studies are few in number, and generally of low quality. This is an area ripe for future research.

AUTHOR CONTRIBUTIONS

SJL participated in developing search terms, initial abstract and title review, full-text review, and data extraction, was responsible for writing the initial draft, doing, and overseeing

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[6] Autism Treatment Network (n.d.). *A parents guide to improving sleep in children with autism.* https://www.autismspeaks.org/sites/default/files/2018-08/Sleep%20Tool%20Kit.pdf.

edits, and was first and primary author of the manuscript. MAL participated in developing search terms, running the search, de-duplicating, initial abstract, title review, full text review, and data extraction and assisted in manuscript development and editing. VS participated in full text review and data extraction, and contributed to the editing process. All authors contributed to the article and approved the submitted version.

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Sensory Processing and Community Participation in Autistic Adults

Nancy Bagatell[1]*, Dara V. Chan[2], Ya-Cing Syu[1], Elena M. Lamarche[3] and Laura G. Klinger[3,4]

[1]Division of Occupational Science and Occupational Therapy, Department of Allied Health Science, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States, [2]Division of Clinical Rehabilitation and Mental Health Counseling, Department of Allied Health Science, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States, [3]TEACCH® Autism Program, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States, [4]Department of Psychiatry, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

Background: Sensory processing differences have been shown to impact involvement in community activities. However, relatively little is known about how these differences affect community participation in autistic adults.

Objective: The objective of this study was to explore how sensory processing patterns of autistic adults impact community participation, including where people go, what they do, the amount of time in the community, and preferred locations.

Methods: We used data gathered from six autistic adults and their caregivers who participated in two studies. From Study 1, we reviewed results of the Adolescent and Adult Sensory Profile (AASP) and transcripts from interviews with caregivers. From Study 2, we reviewed GPS tracking data and transcripts from structured interviews with autistic adults focused on community participation. We read transcript data, identified quotes related to sensory processing and community participation and constructed individual participant narratives which linked findings from interviews, AASP, and GPS tracking.

Results: Participants included three males and three females ranging in age from 29 to 51. Each participant had a unique sensory processing profile that influenced where they went, the activities in which they engaged, how much time they spent in the community, and their preferred locations. Those whose sensory processing patterns indicated sensory sensitivity and sensory avoiding described the experience of certain environments as overwhelming and fatiguing and thus spent less time in the community and visited fewer places than those with other sensory processing patterns.

Conclusion: Results highlight the importance of sensory processing, especially as it impacts participation in the community. Sensory processing patterns should be considered along with other personal and contextual factors when assessing community participation and personal sensory processing patterns should be matched with activities and environmental demands.

Keywords: community participation, sensory processing, autism, adults, geographic positioning system

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Batya Engel-Yeger,
University of Haifa, Israel

Reviewed by:
Gianluca Serafini,
San Martino Hospital (IRCCS), Italy
Stacey George,
Flinders University, Australia
Jewel Crasta,
The Ohio State University,
United States

Correspondence:
Nancy Bagatell
Nancy_Bagatell@med.unc.edu

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INTRODUCTION

Participating in community life, including work, school, leisure, and instrumental activities, such as doing errands and going to the gym, is considered an essential component of health and wellbeing for individuals across the life span (Khetani et al., 2013; Kuykendall et al., 2015). Participation involves having access and opportunities to meaningfully and actively engage in activities and connect with others (Hammel et al., 2008). In the International Classification of Health, Function, and Disability model (ICF; World Health Organization, 2010), both person and environment (contextual) factors contribute to participation. Despite its importance, literature consistently reflects that people with disabilities have lower rates of community participation than people without disabilities (Verdonschot et al., 2009; Askari et al., 2015). This is particularly true for autistic individuals.[1] Studies consistently indicate that autistic children and youth participate in fewer activities with less frequency than typically developing peers (Hilton et al., 2008; Potvin et al., 2013; Egilson Snæfrídur et al., 2017). This pattern of reduced community participation has been found to continue into adulthood. A longitudinal review of the National Longitudinal Transition Study-2 (NLTS-2) data reported a significant decrease in community participation from adolescence to adulthood, with one community activity per year considered a positive result (Myers et al., 2015). Autistic adults also report being less satisfied with their participation than typical adults (Song et al., 2021). Additionally, despite interest in activities in the community, autistic adults report they do not actually participate in these activities (Shea et al., 2021).

Relatively little is known about the determinants or predictors of these limited patterns of participation. Studies that do address the determinants of reduced participation suggest a confluence of many factors. Song et al. (2021) noted how environmental factors such as access to services and type of residential setting influenced community participation. Chan et al. (2021) found autistic adults who had a higher density of bus stops within a half mile of their home location had higher rates of volunteering, getting together with friends, and being invited to activities with friends. Additionally, in a scoping review of the literature on the participation of autistic children and youth, Askari et al. (2015) noted that environmental factors such as family support and social attitudes, the social and communication demands of the activity, and the clinical characteristics of autism such as restricted interests, challenging behavior, and sensory processing differences have been reported to impact community participation.

Sensory processing, the ability to register and modulate sensory information and respond to environmental demands, is a fundamental component of everyday life. It is through our senses that we interpret, experience, and respond to life events. Each person has a unique way of processing sensory information based on their nervous system, life experiences, and cultural values and beliefs. Sensory processing differences are typically described as either sensory hypersensitivity (a low neurological threshold) or sensory hyposensitivity (a high neurological threshold) which result in unique behavioral responses and preferences. According to Dunn (1997), people may seek out sensory input, avoid sensory input, have difficulty detecting sensory input, or have greater sensitivity to sensory input.

Sensory processing differences are commonly reported in autistic children, with prevalence rates of 56.8–92.5% (Dellapiazza et al., 2021). Compared to neurotypical children, autistic children demonstrate more difficulty filtering sensory stimuli and regulating responses to sensory input, such as being easily distracted by background noise or having increased sensitivity to tastes and textures of food (Tomchek and Dunn, 2007; Tomchek et al., 2014). These unique sensory processing behaviors may limit participation in social and recreational activities (Hochhauser and Engel-Yeger, 2010; Reynolds et al., 2011) and impact family activities and routines with families avoiding going places and attending events in the community that do not fit with their child's sensory preferences (Schaaf et al., 2011; Bagby et al., 2012). In the ICF model, the individual's sensory processing pattern, a person factor, interacts with the sensory environment of locations visited in the community. Participation is limited when sensory preferences do not match the sensory stimuli of the environment where desired community activities occur.

Sensory processing differences are also common in autistic adults, with prevalence rates ranging from 77 to 95% (Crane et al., 2009; Gonthier et al., 2016). Studies examining sensory processing profiles suggest that patterns may vary. For example, using sensory processing survey measures, Tavassoli et al. (2014) and Syu and Lin (2018) reported more overresponsivity in autistic adults without intellectual disability, while Crane et al. (2009) noted more diverse sensory patterns in this population. Additionally, Gonthier et al. (2016) reported lower registration behaviors and less sensory seeking behaviors in autistic adults with an intellectual disability. The impact of sensory processing patterns on everyday life has also been explored in studies using qualitative methods. In these studies, autistic adults describe how their participation in the community is affected by sensory experiences, such as being unable to go to nightclubs with friends or being distracted by colors of signs in the workplace (Robertson and Simmons, 2015; Clince et al., 2016). To date, no study has explicitly explored how autistic adults' sensory processing patterns influence community participation, specifically where people go, how often they are in the community, and their preferred activities and locations. This study offers a novel approach by integrating qualitative interviews, quantitative surveys, and Geographic Positioning System (GPS) tracking to understand the impact of sensory processing on community participation in autistic adults.

MATERIALS AND METHODS

In this paper, we report on data gathered from six autistic adults and their caregivers who participated in two different studies. Both studies were approved by the university Institutional Review Board.

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[1] We have chosen to use identity first language (autistic) rather than person-first language (person with autism) given the preferred language of many autistic self-advocates (Bury et al., 2020; Botha et al., 2021).

Study 1

Study 1 was a long-term follow-up study to assess adult outcomes of individuals who were diagnosed with autism as children between 1969 and 2000 at a university-based autism center. Participants (n = 55) completed a battery of assessments including IQ (Stanford Binet 5) and adaptive behavior (Vineland Adaptive Behavior Scales 2; VABS-2). Caregivers completed an interview focused on services and future plans and the Adolescent and Adult Sensory Profile (AASP). For this paper, we used demographic information and full-scale IQ (FSIQ) to describe our participants and the results of the AASP and transcripts from the VABS and caregiver interview for further analysis. These data were collected from 2013 to 2016.

Study 2

Participants for Study 2 were recruited from Study 1. Study 2 was a mixed methods study focused on assessing community participation using GPS tracking with 23 autistic adults over a 1-week period. After the study tracking week, participants completed a follow-up visit to review the GPS maps created and participated in a structured interview regarding community activities, barriers to participation, and the importance of different locations visited. These interviews were recorded and transcribed verbatim. Data were collected from 2016 to 2017.

The samples of the two studies were compared to identify individuals who participated in both studies. This comprised a sample of 10 individuals.

Measures

Adolescent/Adult Sensory Profile

The Adolescent/Adult Sensory Profile (AASP; Brown and Dunn, 2002) is a 60-item questionnaire which assesses behavioral responses to sensory experiences in everyday life. The questionnaire is for individuals ages 11 to 65. It is based on Dunn's (1997) sensory processing model. There are two key constructs in this model: neurological thresholds and self-regulation. One's neurological threshold, the point at which one notices and responds to sensory stimuli, can range from low to high. Self-regulation is also on a continuum, with behavioral responses ranging from passive to active. When these continua intersect, sensory processing patterns can be identified as: low registration, sensation seeking, sensory sensitivity, and sensation avoiding. Items on the AASP reflect the following sensory categories: taste/smell, touch, movement, auditory, visual, and activity level. Respondents rate the frequency with which they respond to each item using a 5-point scale (1 = almost never, 2 = seldom, 3 = occasionally, 4 = frequently, and 5 = almost always). This results in a total score for each quadrant ranging from 15 to 75. Higher scores indicate a higher frequency of each sensory processing pattern. Based on raw scores, sensory processing patterns are described as: much less than most people (2% of the population); less than most people (14% of the population); similar to most people (68% of the population); more than most people (14% of the population); and much more than most people (2% of the population; Brown and Dunn, 2002). The AASP is a reliable and valid tool which has been used in other studies to assess sensory processing in autistic adults (Crane et al., 2009; Horder et al., 2014).

Community Participation

Drawing on previous research (e.g., Hordace et al., 2014; Brusilovskiy et al., 2016), community participation was measured through the GPS tracking data collected over the 1-week study period and qualitative data from the follow-up structured interview in Study 2. Participants carried PocketFinder GPS trackers which recorded latitude/longitude coordinates of their location in the community every 2–5 min. Participants (or participants and caregivers) completed daily travel diaries during the 1-week period, providing more context to the locations visited such as the purpose of the activity, whether the activity was done alone or with others, and transportation used. From the GPS data, number of unique locations visited in the community, time spent away from home, and activity space size were examined as primary outcome measures of participation. Activity space was calculated as a 1 standard deviation ellipse using ArcGIS mapping software to incorporate the distance from one's home to the community locations visited during the study week, representing individuals visit some, but not all locations each day (see **Figures 1–6**).

In addition to the GPS data, transcripts of the structured interviews with the autistic adults were reviewed. Questions of particular interest for the current analysis included as: "Can you tell me about any barriers you faced this week to participating in activities outside of your house?" and "Looking at the map and all of the places that you visited this week, including your home, which places are most important to you? Why?"

Data Analysis

The analysis process for the current investigation involved creating a participant narrative linking sensory processing patterns to community participation. The study team met to examine potential patterns identified on the AASP in conjunction with GPS tracking measures, activity space maps, and summary

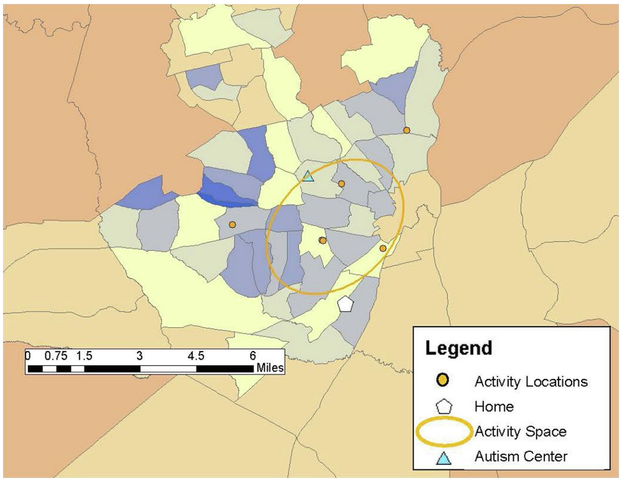

FIGURE 1 | Steve's activity space (23.45 mi^2) reflecting visits to a few locations dispersed throughout his community area during the 1-week study period.

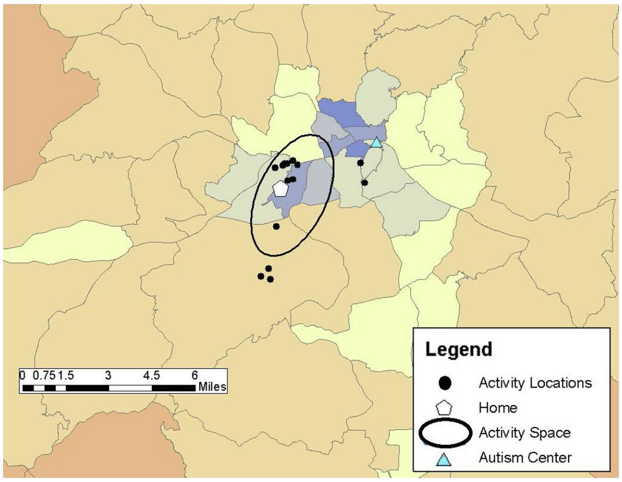

FIGURE 2 | John's activity space (8.51 mi^2) based on visiting several locations clustered close to his home and to each other during the 1-week study period.

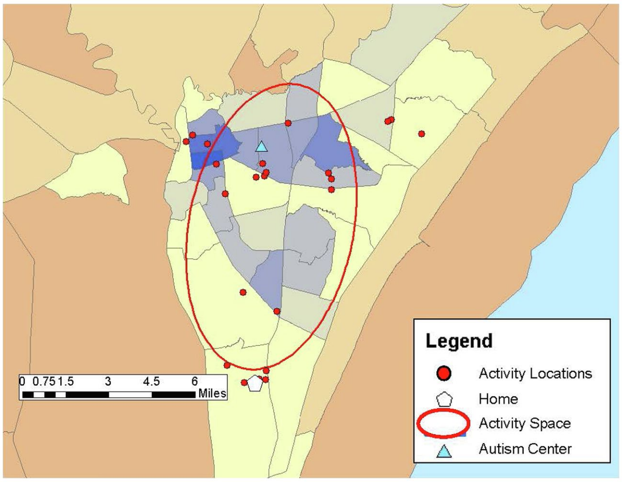

FIGURE 3 | Sherri's activity space (45.22 mi^2) shows both the wide dispersement and a large number of locations visited throughout her community area during the 1-week study period.

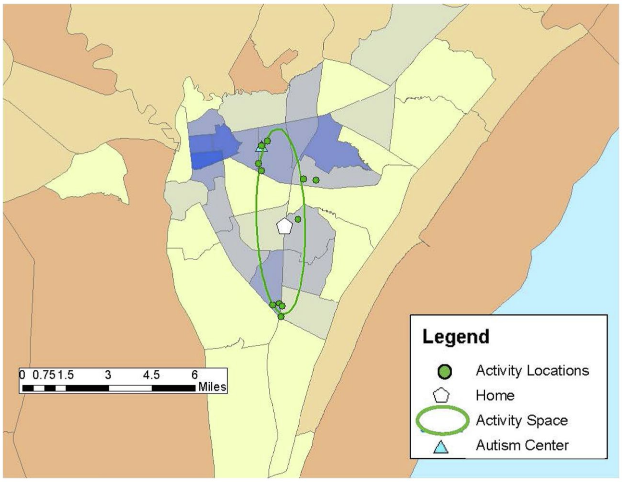

FIGURE 4 | Pete's community locations and activity space (8.6 mi^2) from the GPS study week reflect his visits to several locations close to home and the autism center he volunteered with during the 1-week study period.

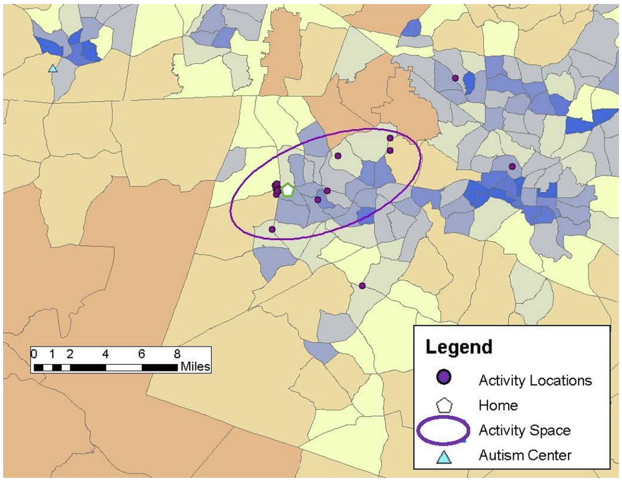

FIGURE 5 | Patti's activity space (44.72 mi^2) based on locations visited in the community during the 1-week study period, reflecting a combination of activities clustered around her home and those requiring greater geographic mobility.

interview data of key questions. Each member of the research team then was assigned two to three participants to complete an in-depth review of the available study data, including reviewing the transcripts from the VABS-2 and caregiver interview from Study 1 and the participant interviews from Study 2. Team members highlighted any content that appeared to be related to the impact of sensory processing in daily activities and community participation. The study team met again to share the findings of these in-depth reviews and selected six participants who had rich data and reflected a range of sensory processing patterns and demographic characteristics. Team members then returned to the data and did a careful review of the transcripts to ensure information related to sensory processing and community participation was not overlooked. The team then met to specifically discuss how information obtained from the GPS tracking (time away from home, number of locations, and activity space) related to sensory processing and community participation. Reviewing and analyzing data multiple times and discussing analytic insights with team members enhanced the rigor of our analytic process. The findings from these six participants are the focus of this paper.

RESULTS

Participants included three males and three females ranging in age from 29 to 51 (see **Table 1** for complete demographic information). Participant living situation and employment status varied, and only one drove independently. Each participant had a unique sensory processing profile (see **Table 2**) that may have influenced where they went, the activities in which they engaged, how much time they spent in the community, and their preferred locations, as illustrated through the case descriptions that follow.

Steve: "We have to drag him out when it's time to go!"

Steve was a 32-year-old African American/Asian male who lived with his family, which included his niece, nephew, and cousin, with whom he spent a lot of time. He reported he has always lived at this family residence. He was not employed and relied on his parents for transportation. His FSIQ was 60. Steve communicated easily and was friendly and outgoing during the research process. Steve spent most of his time during the study week at home since his mother, his primary form of transportation, was ill. However, he was "out and about" with his family an average of 2 hours a day running errands, transporting other family members, and going to fast-food restaurants. He enjoyed interacting with people in the community and noted that he sometimes "gives them a hug." Although Steve's mother noted his community activities were less during the data collection week than during a typical week, Steve visited seven different places with an activity space of 23.45 mi^2 (**Figure 1**) and spent most of his "out and about" time in the car. Typically, Steve spent time playing basketball at the community center and enjoyed ice skating and participating in Special Olympics. His mother indicated that Steve also enjoyed parties at the community center, and that he loved music and dancing. She recounted, "We have to drag him out when it's time to go!" A favorite activity that occurred once a year was attending the State Fair where Steve enjoyed going on rides and eating different foods. He indicated that his most important place was the mall.

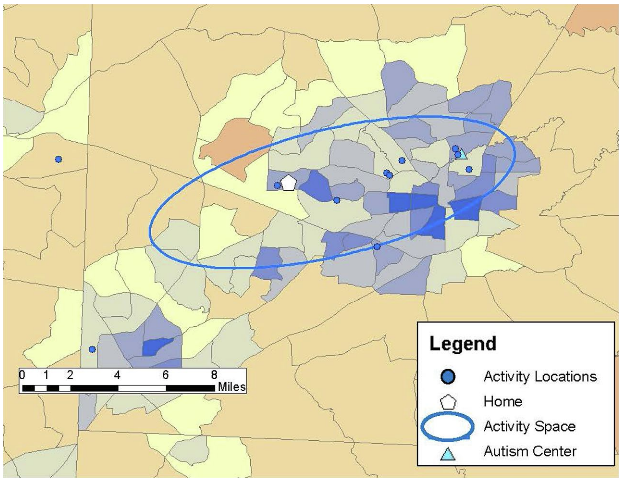

FIGURE 6 | Beth's activity space (64.51 mi^2) showing the wide dispersion of community activity locations from the GPS study week, particularly to visit her family in another town on the weekend.

Steve's scores on the AASP suggest that his registration is in the typical range, his sensation seeking is less than others, his sensory sensitivity is much less than others, and his sensation avoidance is much less than others. Overall, Steve's sensory processing pattern supported his participation in activities in the community and enabled him to visit sensory-rich environments, interact with people in the community, and enjoy participating in activities such as sports and dancing that provided movement experiences. Steve's community participation was not limited by his sensory processing patterns but rather was constructed to fit with his family's routines and activities.

John: "I usually deal with a lot of things online."

John was a 33-year-old, White male who lived with his grandmother. He reported living in his current residence for about 18 years. He was not employed and relied on his grandmother for transportation. Although he was able to drive himself, he described it as a scary activity that "plays with my senses." His FSIQ was 104. John communicated readily, though had a slight tendency to mumble at times. He spent most of his time at home, with an average of just over an hour away from home each day. He had an activity space of 8.51 mi^2 (**Figure 2**). His community activities for the GPS tracking week centered around picking up food at a series of drive-through, fast-food restaurants. He also ran errands with his grandmother as he described that she did not like to go places by herself, and had a few medical related locations based on a recent toe injury. He indicated his favorite place was being home, preferring the more controlled environment of online social interactions. He stated, "I usually deal with a lot of things online, so I do not usually have to worry much about meeting people face to face or whatever..." When asked if there were any places he wished he could spend more time, John noted:

I'm content with the social interaction I get, as I said, that most of my social interactions are online. And that matters

TABLE 1 | Demographic information.

Case	Age	Gender	FSIQ	Race	Living status	Employment	Transportation
Steve	32	M	60	Asian/African American	Family	None	Parents
John	33	M	104	White	Family	None	Family
Sherri	29	F	80	White	Group Home	Part time	Others
Pete	49	M	77	White	Family	Part time	Drives
Patti	31	F	78	White	Apartment (Roommate)	Part time	Bus, others
Beth	51	F	40	White/American Indian	Group Home	None	Others

TABLE 2 | Sensory processing patterns and GPS tracking data.

Case	Low registration	Sensation seeking	Sensory sensitivity	Sensation avoiding	Unique locations	Time away (Hours:Mins)
Steve	Similar to Most People	*Much Less Than Most People*	*Much Less Than Most People*	*Much Less Than Most People*	7	02:01
John	*Much More Than Most People*	*Less Than Most People*	*More Than Most People*	*Much More Than Most People*	14	01:22
Sherri	Similar to Most People	Similar to Most People	Similar to Most People	*More Than Most People*	25	08:01
Pete	Similar to Most People	Similar to Most People	*Less Than Most People*	Similar to Most People	11	05:48
Patti	*More Than Most People*	Similar to Most People	Similar to Most People	Similar to Most People	17	05:03
Beth	Similar to Most People	*Less Than Most People*	*More Than Most People*	*Much More Than Most People*	11	03:46

more to me than like in-in person because of the shield of anonymity it provides… because we can be who we want to be on the [inter]net, for the most part.

John's scores on the AASP suggest that his sensory registration is higher than others, his sensation seeking is less than others, his sensory sensitivity is slightly more than others, and his sensation avoidance is much more than others. Overall, John's sensory processing pattern supports his preference to stay home and limit his participation in activities in the community, consistent with the GPS data. He noted he is content to engage in online social activities with his presence in the community mainly to pick up fast-food or assist his grandmother in running errands. However, he also reported he and his grandmother strategically plan their day every morning to map out how to complete community activities in the most efficient time as a desire to save money on gas, so financial considerations may also contribute to his low time away from home and limited community activities.

Sherri: "I'm very much happy with stuff I am doing now."

Sherri was a 29-year-old White female who lived in a group home. She had been living in the group home for 6 years. She held two part-time jobs, working as a stock clerk at a retail pharmacy 2 days a week, and as a field trip assistant at a children's museum 1 day a week. She relied on the group home staff workers or family members for transportation to various activities. Her FSIQ was 80. She often deferred to her staff member who was present during the GPS interview for confirmation of answers, or at times needed prompting by the staff member to be able to answer some of the questions. Sherri spent most of her time during the week away from the group home, spending an average of 8 hours a day in the community. She was involved in a number of activities, visited 25 unique locations during the study week, and had an activity space size of 45.22 mi^2 (**Figure 3**). Sherri reported the drug store where she worked was the location most important to her. In addition to her two part-time jobs, she also volunteered at a food bank, a hospital, and a day program multiple times a week. Other activities included going grocery shopping, browsing in a bookstore, going to the bank, and attending practice for Special Olympics. She also walked for exercise and participated in a yoga class at the YMCA. Sheri spent time visiting friends and neighbors and went to her parent's house. In addition to these activities that were part of her typical routine, she also engaged in several events during the study week that were special events, including attending a Special Olympics social event, a holiday party at the day program where she volunteered, and going out to eat at a restaurant and to a water theme park for her roommate's birthday celebration. At times these activities occurred within the same day without breaks or returning home, but this did not seem to bother Sherri, who noted, "I had a great time [at work] and then we went back to the day center for the party." She reported she had no barriers to participating in activities during the week.

Sherri's scores on the AASP indicate she has no sensory processing concerns, which is consistent with her high engagement in a variety of community activities. Without sensory processing limitations, she was able to participate in both routine and non-routine activities during the week, including several social activities. Her sensory profile allowed for her involvement with a number of routine, scheduled activities arranged through her group home, but she was highly involved in social activities with others as well. Sherri was generally satisfied with her participation in the community. She stated, "I'm very much happy with stuff I am doing now," but added she wished she could do more activities.

Pete: "It just feels beautiful to feel."

Pete was a 49-year-old, White male who lived with his mother. He had lived in the same home his entire life. He had a FSIQ of 77 and communicated well though he had a slight stutter at times. Throughout a typical week Pete visited 11 unique places with an activity space of 8.6 mi^2 (**Figure 4**) and frequently drove himself to these locations. He spent more than half his day away from home (averaging nearly 6 hours per day) but chose locations that were close to home. Pete worked part-time doing light janitorial work and volunteered at several community locations including the library and two local service agencies. He had several favorite restaurants and cafes that he regularly visited for lunch after working or volunteering. Pete noted that at one café the barista knew him so well that "when she sees me coming, pulling up in the parking lot…she prepares for me either an Incrediberry smoothie or a 12-ounce latte." He participated in grocery shopping with his mother, and he was active at church through weekly attendance at religious services, a monthly prayer breakfast, and singing with the choir. In addition to the places visited during the GPS study week, he reported he enjoyed going to music and bookstores around his local community and taking walks outside around his home and community. He loved to be at the beach saying, "It just feels beautiful to feel, just feels beautiful to hear, hear the ocean feel…that ocean breeze blowing." Spending time with family was also an important activity for Pete. He indicated his most important place was his local autism agency, which had been a part of his life since he was a preschooler, and he noted his "whole life is centered around the program itself."

On the AASP, Pete's scores indicated no concerns with sensation avoidance or sensation seeking; his registration was within the typical range but approaching higher than typical, and his sensory sensitivity was lower than the typical range. While he worked and volunteered across four locations throughout the week, at each place he engaged in highly repetitive tasks (cleaning, paper shredding, copying, book shelving). This daily pattern may reflect a need for variability in the location and daily tasks (high registration), yet his low sensation sensitivity allowed him to focus on repetitive tasks with less distraction from outside stimuli. Pete was able to construct a set of weekly activities and engage meaningfully across all the community locations he visited that met his sensory needs and where he felt personally fulfilled.

Patti: "The worst thing you can do to her is take away an activity."

Patti was a 31-year-old White female who lived in a supervised apartment in an urban area with a roommate who also had a disability. She had lived in the apartment for 6 years. Patti worked part time at a retail drug store 2 days per week and was involved in several activities in her community area, often traveling great distances to these activities. To traverse the community, she rode the bus independently to routine locations, such as to work or to get fast-food; otherwise, she received rides from apartment staff, a personal support, or her parents. Her FSIQ was 78 and she communicated easily, although high levels of anxiety were apparent at times during the interview through the use of repeated questions. Patti was very active in the community during the week, visiting 17 unique locations and averaging 5.5 hours per day away from her apartment, with an activity space of 44.72 mi^2 (**Figure 5**). During the study week, Patti spent time in several activities that were part of her regular routine, including attending a day program, drama and dance classes, going to the YMCA and taking walks in her neighborhood for exercise, and visiting her parent's house on the weekend. She also went to the bank, grocery shopping, and picked up fast-food. In addition, she participated in a social activity sponsored by her supportive housing. Although not part of the study week, Patti noted the mall was one of the most important places to her: "I love to shop for things. And go to the arcade." Routines and schedules were very important to Patti, as she noted she was very comfortable in her apartment since it allowed her to keep her routines.

Patti's sensory profile on the AASP showed she had low registration, suggesting that she may miss sensory input and therefore not be affected in situations with high sensory stimuli. Her sensory processing profile was consistent with her ability to tolerate activities in a variety of environments as she participated in many activities in the community. In the caregiver interview, her parents shared, "She loves activities, yes. The worst thing you can do to her is take away an activity." However, it is noteworthy that these activities were part of her regular routine, which could be consistent with individuals with low registration. In the interview with her parents, they shared that Patti has high anxiety and obsessive–compulsive disorder, and often engages in her routines for self-soothing and to create predictability in her life. Her parents also noted, "She's loud. Very loud. Extremely loud, [and] does not realize when she's being loud," which may reflect her low registration of her own auditory output. A low registration pattern, often associated with not noticing sensory stimuli, may have contributed to her parent's concerns with her eating behavior, as they shared in the caregiver interview:

> She eats too much food too fast, she talks when she, ugh it's horrible. Her table manners are like … she's not really aware, just like with her loud talking, that, that there's food dropping and stuff.

However, they also noted the impact of her anxiety that may contribute to her lack of external awareness: "It's that her anxiety, you know, kind of keeps her focused on herself and her needs."

Beth: "She does not like loud environments."

Beth was a 51-year-old White/American Indian female who had lived in her current group home for 27 years. She was not employed and relied on others for transportation. Her FSIQ was 40, and she had communication challenges, often repeating sounds during the GPS interview or clapping hands and vocalizing when she was asked questions. Though Beth was fairly social, she did not want people to hug or touch her. On weekdays, Beth spent most of her day at a day program and usually went for a ride with the group home staff and peers for an average of 4 hours per day. Beth went to her sister's house every Friday and stayed for weekends. During the study week, Beth visited 11 different places (activity space of 64.51 mi^2, **Figure 6**) with group home staff or her family, including activities of shopping, exercising, and dining. According to her siblings, besides these typical activities, she also enjoyed her time at the music center and church, especially when they had musical programs, because of her love for music. The most important places to Beth were her siblings' houses. She was comfortable at both places and happy to stay with the family, sometimes watching concerts together on television. However, Beth's siblings mentioned her dislike of loud sounds was a barrier to community participation as they noted, "We cannot take her anywhere real loud," and "She does not like loud environments, a lot of activity." The family carefully chose restaurants and shops they visited to prevent Beth from sensory overload; they stated that "the big Walmarts get on her nerves… that's a lot of stimulation there."

Beth's scores on the AASP suggested that her registration was in the typical range, her sensory seeking was less than others, her sensory sensitivity was more than others, and her sensation avoidance was much more than others. Beth's sensory processing pattern may impact her participation in the community and contribute to her avoiding sensory-rich environments and being physically intimate with others. Overall, Beth's participation in the community appeared to be related to not only her sensory processing patterns but also how her days were constructed by the group home and her family.

DISCUSSION

The profiles presented highlight the importance of sensory processing in daily life, especially as it impacts participation in the community for autistic adults. While recent studies have noted how contextual factors such as residential setting, geographic location, and availability of services affect community participation patterns (Chan et al., 2021; Song et al., 2021), this is, to our knowledge, the first study to examine sensory processing patterns in conjunction with GPS tracking, travel diary data, and semi-structured interviews, which provided information on barriers to and satisfaction with community participation. Examining multiple sources of data revealed individuals whose families reported their autistic adult had extreme sensation avoiding profiles, such as John and Beth, spent less time in the community during the study week, while those who did not have sensory sensitivity or high sensation avoiding, such as Sherri, Pete, and Patti, spent more time participating in activities in the community. Although Steve had the lowest sensory sensitivity and sensory avoidance scores of the group, his GPS data was more similar to John and Beth, with less time spent in the community. His limited participation, however, was attributed to his mother being sick during the study week, reflecting a tangible example of the often-reported relationship between community participation and access to transportation (Badia et al., 2011; Lubin and Feeley, 2016), and underscores its importance.

The findings from our study may also provide context for past community participation research. Using survey data comparing community participation between autistic adults and those in the general population, Song et al. (2021) noted significant differences in the amount of participation as well as the types of community activities rated as important. However, the authors note these findings may be more indicative of barriers to participation rather than participation preferences (Song et al., 2021). The interviews with the autistic adults revealed participants were participating in activities and environments they reported as important to them. Notably, those whose sensory processing patterns did not include extreme sensation avoiding or sensory sensitivity (Steve, Sherri, Pete, and Patti) all identified locations in the community where they engaged in desirable activities as the most important locations to them, while John and Beth, who both were high in sensory sensitivity and sensation avoiding, reported the familiarity, comfort, and perhaps predictability of the family home environment as their favorite location. Combining GPS and participant and caregiver interview data with sensory processing profiles allowed a more comprehensive view of how these sensory preferences may impact community participation.

The current study also contributes to the sensory processing literature confirming that sensory processing differences continue into adulthood and may influence how individuals engage with their environments. Autistic adults may either actively manage sensory responses to the environment or may not attune to cues in the environment that may promote participation (Crane et al., 2009; Tavassoli et al., 2014; Gonthier et al., 2016; Syu and Lin, 2018). The current findings contribute to the literature by suggesting that certain locations in the community may present sensory environments that limit participation for autistic adults, for example, environments that are noisy or unpredictable. Preferences for participation in specific community activities may also be shaped by one's sensory processing profile. As noted above, in the cases of Sheri, Patti, and Pete, their sensory processing profiles, which were largely "similar to most people," allowed participation in a variety of environments. In contrast, John intentionally chose to limit his time in the community, preferring the home environment and online social interactions that fit with his sensory processing profile characterized by higher sensory avoidance. Similarly, Beth's family was mindful of seeking environments that did not cause her distress based on her heightened sensitivity to sensory input, as reflected in her sensory processing profile.

In addition to considering the sensory aspects of locations in the community, findings highlight how sensory demands of activities in conjunction with environmental demands impact community participation. For example, Steve had a strong preference for activities that provided movement, such as basketball and dancing. Given his sensory profile characterized by "much less than most people," Steve was able to participate in these activities in sensory stimulating environments in the community as well as in a more sensory controlled environment at home. However, given Beth's sensory profile of heightened sensory sensitivity and sensory avoiding, Beth was not able to participate in listening to music in the community; however, she was able to enjoy music where the volume of sound and the density of people could be better controlled given her living situation.

Past survey research on the impact of living situation on community participation of autistic adults noted that adults who live with family members have less community participation than those living without family members (Dudley et al., 2019; Song et al., 2022). This may be due to family members being primarily responsible for planning community activities for individuals into adulthood (Levy and Perry, 2011; Gray et al., 2014), where often they need to prioritize managing daily living activities over social events (Cheak-Zamora et al., 2015). Family members may also wish to protect their autistic adult from negative community interactions based on past experiences and prefer keeping to home-based activities (Ryan, 2010; Song et al., 2022). The current study provides support for families similarly assessing how "sensory-friendly" activities and environments are and gravitating to those that are compatible to their autistic adults' sensory preferences. It is possible that since family members completed the AASPs, that the corresponding GPS data reflects families planning activities based on their own perceptions of the autistic adult's sensory preferences. It is unclear, however, if lower rates of participation are indicative of fewer suitable sensory compatible options in the community, or simply the identification of a few preferred activities and locations that are incorporated into one's routine.

Routines, an integral part of daily life that provide predictability, may be particularly important for autistic adults, due, in part, to their sensory processing patterns. For example, John, whose sensation avoidance was "much more than other people," structured his day so that he was in the community at less busy times. He also spent much of his time at home, likely because the sensory stimuli were more predictable and under his control than in the community. This finding aligns with Little et al. (2015) who reported that autistic children with more hyperresponsiveness to sensory stimuli tended to participate less in community activities than activities at home. This may be because at home activities were more routinized, and the sensory stimuli are more predictable than activities outside the home environment (Little et al., 2015).

The sense of predictability, however, is not limited to the home environment. For example, Patti, who presented with low registration to sensory stimuli, enjoyed engaging in various community activities as a part of her routine. While people regularly engage in activities at certain places, they may have expectations of the sensory environment, for example, the smells, light, and sound. These expectations become habitual as the person repeatedly engages in the activity and serve as "sensory anchors" that provide a sense of predictability (Bailliard, 2015). Sensory anchors help assure that the activity in which people regularly participate will proceed as anticipated (Bailliard, 2015). For Pete, who visited the same café and ordered the same smoothie for his lunch after work, the smell and the sound of the café in the afternoon and the texture of the smoothie may steer him to maintain these routine behaviors. Overall, autistic adults may choose predictable and controlled environments and participate in activities with which they are familiar to prevent feeling dysregulated or distressed due to unexpected sensory stimuli. In this way, routines may be part of a coping strategy established by the individual or caregiver to manage distress associated with sensory profiles (Crane et al., 2009). Established routines of purposefully chosen, meaningful activities may be an example of a coping strategy developed throughout the lifespan, particularly for those like Steve, John, Pete, and Beth who lived in the same community, and same living situation, for most of their lives.

Implications for Research or Practice

Environmental factors hold great promise for change and are therefore an attractive target for intervention efforts to increase participation outcomes (Henninger and Taylor, 2012; Tobin et al., 2014). As awareness of the sensory environment's impact on limiting community activities for autistic individuals has grown, efforts have shifted away from changing the person's sensory processing to providing more sensory-friendly environments and event days, for example, at museums, movie theaters, and sporting events. These efforts at changing the environment rather than the person have demonstrated some success in improving participation (Fletcher et al., 2018). Results from the current study provide preliminary support that autistic individuals are able to participate in meaningful community activities when individual preferences for both sensory input and desired community activities as well as the sensory demands and opportunities of the environment were considered.

It is important for practitioners to assess sensory processing patterns and educate clients and caregivers about how sensory processing patterns impact participation. Practitioners can assist clients in matching personal sensory processing patterns with activity and environmental demands. Furthermore, practitioners can collaborate with clients to structure routines that facilitate community participation and develop coping strategies for situations when there is a mismatch between one's sensory profile and environment. It is also critical that efforts aimed at advocating for sensory-friendly environments consider the variety of sensory processing patterns of autistic adults. Ongoing research is needed to further explore the relationship between sensory processing and community participation. This research can contribute to the development of interventions and other initiatives to support the meaningful participation of autistic adults regardless of their sensory processing capacities.

Limitations

This study included autistic individuals with differing demographic, autistic, and sensory profiles and offers a novel approach to studying sensory processing and community participation. However, the study does have limitations. One limitation is that data were drawn from two studies, neither of which were designed to address sensory processing in detail nor to look specifically at the relationship of sensory processing and community participation. Observation and focused interviewing would add richness to the exploration of sensory processing (Bailliard, 2011). Caregiver and participant interviews designed to address the two constructs together could also yield rich data. Additionally, the AASP was completed by caregivers rather than the autistic adults themselves. Therefore, scores reflect caregivers' perceptions of their adult child's sensory processing rather than the adults themselves. Research suggests family members may underestimate sensory impact on daily life (Crane et al., 2009). The data set of six cases examined did not include individuals who scored high in sensation seeking; thus, we did not explore what community participation looks like for autistic adults with this profile. Finally, limited information about the participants' satisfaction with their community participation was obtained.

CONCLUSION

Sensory processing patterns should be considered along with other personal and contextual factors when assessing community participation, both in research and practice. In the current study, those whose sensory processing patterns indicated sensory sensitivity and sensation avoiding described the experience of certain environments and activities as overwhelming and fatiguing and thus either spent less time in the community or visited fewer places compared to those with other sensory processing patterns. Additionally, they utilized adaptive strategies such as structuring daily routines and using sensory anchors. Individuals whose sensory processing patterns were lower in sensory sensitivity and sensation avoiding participated in diverse and preferred activities in their communities. While reviewing the sensory processing and community participation data yielded notable patterns, time and participation in the community, was not the only factor related to sensory processing profiles; other factors such as access to transportation, employment status, finances, and living status appeared to influence time spent in the community and community engagement. Given the importance of community participation for health and wellbeing, further research is needed to understand both the person and contextual factors that support and limit autistic adults' full participation in community life.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the University of North Carolina at Chapel Hill. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

LK, DC, and NB contributed to the study conception and design of the studies. DC, EL, and NB contributed to the acquisition of data. DC, NB, EL, and Y-CS contributed to the analysis and interpretation of data. All authors contributed to the writing of the manuscript. All authors have approved the final version of the manuscript and are accountable for the work described. All authors contributed to the article and approved the submitted version.

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Interoception: A Multi-Sensory Foundation of Participation in Daily Life

Carolyn M. Schmitt[1]*† and Sarah Schoen[1,2]†

[1] Sensory Therapies and Research (STAR) Institute, Centennial, CO, United States, [2] Rocky Mountain University of Health Professions, Provo, UT, United States

The purpose of this article is to examine evidence that broadens the clinical perspective on interoception as an imperative consideration for individuals with mental health and sensory processing challenges. The central supposition is that interoception is broader than just signals from the viscera. Rather, interoception refers to perceptions of bodily signals and bodily states that construct a subjective representation of the experience. These representations are then utilized for categorizing the sensory attributes and constructing meaning. Thus, this updated conceptualization presents interoception as a complex multidimensional system, with bidirectional features. The interplay between the brain and the body is necessary to maintain homeostasis as well as respond adaptively to the changes in one's internal and external environment. As a sensory capacity, interoceptive information must be processed and interpreted before it can be integrated into a personal experiential history. Interoception supports both body and mental functions and as such, interoceptive processes support health and wellness by establishing a felt sense of psychological and physiological safety that is foundational to meaningful participation in life. The information presented in this article is central to the pursuit of evidence-based best practices for any professional wishing to integrate consideration of interoception into their clinical practice.

Keywords: interoception, sensory integration, sensory processing, sensory processing difficulties, ICF (international classification of functioning disability and health), occupational therapy (OT)

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****Correspondence:***
Carolyn M. Schmitt
carrie.schmitt@sensoryhealth.org

†These authors have contributed equally to this work and share first authorship

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INTRODUCTION

The concept of interoception was first introduced by Nobel Prize winning scientist, Dr. Charles Sherrington. He defined interoception as "sensations from the interior of the body, especially the viscera" (Sherrington, 1906). The past 116 years of scientific advances have expanded knowledge regarding interoceptive processing. Interoception is now defined as the "process of how the nervous system senses, interprets, and integrates signals originating from within the body" (Quigley et al., 2021, p.29). As awareness of interoception grows, the relevancy of interoception to participation in daily life is consequential in determining the future direction of clinical and research fields (Craig, 2015; Tsakiris and Critchley, 2016; Mahler, 2017; Khalsa et al., 2018; Hample et al., 2020). In 2019, the National Institute of Health (NIH) convened a research workshop on the science of interoception and its role in neurological disorders (Chen et al., 2021). One of the priorities identified in that workshop was to grow the collective understanding of how "integrative health approaches may modulate the interoceptive processes and interoceptive clinical outcomes" (U.S. Department of Health and Human Services, n.d.).

Clinicians across many disciplines including mental health and sensory health practitioners are uniquely positioned to consider the impact of interoceptive sensory processing on body functions and structures which effect participation in daily life. This point of view could answer the NIH's call to action by providing a strong example of the implications of interoception to clinical practice. At its essence, interoception represents the inter-relatedness of sensory, motor, and mental functions enabling perception and participation (Tsakiris and Critchley, 2016). Clinicians from a variety of professions will benefit from expanded knowledge of the contribution of movement and sensation (bottom-up) to mental functions (top-down) and vice versa. In short, movement of the body and interoceptive sensation are the entry points for sense data in bottom-up approaches. Sensory motor experiences are used to inform sense of self, self-regulation, and participation in daily life. In top-down approaches, cognition is utilized to focus attention on the body and make meaning of experience. In this approach, experience changes through understanding whereas in a bottom-up approach, understanding emerges from the experience (Ogden et al., 2006; Ceunen et al., 2016). An approach that includes both top-down and bottom-up strategies reflects a mind-body integrated approach and will guide a common understanding of the impact of interoception on well-being. Interoceptive capacity and its processes support human functioning which is essential to promote meaningful participation in life.

Over the past several years, researchers in multiple fields recognize the contribution of interoception to their area of interest, i.e., trauma, emotion, toileting, hunger and thirst, mental health, the experience of self, decision making, and perception of time (Whitehead and Drescher, 1980; Gallagher, 2000; Drake et al., 2010; Tsakiris et al., 2011; Herbert et al., 2013; Ohira et al., 2013; Suzuki et al., 2013; Herbert and Pollatos, 2014; Pollatos et al., 2014; Barrett and Simmons, 2015; Stevenson et al., 2015; Schreuder et al., 2016; Critchley and Garfinkel, 2017; Grabbe and Miller-Karas, 2018; Quadt et al., 2018; Schaan L. et al., 2019; Schaan V. K. et al., 2019; Zamariola et al., 2019; Mitchell et al., 2020; Quigley et al., 2021). Understanding this proliferation of research is central to the pursuit of evidence-based best practices for any clinician wishing to consider the role interoception may play in impacting function and meaningful participation.

The purpose of this article is to highlight evidence that broadens perspectives on interoception as a critical component of clinical intervention. Interoception does not only refer to perceiving signals from the viscera but rather, interoception refers to perceptions of bodily signals and bodily states, that are generated to construct subjective experience (Fazekas et al., 2020). An expanded definition and interpretation of interoception has been widely considered and the definition presented is based on neuroscience literature. Interoception creates an experiential history within each person, which is utilized for categorizing the sensory attributes of that experience and constructing meaning (Barrett, 2017). Therefore, our aim is to encourage clinicians from every discipline to consider a broader perspective of this multi-dimensional sensory capacity. Interoception is situated within the International Classification of Function (ICF) (World Health Organization [WHO], 2001) conceptual framework of human functioning to illustrate its broad applicability. Viewing interoception as a key component of multi-sensory integration sets the stage for a closer look at the central role interoception plays in body and mental functions that contribute to activity and participation and thus, to overall health and wellness. To illuminate this viewpoint, clinical examples from occupational therapy illustrate how differences in interoceptive sensory processing can impact function and may drive individuals to seek clinical intervention. The final objective is to integrate relevant information and highlight the central role of interoception's contributions to overall health and wellness.

Interoception: An Expanded Definition

Recent definitions of interoception embrace the complex, bidirectional interplay between the brain and other organs that is necessary to maintain homeostasis in the moment as well as manage physiological stressors reflective of allostatic processes (Chen et al., 2021; Quigley et al., 2021). Interoceptive sensation originates within the body and travels to the central nervous system. It provides a moment-to-moment physiological representation of the body's preconscious and conscious internal landscape (Quadt et al., 2018; Tsakiris and dePreester, 2018; Harrison et al., 2019). Interoceptive capacities are used to survey the body and respond to the information based on salience. This information is then communicated to the brain. When the interoceptive information is salient enough that it is deemed important, the brain makes meaning of the incoming sensations (e.g., "My stomach aches, I need to eat"; "I feel lethargic, I don't feel like playing with my peers"; "My throat hurts, I may be sick") (Barrett, 2017). If more information is needed to direct action, communication for further sense data is generated *via* descending pathways. While it is the brain that is primarily responsible for interpreting these signals, a notable difference in modern definitions is the inclusion of body regulation through descending pathways (Chen et al., 2021).

Importantly, interoception is not a unitary sensory domain. It is a multidimensional, complex system representing the integration of multiple senses. Sherrington introduced the word interoception connoting interior receptor, which stands in contrast to exteroception, which he recognized as sensation coming from an external source (Sherrington, 1906; Ceunen et al., 2016). Because these sensations were understood to have an origin that was internal or external to the body, early research on body awareness focused on the more easily reproducible exteroceptive signals (Botvinick and Cohen, 1998). We now recognize that those studies were highlighting the power of multi-sensory integration (Tsakiris et al., 2007). A broadened view of interoception as well as advances in neuroscience allow researchers to more fully understand the origin of body awareness and thus demonstrate the important role interoceptive signals play in shaping bodily self-awareness (Quigley et al., 2021) as well as emotion regulation (Price and Hooven, 2018). Contributing to an ordered sense of self is the consideration that the multisensory, interoceptive body summary is a major contributor to regulation, which maintains internal dynamics in balance (Petzschner et al., 2021).

Individuals rely on the automaticity of the sequence of physiological sensation, significance, awareness, and interpretation (Khalsa et al., 2018). When interoceptive signals are processed as anticipated, the result is the ability of that person to trust their body signals (Herbert and Pollatos, 2012; Owens et al., 2018). When interoceptive signals are reliable, by serving to achieve and maintain homeostasis and support overall health and wellness, interoceptive experience establishes a felt sense of safety (Price and Hooven, 2018). In this way, interoception supports the freedom to participate in meaningful activities while trusting one's body to generate consistent, relevant sensation.

Interoception Viewed Within a Conceptual Framework of Human Functioning

Interoception is referred to in some literature as an eighth sensory system (Miller et al., 2014; Craig, 2015; Mahler, 2017; Zhou et al., 2021). While this conceptualization draws attention to this critical aspect of human function and is an important step in the evolution of understanding, advances in neuroscience have helped better define the breadth and depth of interoceptive processes. Thus, the expanded definition of interoception addresses its integrative sensory capacity and bidirectional influence and highlights interoception's role in dynamic processes reflecting both its sensory and regulatory nature.

The relationship between interoceptive sensory processing and meaningful participation in daily life can be conceptualized using the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) (World Health Organization [WHO], 2001). The ICF framework articulates the inter-relatedness of body functions and structures as well as individual activity and societal participation within health-related human experience. Specifically, this framework considers "multiple dimensions of human functioning synthesizing biological, psychological, social and environmental aspects" (Kostanjsek, 2011, p. 1). Interoceptive sensory processing can be categorized within body functions and structures in the ICF framework. Thus, this conceptualization of interoceptive differences suggests a bidirectional impact on activity performance and participation in life. Overall health and wellness come from the dynamic interplay amongst all these factors.

Applying a health framework with a biopsychosocial lens allows a broader perspective of interoception rather than being linked to a single issue (e.g., emotions) or a specific diagnosis (e.g., autism) (Mahler, 2017; Hample et al., 2020). This lens highlights evidence that interoception underlies many processes of physical and mental human functioning that clinicians across professional fields address in practice (Stucki et al., 2007; Fischer et al., 2017; Khoury et al., 2018). Thus, an expanded approach and the application of a world-recognized framework that considers the multiple elements of this complex multi-dimensional system is warranted. The continuum of health states described in the ICF, specifically the variations in body and mental functioning, is strongly informed and impacted by interoceptive sensory processing. The impacts of this on optimal participation in life will be illustrated in forthcoming clinical examples.

INTEROCEPTION AS A DIMENSION OF HEALTH

It is important to consider interoception's contribution to overall health and wellness. Interoceptive capacity acts in the body by allowing basic functions to be automated while one interacts with the external world (Quigley et al., 2021). These signals are essential for regulating many physiological functions (e.g., heart rate, digestion, and body temperature) as well as for psychological experiences ranging from valence to emotion to motivations which acts as a driving force for adaptive behaviors (Khalsa et al., 2018; Chen et al., 2021). It is this interoception-driven adaptive behavior that allows individuals to embody meaningful participation.

Interoception is foundational to the experience and awareness of self and supports one's ability to trust that their body is relaying and regulating interoceptive sensation in a reliable way (Oldroyd et al., 2019; Chen et al., 2021). Health and wellness come from a sense of agency and a sense of self that contributes to feeling 'in control' and mastering interaction with the external world (Di Fabio and Palazzeschi, 2015). A sense of safety comes from the consistency, reliability, and accuracy of how we interpret interoceptive experiences and use those experiences to direct future action (Barrett and Simmons, 2015).

Our body functions are designed to draw context from the environment using sensory data. Through contextual experience, sense data can produce either accommodation and integration or a felt sense of dissimilarity and possibly distress (Meyers-Levy et al., 2010; Köteles, 2021). For example, emotional events may be marked by such somatic reactions as tightening the muscles or increases in heart rate prior to the emotion being brought to consciousness (Barrett, 2017). Individuals count on their body to direct attention to these basic functions so that if we need to flee an unsafe situation or more commonly, void the bladder or eat some food, our bodies comply (Drake et al., 2010; Stevenson et al., 2015). When this process is being perceived or interpreted inaccurately or inconsistently, one's sense of safety, health and wellness are threatened.

Interoceptive sensory stimuli also assist the brain in creating neural representations of the self and the world (Tsakiris and Critchley, 2016). Importantly, these mental representations underlie perception and drive action. The constant flow of interoceptive stimuli determines the degree of action; memories are stored so that there is a reliable reference to refer to that helps make actions readily available and efficient (Seth et al., 2012). This helps dictate choices and actions of the best ways to respond. For example, when approached by a familiar friend, it is easy to decide to spend time with that friend because the bodily signals convey pleasure and spark memories of past shared experiences. Decisions and actions are then clear about where and how to engage in relationships in the present or future. This ability to direct action appropriate to the context of a situation is also fundamental to one's felt sense of safety and actual safety.

Interoception is therefore critical for ensuring the stability of the organism in a changing environment as well as the adaptability to external changes. Awareness of the interoceptive body may be fundamental to the unity of the self (Tsakiris and Critchley, 2016). Thus, it appears that interoception has a broader role than once thought that encompasses not only homeostasis and the formation of emotions but how one experiences the self as well as one's experience of others in social relatedness and meaningful participation. For these reasons interoception is implicated in achieving health, and a pervasive sense of well-being.

OVERVIEW OF THE IMPACT OF INTEROCEPTION ON HUMAN FUNCTIONING

Looking at interoception as a key component of multi-sensory integration and considering interoceptive processes in the preconscious control of one's physiological state sets the stage for a closer look at the central role interoception plays in body and mental functions that contribute to activity and participation and thus, to overall health and wellness.

Interoception and Multi-Sensory Integration

For decades, interoception has been integral to the practice of many disciplines from occupational therapists specializing in sensory integration (Ayres, 1972, 1994) to psychologists specializing in emotion (Damasio, 1996, 1999, 2010). These pioneers recognized both somatic and visceral contributions to the integration of interoceptive sensation. Somatic sensory contributions were described as central to the development of the bodily self and physiological alterations to the body's internal state prior to the formation of an emotion (Damasio, 1996). Similarly, these contributions were recognized as central to the development of one's body scheme, body map, or body percept, which is the brain's internal representation of the body (Ayres, 1994). Additionally, internal organ receptors were acknowledged to play a crucial role in regulation of the autonomic nervous system as well as in overall mental and physical health (Ayres, 1994; Damasio and Carvalho, 2013).

Adding to the understanding of interoceptive awareness, which includes this broader conceptualization of somatic and visceral contributions, Khalsa et al. (2018) proposed dividing the concept of interoceptive awareness into components such as attention, detection, magnitude, discrimination, accuracy, insight, and sensibility (Khalsa et al., 2018). Differentiation of these processes are critical to understanding the complex progression involved in the development of body scheme and sense of self. Sensing, determining salience, and interpreting and integrating sensory afferent information from multiple bodily systems is an act of multi-dimensional sensory integration. The multi-dimensional complexity of interoception has also been recognized as an underlying mechanism of many psychiatric disorders (Khalsa et al., 2018; Khoury et al., 2018). This has led to the development of a broader range of interventions based on a focus on bodily sensations, cognitive awareness, and behavioral training (Khoury et al., 2018). Accordingly, interoception should be thought of as a multifaceted system that provides a continual flow of internal sensation that is added to the exteroceptive data in a complex multisensory integration process.

Interoception as a Preconscious Process

Many conceptualizations of interoception focus largely on one's level of conscious awareness (Cameron, 2001). In research, for example, laboratory interoceptive measurement tools compel the subject to focus their attention on an interoceptive sensation such as heart rate as a measure of their interoceptive awareness (Sukasilp and Garfinkel, 2022). This type of research favors the cognitive and conscious experience in the study of interoceptive abilities (Garfinkel et al., 2015). Yet, top-down, voluntary focused attention differs from everyday circumstances. Humans typically do not consciously or intentionally monitor their interoceptive sensations. Interoceptive body sensations operate by automatically requiring attention when a shift in body resources demands a person to act to maintain homeostasis (Köteles, 2021). This suggests that interoception operates at the preconscious level wherein a person is primarily unaware of their bodily processes, but these processes can enter consciousness when top-down attentional resources are directed to the process (Balconi et al., 2017).

The idea that interoception is not limited to conscious perception, but extends to and primarily functions as preconscious perception, is an important distinction (Damasio and Carvalho, 2013; Sukasilp and Garfinkel, 2022). Quadt et al. (2018) consider interoception an overarching term for several processes including (a) afferent sensory signaling, (b) neural encoding, representation, and integration of the information concerning our internal body state, (c) how this information influences other perceptions, cognitions, and behaviors, and (d) the consciously accessible physical sensations and feelings generated by these representations. Three of the four processes are preconscious. This differentiation of interoceptive processes is important to clinicians because interoceptive processes are implicated in the preconscious control of one's physiological state, which forms the basis for emotions, behavior, and cognition (Quadt et al., 2018). Over-emphasizing the conscious mind over the sensing body obscures the wholistic consideration of the mind-body connection and diminishes the importance of preconscious interoceptive processes. Damasio and Carvalho (2013) capture the nuance of sensory perturbations (experienced when reality does not match mental predictions) and their role in eliciting and informing cognitive interoceptive attention. A dynamic relationship exists in the contribution of physiological body function to mental functioning (e.g., higher-level cognition, attention, memory, affect, perception, etc.) and vice versa (one's mental state influences the body's physiological state). This recognition of the dynamic, preconscious features of interoceptive sensation will serve clinicians in establishing bottom-up intervention strategies to improve interoceptive abilities.

The Contribution of Interoception to Body Functions and Structures Affecting Participation

Within the ICF framework, the list of Body Functions and Structures are representative of the two branches of the interoceptive system, the visceral system reflected by internal organ functions (e.g., cardiovascular, respiratory, genitourinary) and the somatic system represented by neuromusculoskeletal and skin structures (World Health Organization [WHO], 2001). Narrow conceptualizations focused solely on the viscera as the primary contributor to interoceptive sensation (Sherrington, 1906). Advances in neuroscience have promoted the inclusion of the somatic systems to the interoceptive domain (Chen et al., 2021). Both visceral and somatic signals originate from the body and are relayed as afferent sensory data (Craig, 2015; Ondobaka et al., 2017; Chen et al., 2021). Once the sensory information reaches the brain, it is integrated with other sense data to represent the physiological condition of the body (Ceunen et al., 2016; Khoury et al., 2018). Linking visceral and somatic bodily sensations with perception supports the development and experience of one's selfhood (Khalsa et al., 2018; Marshall et al., 2018; Tsakiris and dePreester, 2018).

Activity performance and participation in daily life are closely interrelated with intrinsic factors such as sense of self (Imms et al., 2015). One's sense of self or the way one perceives one's body from the inside interacts with and enhances the way one perceives one's body and other people's bodies externally (Ondobaka et al., 2017). These findings underscore the importance of considering visceral and somatic interoceptive sensation and their role in multisensory processing as it allows individuals to experience their bodies as their own and thus impacts their functional participation (Tsakiris et al., 2011; Suzuki et al., 2013). The following section will present data on the role visceral and somatic sensory afference and illustrate how interoceptive sensory differences impact function and affect meaningful participation.

Visceral Sensory Afference

Tsakiris and dePreester (2018) use the term visceral afference to refer to internal sensory information that is processed within the viscera of the interoceptive system. The authors also include olfactory and gustatory receptors (chemoreceptors) in the visceral system while Craig (2015) indicates that pain and temperature receptors are considered interoceptive (e.g., stomachache) or exteroceptive (e.g., burn) based on the source of the sensory experience. Chen et al. (2021) further delineate these internal sensory signals into three types: biochemical, mechanical forces, and thermal or electromagnetic signals. Though the receptor characteristics and neural pathways vary, an understanding of the central role of afferent visceral signaling to an individual's physiological state contributes to clinical considerations of issues such as digestive functions, including discrimination of hunger/satiety, or gastrointestinal and urinary tract functions, such as bowel and bladder voiding.

Clinical Example of Visceral Sensory Afference

This clinical example highlights the role of visceral-based factors in the treatment of a teenager with differences in sensory processing and integration. Evelyn is a 15-year-old girl who first received occupational therapy services at age eight. At that time, standardized testing revealed deficits in sensory discrimination and sensory-motor abilities, supported by parent rating of dysfunction in Evelyn's reactivity to sensory experiences. She returns seven years later seeking occupational therapy due to recent weight gain and the challenges associated with attending high school while still on a toileting schedule. A review of systems indicates no medical concerns about the function of her gastrointestinal or urinary tract function. In gathering intake information, Evelyn reports eating without ever perceiving feeling satisfied/full (lack of awareness/sensory under-responsivity) and being unable to discern (sensory discrimination) the need to empty her bladder or bowel. Research suggests that the forebrain mediates the transition between urine storage and urine voiding (Drake et al., 2010). This process is dependent on visceral afferent interoceptive sensory information from the bladder to guide the timing of the transition between the two phases (storage and voiding). Regarding Evelyn's weight gain and reported challenges feeling satiety, Herbert et al. (2013) and Herbert and Pollatos (2014) found evidence for reduced interoceptive sensitivity in overweight and obese individuals by identifying challenges in the detection of bodily changes associated with feeling full. The threshold required for Evelyn to register bladder and stomach fullness is high. Her bladder and stomach must be very full for her interoceptive sensation to rise to a level of salience so that her cognitive attention guides her action to void her bladder or stop eating. In a recent study, Mitchell et al. (2020) found a significant positive correlation between altered interoceptive awareness and hypo/hyper-reactivity to sensation. Utilizing a sensory integrative intervention framework to address sensory under responsivity would focus on enhanced stimulation of bodily sensations, accompanied by, or linked to cognitive awareness. The intervention prioritizes both bottom-up sensing and top-down regulation, engaging bi-directional sensory data (Chen et al., 2021). This is accomplished by offering opportunities for multi-sensory experiences and exploration through active participation in age appropriate sensory-motor experiences (e.g., dance, balance work, exploring sensory strategies that alter arousal through touch, smell, movement or sound), which is both internally motivating and calibrated to promote success (Ayres, 1994; Caçola, 2016; Miller et al., 2018). In addition, cognitive strategies such as asking questions about her sensation and using body mapping to locate those sensations direct Evelyn's attention to her bodily experiences. Simply put, clients like Evelyn are supported when the objective of intervention is to maximize the interplay between brain-body processes and enhance bodily signals allowing for the interoceptive sensation to be recognized as meaningful. The goal is to support Evelyn's pursuit of meaningful and successful participation at school and home through improved interpretation of visceral interoceptive sensory processing.

Somatic Sensory Afference

Somatic afference refers to the activation of receptors in the somatic system of muscles and joints. These are senses that help individuals gather information about one's internal and external world and one's relationship to it (Quadt et al., 2018). Considering somatic afference is an important feature many clinical interventions frequently use for psychiatric disorders as well as motor disorders affecting participation in daily life (Khalsa et al., 2018; Khoury et al., 2018).

Clinical Example of Somatic Sensory Afference

Somatic interoception can be best understood through another clinical example. Emma is a ten-year-old referred to occupational therapy due to concerns regarding performance in group athletics and social interaction with peers, including physical education classes at school, organized sports teams, and playing with peers during recess. She appears clumsy, runs into her peers, is not goal-directed in her actions, and is unable to learn new games easily. Standardized testing revealed significant challenges in upper limb coordination, bilateral coordination, and balance as well as dysfunction in sensory discrimination in vestibular and proprioceptive processing. Difficulty was noted interpreting information from her muscles and joints and vision while simultaneously moving through space. She registers the input but is unable to interpret the details necessary to generate smooth, coordinated motor efforts. The result is poorly refined movement which impacts her ability to participate fully in age-appropriate and meaningful play. Administration of the Multidimensional Assessment of Interoceptive Awareness, Youth Version (MAIA-Y) (Jones et al., 2020) reveals below average scores in the categories of Noticing (awareness of body sensations) and Body Listening (ability to attend to bodily sensation for psychological insight). This assessment assists in clarifying the origin or generation of the sensory signaling as a function of input from multiple visceral and somatic sources across temporal domains. Interoception has an undeniable role in differentiating these stimuli and in integrating these sensations (Craig, 2003, 2009, 2015). This example captures the complexity of interoception's contributions to body awareness, embodiment, and sense of self. Gallagher (2000) elaborates on this association by recognizing that the bodily sense of agency and ownership for motor action is based on sensation, which precedes action. Once the process is conscious, the brain generates intention and drives action.

The sensation referred to here is interoceptive in nature and contributes to motor coordination in collaboration with stored representations of past motor experience. Motor experience was emphasized during Emma's intervention, with multisensory feedback to enhance the discrimination of interoceptive sensation and support the refinement of motor coordination in time and space. The focus on somatic awareness in intervention incorporated repetitive, rhythmical movements within the context of body-based activities in the sensory gym. Additionally, slow controlled movements of varying speed and timing were combined with examples provided through mirroring activities/movements. This type of sensory and motor exploration was encouraged so that sensations would be approached with interest, variety, and curiosity (Ogden and Minton, 2000; Hricko, 2011; Levine, 2018; Goldstein, 2021).

The Contribution of Interoception to Mental Functions Affecting Participation

Interoception is also foundational to the mental functions relevant to wellbeing and health and makes significant contributions to the attainment and maintenance of these mental functions. Specific mental functions relevant to clinical consideration of interoception include affective, cognitive, and perceptual components. Affective neuroscience research frequently adopts predictive processing models which explore how predictions and prediction errors generate subjective experience and inform neural representations of the world (Barrett, 2017; McTighe and Willis, 2019). The formation of a neural representation of the world demonstrates the intersection of mental functions and interoception (Quigley et al., 2021).

The Predictive Processing Framework

The predictive processing framework clarifies how interoceptive signals affect mental function. Sensory signals from the body are processed by the central nervous system (Barrett and Simmons, 2015; Quadt et al., 2018). The brain compares the sensation to past experience to formulate a prediction or hypothesis that can be tested against incoming sensory signals. If ambiguity or an error in that prediction exists, there are three options: (a) transmit the error back along cortical connections and modify the prediction; (b) generate an action/response/movement to match the predicted sensations; or (c) regulate the attention to the incoming sensory signals (Barrett and Simmons, 2015). The brain's job is to utilize this information for higher-level cognitive functions as well as emotion, attention, memory, thought, and experience of self and time (Pollatos and Schandry, 2008; Matthias et al., 2009; Werner et al., 2010; Pollatos et al., 2014; Barrett and Simmons, 2015; Critchley and Garfinkel, 2017). The contribution of interoception to mental function entails attending, interpreting, and prioritizing the stimuli that will promote the body/brain's ability to achieve and maintain internal order for optimal health, safety, and survival.

The forebrain uses the above process to form a concept based on available sensory input (McTighe and Willis, 2019). The concept formation is important to efficient use of the brain's power in the moment as well as in the future. In grouping some things and separating others, the brain becomes more efficient and better able to interpret the meaning of incoming sensory inputs. The brain uses this process to make meaning of sensations from both outside as well as inside the body. Past experiences are organized into concepts that are used to guide actions and give meaning to incoming sensory signals (Barrett, 2017; Ondobaka et al., 2017).

Interoception and Emotion

It has long been held that emotion is inextricably linked to unique bodily states (James, 1994). Emotions arise through the interaction of descending bodily predictions and ascending prediction errors (Critchley and Garfinkel, 2017). Schreuder et al. (2016) note that harmonious multi-sensory stimuli enhance emotional, cognitive, and behavioral responses while disparate stimuli negatively impact emotion and adaptive behavioral responses. The congruent or incongruent processing of multi-sensory stimuli may be a contributor to or underlie behavior regulation. And while behavior is not controlled by emotion, sensory input plays an important role in how one feels, how one understands that feeling, and thus how one behaves (Herbert and Pollatos, 2012; Schreuder et al., 2016). Quadt et al.'s (2018) interoceptive predictive processing framework explores these brain-body interactions, to the extent that prediction errors raise interoceptive sensations to the level of cognitive awareness and thus may contribute to both physical and mental health concerns presenting as emotional impairment.

Clinical Example of Emotion

This example highlights relevant mental and emotional-based factors practitioners may encounter in children with sensory integration and processing differences. Justin is an 8-year-old boy who is accompanied to occupational therapy by his parents who express concern for his emotional volatility at home and school causing significant relational strain and reduced social participation. Standardized testing revealed developmental dyspraxia resulting in problems in organization of movement and motor planning difficulties. Justin is described as escalating from "zero to 100" in a matter of moments and across a variety of situations/contexts. Emotion regulation is frequently impacted in children who experience dyspraxia due to the high levels of frustration they encounter when attempting to participate in everyday activities. Parented conscientiously, Justin has been taught plentiful top-down, cognitive strategies. However, Justin is frequently not able to access or apply these strategies as he is often living in a state of generalized stress and dysregulation. Applying the interoceptive predictive processing framework to the clinician's clinical reasoning, it is hypothesized that Justin's system is encountering repeated unexpected sensory signals, eliciting prediction errors, and causing stress that exceeds his homeostatic threshold. Beyond this homeostatic threshold, activation of his stress response means executive functions and cognitive regulation strategies are unavailable to him (Dang, 2016). This reflects a shift of interoceptive resources away from homeostasis and toward a fight or flight or freeze reaction (Porges, 2009). Justin often exhibits a fight response disrupting his home and school environments. When the actual experience does not match Justin's predictions, a prediction error arises. This prediction error disproportionately affects Justin's narrow range of emotion regulation (Tsakiris and Critchley, 2016). Intervention focusing on improved sensory discrimination will support progress toward improved praxis which will promote emotion regulation through a reduction in frustration. Prioritizing activities that are not so easy they are not beneficial but not too challenging to be unachievable will promote a reduction in prediction errors and aim to widen the amount of time Justin spends in desirable regulatory states. Using this approach, clinical intervention shifts the focus away from an over-reliance on cognitive strategies to focus on non-verbal, preconscious bodily responses and movement activities that are adaptive to the situational challenge. Justin was not functioning adaptively within his home or school environment. An intervention designed to help Justin achieve and maintain a regulated state from which to express appropriate responses to environmental demands promoted participation in both meaningful tasks and relationships.

Other Mental Functions

Evidence exists that interoceptive sensory processing plays a crucial role in higher-level cognitive functions, attention, memory, and the experience of self and time (Pollatos and Schandry, 2008; Matthias et al., 2009; Werner et al., 2010; Pollatos et al., 2014; Barrett and Simmons, 2015; Critchley and Garfinkel, 2017). Craig (2009) and Critchley (2009) have both identified the insula as the recipient of visceral and somatosensory input. As such, the insula is thought to play a significant role in the integration of interoceptive sensation contributing to the neural representation of bodily and mental states (Damasio, 1999). Ohira et al. (2013) explored the neural basis of decision-making looking primarily at the anterior portion of the insula. They found that the role of interoception in bodily states had implications for decision-making due to the strategic location of the insula as a hub linking visceral and somatic input with the prefrontal and limbic regions (Craig, 2009; Critchley, 2009). Matthias et al. (2009) investigated interactions between interoceptive awareness and measures of attention finding that interoceptive perception may moderate visual processing and utilize brain processing resources of the self-focused attention system.

Multiple researchers document a substantial role of interoceptive stimuli, particularly visceral feedback, in implicit memory processes (Werner et al., 2010). Pollatos and Schandry (2008) investigated the relationship between interoceptive awareness and the conscious processing and memory of emotional information. High levels of interoceptive awareness correlated with stronger responses to positive or negative stimuli, suggesting that interoceptive processing of emotionally heightened stimuli improves our ability to form memories of that stimuli. Conversely, when stimuli trigger the fight, flight, or freeze response, the experience is less likely to be encoded in explicit memory (Siegel, 2008). Applying this to individuals who experience sensory integration and processing differences resulting in high levels of stress and heightened negative emotions suggests their ability to establish explicit memories may be negatively impacted.

Clinical Example of Other Mental Functions

Scarlett is a 16-year-old girl who seeks occupational therapy because of concerns related to sensory over-responsiveness to sound and touch as well as difficulty with emotion regulation. Over responsivity was reported on self-report and parent-report measures as well as during standardized testing in the clinic. Over-responsiveness is characterized by responses to sensory stimuli that are faster, longer, or more intense than what would be expected with typical sensory responsivity (Miller et al., 2007). Despite her extremely high IQ, her sensory differences result in challenges in self-expression particularly as it relates to decision making and problem solving. Scarlett reports living in a constant state of stress. Sounds produce a heightened experience that triggers the fight, flight, or freeze response, and are likely not being encoded in explicit memory. She indicates feeling confused by sensory signals from a young age and constantly feeling overwhelmed by auditory and tactile input. She is intellectually gifted but reports struggling to manage the incongruence between her mind and bodily experiences. Decision-making is particularly impacted. For example, in multisensory environments like a restaurant, when faced with ordering food from a menu, 16-year-old Scarlett completely freezes due to her over-responsivity. She is reliant on her family members to order for her. Her concerns reflect a challenge in executive functions and body-based regulation resulting in frustration and inaction. For Scarlett, her body's protective response is funneling interoceptive resources away from homeostasis and toward a freeze reaction (Porges, 2009). This compensatory strategy affects the encoding of memories necessary for problem solving and decision-making. Scarlett's experience highlights the relevance of interoceptive sensory inputs' cascading effect on complex social behaviors including the demand for executive function (Adolfi et al., 2017). Knowledge derived from research establishes that instances of homeostatic perturbation offer a period of time in which the conscious perception of interoception can be elicited (Critchley et al., 2004). Scarlett's clinician utilizes this as a tool for intervention by incorporating opportunities for physiological exertion that require a homeostatic shift or tax the system in a way that the system can respond with a rebalancing or return to homeostasis. In response, timely use of cognitive strategies such as attending to, and labeling bodily sensations is advantageous. The goal of this strategy is to generate sensory stimuli through movement of the body and then engage the forebrain by making interoceptive sensory stimuli conscious, thus formulating awareness and driving behavioral responses. This example can guide practitioners to incorporate bottom-up and body-based interventions along with cognitive strategies to drive adaptive behavioral responses but most importantly to work toward body and mind congruence which offers a felt sense of safety and promotes purposeful engagement in life.

CONCLUSION

The proliferation of evidence on the pervasive influence of interoception offers a timely opportunity. Future clinical and research endeavors can be carefully considered to offer an expansion of knowledge as well as a new dimension to the science underlying intervention. The knowledge base provided from multiple fields provides a powerful and undeniable insight into the role of interoception in the interaction between body, brain, and mind. To further the knowledge, there is a need for the development of interoceptive assessment tools. These tools need to document the association between interoception and engagement in meaningful participation. The ability to assess interoception in support of meaningful participation will guide clinicians in understanding interoception's role in the underlying sensory processes. Where differences in interoceptive processing are captured, these differences can be related to indicators of diminished function. Drawing from this, therapeutic intervention which targets interoception could prove to support the individual's sensory health and wellness.

In support of the evidence related to interoceptive capacity, interventions that are developed need to support both top-down and bottom-up foundational strategies (Khoury et al., 2018). The evidence generated must test intervention procedures across the lifespan and encompass a variety of clinical populations. Interventions addressing body-based activities, bodily sensations, and body awareness, for example, could improve interoceptive accuracy, interoceptive regulation, interoceptive self-efficacy, and support remediation of many clinical disorders impacting function (Fischer et al., 2017; Khoury et al., 2018). The anticipated improvement in the ability to detect and distinguish interoceptive signals may prove helpful in contextualizing this sensation for improved meaning-making which drives a felt sense of safety and promotes well-being. Such efforts will grow the collective understanding of how evidence-based practice impacting interoception can support meaningful participation in life through improved sensory health and wellness.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work, and approved it for publication.

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"When I'm in Pain, Everything Is Overwhelming": Implications of Pain in Adults With Autism on Their Daily Living and Participation

Merry Kalingel-Levi[1]*, *Naomi Schreuer*[1], *Yelena Granovsky*[2,3], *Tami Bar-Shalita*[4], *Irit Weissman-Fogel*[5], *Tseela Hoffman*[5] *and Eynat Gal*[1]

[1]Department of Occupational Therapy, Faculty of Social Welfare and Health Sciences, University of Haifa, Haifa, Israel, [2]Laboratory of Clinical Neurophysiology, Bruce Rappaport Faculty of Medicine, Technion, Israel Institute of Technology, Haifa, Israel, [3]Department of Neurology, Rambam Health Care Center, Haifa, Israel, [4]Department of Occupational Therapy, School of Health Professions, Faculty of Medicine, Tel Aviv University, Tel Aviv, Israel, [5]Department of Physiotherapy, Faculty of Social Welfare and Health Sciences, University of Haifa, Haifa, Israel

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University of Missouri, United States

***Correspondence:**
Merry Kalingel-Levi
Miryam.kalingel@gmail.com

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Pain sensation in autism spectrum disorder (ASD) has been a growing research field in the last two decades. Existing pain research has focused on pain sensitivity, suggesting either hyposensitivity or hypersensitivity to pain in individuals with ASD. However, research about other aspects of pain experience is scarce. Moreover, most pain-related research in ASD focused on quantitative measures, such as neuroimaging or parental reports. Instead, this paper aimed to illuminate the various aspects of pain experience as perceived by adults with ASD. Its descriptive qualitative research design incorporated semi-structured interviews and deductive thematic analysis. This phenomenological approach captured the subjective pain experience through the lens of people with ASD. Four primary themes emerged from the data: (a) physical pain experience, including the sequence of pain sensitivity, pain awareness, pain-related emotional aspects, and pain communication; (b) direct and indirect coping strategies; (c) function and participation outcomes; and (d) suggestions for Healthcare Providers. The findings echo the crucial role of pain awareness and communication in the pain experience of people with ASD. These two factors have been reported as profoundly influencing coping strategies, function, and participation. The results emphasize the need to expand the exploration of pain in this population, calling for greater understanding, and listening to this population's unique pain profiles and experiences to promote better-suited evaluation, diagnosis, and intervention in pain conditions.

Keywords: pain sensitivity, pain processing, pain awareness, coping strategy, function

INTRODUCTION

Autism spectrum disorder (ASD) refers to complex neurobehavioral and neurodevelopmental conditions characterized by persistent deficits in social interaction and communication and restricted and repetitive patterns of behavior or interests. The onset of these symptoms appears in the early developmental period and results in impaired daily functioning (Tantam, 2012; American Psychiatric Association, 2013).

The *Diagnostic and Statistical Manual of Mental Health Disorders* (5th ed.; *DSM-5*) definition of ASD by American Psychiatric Association (2013) includes sensory features as one of four restricted/repetitive behavior diagnostic criteria. It defined *sensory features* as "hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment" (50). Sensory features refer to patterns of behavior suggesting differences in how daily sensory stimuli are processed (Schaaf and Lane, 2015). They may manifest differently across individuals with ASD and across time and contexts for the same person. These differences presumably result from individual capacities combined with challenges encountered in complex physical and social environments (Baranek et al., 2006).

Sensory feature differences may manifest in sensory thresholds and self-regulation strategies. Sensory thresholds range from high (slow to detect) to low (quick to detect); self-regulation strategies range from passive (not troubled by sensory stimuli) to active (reactive to sensory stimuli). Such sensory profiles characterize every human being and are conceptualized as continua (Dunn, 2014). However, *sensory atypicalities* characterize only some individuals and are more common among individuals with ASD (Little et al., 2018).

Sensory features have been noted among individuals with ASD since the earliest recorded case studies. The descriptions of Kanner (1943) included pleasure and enjoyment in the presence of sensory stimuli and increased sensory sensitivity to other stimuli. Asperger (1944) also described children with ASD demonstrating hypersensitivity in some circumstances but ignoring or seeking specific stimuli in other situations.

The two most common behavioral manifestations of sensory atypicalities are hypo- and hyperresponsiveness to sensory input, with probable differing response profiles across and within sensory modalities (Baranek, 2002; Tavassoli et al., 2018). According to Miller et al. (2007) sensory processing model, low sensory thresholds characterize individuals who cope with sensory overresponsivity. These individuals respond to sensation with more intensity or for longer durations than do those with typical sensory responsivity. Hence, they represent a *sensory-sensitive* sensory profile. Individuals who cope with high thresholds are divided into *sensory under-responsivity* and *sensory seeking* subgroups. The first group disregards or does not respond to sensory stimuli in their environment and appears not to detect incoming sensory information. The second group craves an unusual amount or type of sensory input and seems to have an insatiable desire for sensation. Atypical sensory features negatively affect the ability to respond adaptively to environmental demands and engage meaningfully in daily occupations (Dunn, 2007; Hochhauser and Engel-Yeger, 2010; Ricon et al., 2017).

Pain is explained commonly in terms of the perceptual activity of a distinct sensory modality. However, some theoreticians claim that pain is a functionally integrated feature of all the senses rather than a distinct sensory modality (Gray, 2014) or attribute pain to other sensory modalities, such as interoception (Craig, 2002).

Nociception is a particular type of pain processing, defined as the encoding and processing of noxious stimuli due to nociceptor activation (Garland, 2012). *Pain threshold* is defined as the amount of time elapsed before the participant reports the stimulus to be painful. The pain threshold is relatively consistent for each person under a given stimulus (Kanner, 2009). Scholars suggested that pain is not only physiological by nature but also a multidimensional phenomenon. In addition to its sensory aspect, pain involves cognitive, motivational, and affective qualities and affects function, quality of life, and well-being (Craig, 2009; Love-Jones, 2019). *Pain* is an unpleasant sensory and emotional experience associated with or resembling that associated with actual or potential tissue damage (Raja et al., 2020). *Pain processing* is the way that the brain recognizes and interprets pain (Garland, 2012).

The neurotypical population also includes individuals with under-responsiveness and over-responsiveness to pain (Bar-Shalita et al., 2019). Research indicated that individuals without developmental disorders and with sensory over-responsiveness demonstrated hypersensitivity to daily painful events and experimental pain, and experience longer pain aftersensation (Bar-Shalita et al., 2014).

Pain research in ASD is scarce and insufficient. The prevailing assumption is that individuals with ASD are hyposensitive to pain (Moore, 2015). Even in the *DSM-5*'s ASD definition, the sensory features component includes "an apparent indifference to pain/temperature" (American Psychiatric Association, 2013, p. 50). In the last decade, the comprehensive analyses of Moore (2015) and Allely (2013) focused on physical pain among individuals with ASD. Moore (2015) concluded that individuals with ASD do not present abnormal pain responses, whereas Allely (2013) acknowledged the presence of pain hyposensitivity in case studies but concluded that physiological reports challenge the ASD pain-hyposensitivity dogma. Those reviews demonstrated the scarcity of knowledge regarding pain perception features. The ASD features, including challenges in social communication and sensory atypicalities, may directly influence the experience and expression of pain (Nader et al., 2004). Those possible influences may affect pain assessment in daily life and, in turn, the quality of care that people with ASD receive (Allely, 2013; Moore, 2015). A better understanding of pain experience features among individuals with ASD is crucial because pain may significantly affect their function, participation, and quality of life.

Over the past 50 years, sensory sensitivity, sensory overload, and perceptual distortions have been reported extensively in autobiographical accounts by individuals with ASD (e.g., Grandin, 1992). They often described overwhelming sensory input as an impetus for social withdrawal (e.g., Grandin, 1996). Several autobiographical accounts focused on sensory experiences (e.g., Elwin et al., 2012) but not on pain specifically. Only one qualitative research focused on the pain experience among individuals with ASD. It indicated that adults with ASD often feel pain differently than neurotypical individuals, and some reported experiencing pain evoked by stimuli that usually do not cause pain in neurotypical adults. In addition, it suggested that pain could hinder individuals' participation in daily occupations and risk their safety (Kornblau et al., 2020).

Considering the significant effects of pain on the lives of individuals with ASD, there is a need to characterize and

TABLE 1 | Participants' personal characteristics.

Participant (pseudonym)	Sex	Age	Family status	Housing accommodation[a]	Occupation
AA	M	29	Single	Apartment in community	Unemployed
AC	M	23	Single	With family members	Student
AD	M	25	Single	Independent living	Musician
AK	M	36	Single	Apartment in community	Integrated circuit designer
BF	F	46	Married	Independent living	Office assistant
BG	M	22	Single	Hostel	Unemployed
EK	F	40	Married	Independent living	Research assistant
GM	F	23	Single	With family members	Unemployed
NB	M	29	Single	Apartment in community	Geographic information systems specialist
NC	F	29	Single	With family members	Jeweler
OK	F	23	Single	Apartment in community	Unemployed
OL	M	22	Single	Hostel	Unemployed
OM	F	29	Single	Apartment in community	Office assistant
RS	M	25	Single	Apartment in community	Student
TC	F	23	Single	Hostel	Janitor

Hostel: arrangement for people with autism who can use community services and be involved in the community; Apartment in community: accommodation for those who can function independently but need support and direction in their independent lives; and Independent living: housing with no external assistance, alone, or with family members (partner, offspring, etc.).

[a]With family members: live with parents or other family members (grandparents, siblings, etc.).

better understand how pain influences their function, how they cope with it, and what they require for appropriate care. Therefore, this study aimed to shed light on how adults with ASD experience and perceive pain, its consequences on their daily living, and their pain-related coping strategies.

MATERIALS AND METHODS

This study is a part of a concurrent parallel mixed methods research (Creswell and Plano Clark, 2011), which included an inclusive, comprehensive quantitative research project and a qualitative study. All interviewees participated in the quantitative research and were purposefully invited to participate in the qualitative research. The current paper addresses the qualitative research only.

This qualitative study used a phenomenological approach to explore the study objectives. This approach is suitable for examining perspectives on complex, ambiguous, and emotionally laden issues. Pain is a prime exemplar of such a phenomenon because it is elusive, involves complex psychosomatic interactions, and is difficult to articulate (Smith and Osborn, 2015).

Participants

We used purposeful and criterion sampling to select participants who could relate to and describe the pain experience (Creswell and Poth, 2017). Inclusion criteria were as: (a) adults with Level 1 ASD, as diagnosed using the Autism Diagnostic Observation Schedule™ (2nd ed.; Lord et al., 2012); (b) verbal performance and full-scale estimate of 80 and above on the Wechsler Abbreviated Scale of Intelligence-II (Wechsler, 2011); and (c) proficiency in the Hebrew language with an ability to provide in-depth descriptions of life experiences. The exclusion criterion was any chronic pain diagnosis.

The sample comprised 15 adults with ASD: seven males and eight females. This sample is not representative of the larger populace diagnosed with ASD, in which the female-to-male ratio is 1:4 (Maenner et al., 2020). We chose a larger representation of women with ASD since they proved more willing to share their experiences and demonstrated the ability to provide deep and rich descriptions and insights. Moreover, the larger representation of women in this study enables echoing the underrepresented population in previous literature. The participants' mean age was 28.27 years ($SD = 6.95$). None had chronic neurological diseases, but three (20%) coped with chronic health conditions that were not pain-related. Two (13.3%) participants had been involved in work/automobile accidents, one (6.6%) experienced a head injury, and four (26.6%) experienced serious upper- or lower-extremity injuries. Nine (60%) participants used medicines, including antidepressants, anxiolytics, antipsychotics, or chronic disease medications. **Table 1** presents additional personal characteristics by participant.

Procedures

The University of Haifa Ethics Committee of the Faculty of Social Welfare and Health Sciences approved this study, and all participants signed an online informed consent form. We assured participants' anonymity and confidentiality by coding and removing their identifying details and allowing them to withdraw from the study at any stage.

Participants were invited to online, face-to-face, in-depth interviews using Zoom videoconferencing software. Each interview lasted 60–90 min and was audio-recorded only. The first author, a trained occupational therapist experienced in working with adults with ASD, conducted the interviews sensitively and facilitated open and safe communication with the participants.

The interviews were adapted to people with ASD by, for example, a preliminary conversation regarding their preferred setting; editing the interview guide while considering simple and concrete language; inviting the participants to ask for clarifications and breaks; reminding them of the option to avoid unpleasant questions; and conducting two follow-up telephone conversations to make sure that they were well after the interview.

Research Tools

We developed an interview guide based on the literature, preliminary results of earlier quantitative research on pain among adults with ASD, and clinical experience. The questions in the interview guide referred to various issues relevant to the pain experience (e.g., subjective definition of pain, pain triggers, changes regarding pain throughout the lifespan, implications of pain on daily function, and strategies to cope with pain). The open-ended questions provided a flexible framework that invited interviewees to lead the interview according to their perspectives while enabling the researcher to maintain conceptual and structural focus on the relevant issues studied among all interviewees.

Data Analysis

We analyzed the interviews by examining thematic content based on the participants' descriptions of their experiences, feelings, thoughts, and perceptions. The analytic process consisted of three stages (Corbin and Strauss, 2015): (1) initial analysis, in which interviews quotations formed textual meaning units and were grouped into initial categories; (2) mapping analysis, which revealed similarities and divergence among the interviewees, potential meanings, examples, perspectives, and best practices; and (3) focused analysis, in which we conceptualized the findings into four major themes.

We stopped analyzing the interviews at participant 15 because we recognized content saturation without new information or themes emerging from the data (Charmaz, 2014).

Initially, the first two and the last authors coded the first three interviews independently, resulting in 42 preliminary categories. They then merged them into 21 final categories through deliberation and arriving at a consensus. These categories were then cautiously mapping the remaining interviews in two brainstorming sessions. The authors validated each category while considering demonstrative quotations from the data. This process resulted in conceptualizing the four main themes and creating a visual model. The whole process was presented to five professionals in the field of pain and ASD, who confirmed the analysis.

The participants' thick and rich descriptions, demographic data related to pain, and contexts ensured the study's trustworthiness. In addition, open conceptual discussions were conducted continually alongside peer-reviewed data processing and the authors' familiarity with the examined phenomena. Comparing the findings with the limited literature available further enhanced the study's credibility.

RESULTS

Four primary themes emerged from the data examining the physical pain experience and its implications on daily life in individuals with ASD: (a) the physical pain experience, including the pain sensitivity, pain processing (i.e., pain awareness and emotional aspects of pain), and pain communication; (b) coping strategies, including direct and indirect strategies; (c) function and participation outcomes; and (d) suggestions for Healthcare Providers. The model in **Figure 1** demonstrates the concepts that emerged from the analysis and their interrelations, echoing the in-depth interviews with adults with autism. This model strengthens previous literature regarding pain by demonstrating examples from first-hand accounts. Additionally, the model suggests new aspects of pain, which were not mentioned in previous studies, such as pain awareness. The uniqueness and contribution of the model will be further discussed in this paper.

Pain Experience

All participants (34 citations) defined *pain* as a significant inconvenient, agonizing, and sometimes-traumatic experience. For instance, EK stated, "It is an unpleasant sensation you want to stop; you cannot completely ignore it. When the pain shows up, you immediately notice, it instantly causes discomfort."

The participants acknowledged the purpose of pain as an indicator that something is wrong, as NC's words demonstrated as: "Pain, when your body is signaling that something is bothering you, is actually the product of what we feel … when something harms the body, when something is not working as it should." Some participants emphasized pain's role as a motivation for action. BG articulated, "Something malfunctions somewhere in one of the systems, so you need to take care of that. Otherwise, [the pain] will get worse."

Most participants showed a clear understanding of pain's purpose and function, which helped them accept and cope with it. "Stomachaches, for example, are something I do not understand, but the pain from an injection is much more bearable because I understand its reason" (AH). However, participants also described stress from ambiguous pain, intensified by their need to understand, classify, and identify its causes.

Three main subthemes were recognized in the pain experience context: (1) pain sensitivity, (2) pain processing, consisting of pain awareness and emotional aspects, and (3) pain communication.

Pain Sensitivity

The participants described various sensory-sensitivity characteristics: hypersensitivity (six participants), hyposensitivity (seven participants), and neutral (two participants). BF's and AC's contradictory reports demonstrated this heterogeneity. BF compared her experience of increased pain sensitivity to others: "Some things that are not painful to others are very painful to me." On the other hand, AC reported decreased pain sensitivity: "I have pain tolerance. I am less sensitive to pain than most of my friends and family members."

Some participants who reported having decreased pain sensitivity also addressed their surroundings' role in shaping their self-perceptions of pain sensitivity. They noted their primary groups saying they were less sensitive to pain. "I know I'm less sensitive to pain because that's what I'd always been told. My parents, friends, and anyone around me told me I am resistant to pain"

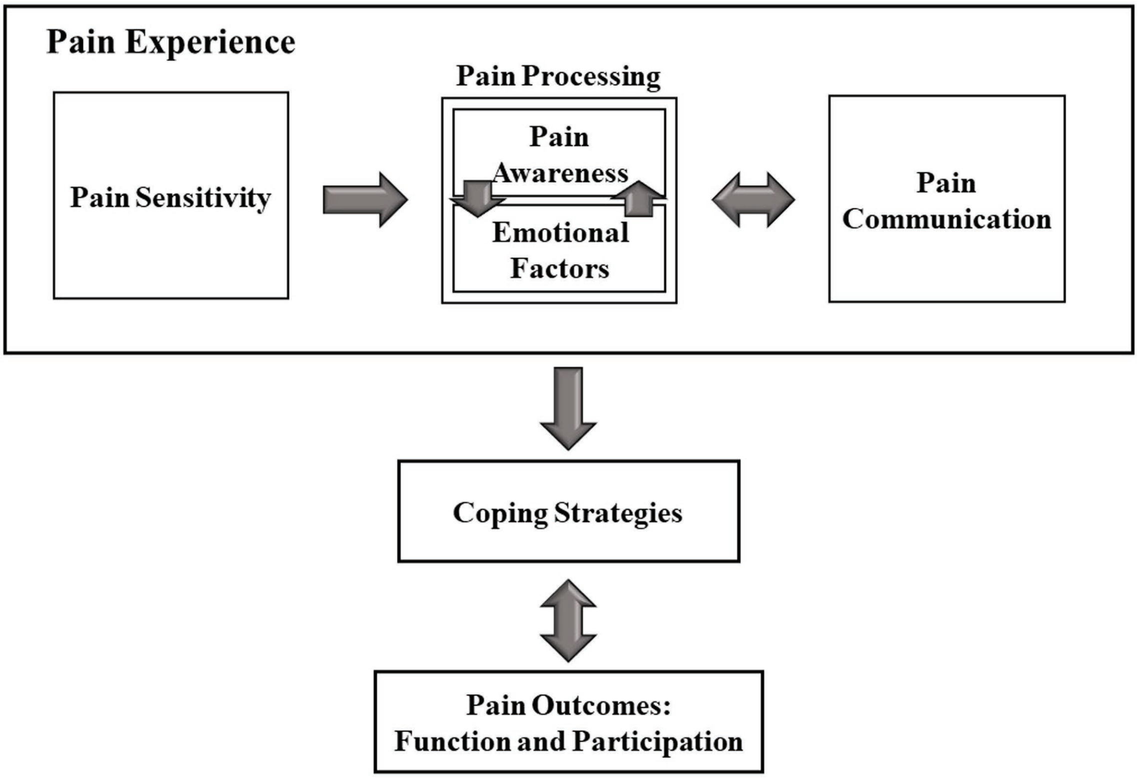

FIGURE 1 | Pain–participation model.

(BG). They described this external input from the surroundings as coming throughout their lifespans. TC shared, "When I was a child, I was very sensitive to pain… Today, I am more resistant to pain. I knew that, and my surroundings kept telling me, ever since I was a child." Like TC's description, AD reported decreased pain sensitivity: "I think when I was younger, I was more sensitive to pain; today, my resistance to pain is higher."

Like AD, most participants who reported changed pain sensitivity described a decreased pain sensitivity throughout their lifespan. Only one participant described the opposite (i.e., increased sensitivity along with the lifespan). Relying on the surroundings' messages as an external input about their own pain experience may result from their difficulties with pain awareness.

Pain Awareness

All participants (43 citations) reported uncertainty about the internal pain experience of ambiguous pain. This uncertainty consisted of three layers: the existence, nature, and severity of pain. Only a few participants reported having a fundamental difficulty recognizing the *existence* of pain (i.e., classifying a stimulus as painful). They described being unsure whether the source of the inconvenience they felt was pain or another physical sensation (e.g., hunger, tiredness, or sensory overflow in non-pain sensory modalities). OM shared, "I know that my reading of myself is wrong. Sometimes I feel physical discomfort and do not know if what I feel is from being tired, hungry, or because a strong noise is overflowing my system."

While only a few participants reported uncertainty regarding the existence of pain, most spoke of challenges defining the second layer, the *nature* of pain. These challenges included identifying the location, intensity, and type (e.g., stabbing, burning, or stinging) of pain: "I do not trust myself when it comes to sensations… If someone asked me where or how much it hurts, I would not know how to answer" (AH). Such experiences demonstrate their challenges during contact with others, especially healthcare providers.

The difficulty in defining pain intensity may be linked to the last layer of uncertainty regarding the pain experience—challenges estimating the pain *severity*. Most participants described these challenges. GM vividly shared her experience: "My leg was caught in the revolving door. I felt a strong pain… I could not understand what my body was signaling to me. Is the pain serious? … I did not know what to do until someone told me I was pale, and the leg did not look as it should. She called an ambulance."

Given their difficulty characterizing the pain experience, participants often tended not to get treatment or to look first for external information. Many described depending on their surroundings to validate and affirm their pain experiences. AH described: "When I go to the doctor, I ask a lot whether what I am doing is good… I am better off asking than making mistakes. I do not trust myself, my reports, and my sensations and need someone else to tell me I am OK, give affirmation, and describe what I feel."

The participants reported their reliance on others for pain-related data as simultaneously reassuring and regulating or confusing and frustrating. These positive or negative feelings resulted from the congruence or incongruence with their interpretations of the surroundings and internal experiences. AH gave an example of negative emotions following a doctor's incongruent interpretation: "I went to doctors on several occasions to understand what I am going through, what is hurting me, and what to do about it, and they did not understand me. It was confusing because the gap between what I felt and what they said I have and the way they treated me was enormous." On the other hand, NB shared a positive experience following a successful interpretation of her sensations with her friend's help: "My ear hurt a lot one time. It drove me crazy. I called a good friend, and she helped me understand that the pain is intense and that I should get checked up… I remember the feeling of relief when she articulated my pain."

These examples reflect the consequences of the participants' dependency on others to cope with pain awareness difficulties. When others successfully interpret their experience and respond accordingly, this coping strategy may facilitate clarification, resolution, and better self-understanding. However, a mismatch between the internal experience and external response leads to confusion, frustration, and misconception regarding personal pain features.

Another external information source about the participants' pain was visual input of body-tissue damage (e.g., bleeding, wound, or swelling) and, to a lesser degree, related physical-environment damage (e.g., broken glass, bent car, or torn clothes). NA shared an example: "I was sitting to the side of the bicycle, and my leg got caught in the wheel. I felt something bad had happened, but I did not know what. Then I saw my sandal was completely torn up, and my leg was stuck; only then did I understand I was in pain."

The participants emphasized the struggle to recognize, interpret, and understand their pain experiences. Interestingly, several attributed pain uncertainties to a general mistrust and misunderstanding of their inner world. NA explained, "I associate the subject of pain perception to social communication. I live my life with the realization and awareness that I misunderstand and misinterpret the world, so I do not trust myself."

Following the general struggle with understanding and interpreting the outer and inner worlds, participants described the need for external information sources to solve the uncertainty and evoked emotional stress.

Emotional Aspects of Pain

Another critical component of all participants' (38 citations) physical pain experiences was pain's emotional aspects. When the participants defined *pain*, they addressed two kinds: physical and emotional. "Both include an unpleasant sensation, but each is caused by different triggers, and their manifestation will be different" (AH).

The participants also described that physical and emotional pain often co-occur or ensue sequentially (i.e., emotional aspects serve as triggers and are evoked by physical pain). Many reported that physical pain triggered negative emotions, such as helplessness, distress, and insecurity. AK reflected, "When I feel pain in my body, when something bad hurts me, my anxiety rises. I am in distress." The participants described that the cognitive, estimated health-and-safety risk level, specifically if life-threatening, also affected their emotional reaction to physical pain. OL explained, "When you realize that the pain will not kill you, it dampens the pain a lot." Conversely, several participants reported underestimating common and frequent pain (e.g., headaches and superficial injuries) when they understood them to be non-life-threatening: "I know that in most situations when I feel pain, it will not kill me. That is why I do not think much of the stomachaches and headaches I frequently experience" (NA).

The participants described that emotional pain might trigger physical pain. OM echoed many others: "When I feel emotional pain—for example, strong anxiety—I immediately feel it in my body… Emotional pain mostly expresses itself with stomachaches." Another effect was emotional pain's amplification of physical pain. "If I am anxious, it does not matter what caused the pain or what kind of physical pain it is, it will be slightly stronger" (NB). As OM's and NB's quotations demonstrated, anxiety was a prevalent emotion that might evoke or amplify pain. On the other hand, most participants reported that awareness, knowledge, and familiarity with the painful stimuli promoted better emotional states by providing a sense of control that decreased the physical pain. "In familiar situations, there is more of a sense of emotional calm, and then the physical pain is less strong" (AK).

The participants' reports indicated a tight bond between the emotional domain and pain experience. This bond was not unidirectional: The emotional aspects of pain and the pain experience concurrently related to each other. Similarly, pain awareness and emotional aspects were reciprocal; both were key factors in pain processing.

Pain Communication

All participants (47 citations) reported difficulties expressing pain and attributed them to (1) fundamental communication difficulties, (2) challenges "translating" the internal experience to words, and (3) challenges using prevalent evaluation tools.

Many participants recognized that social interaction deficits deriving from ASD characteristics were a significant factor causing them difficulties expressing their pain and being understood. NB conveyed, "Because of my autism, I usually find it hard to describe what I need or want since it is hard for me to talk to people. When I try to address them, I realize, time after time, that they do not understand me… This manifests when I try to talk to others when I am experiencing pain."

The participants reported that coping with physical pain, accompanied by emotional reactions, requires effort and tools—leaving little for coping with communication challenges. BG articulated, "I cannot muster the strength and effort needed to express myself [when I am in pain]. It's always hard for me to communicate, but pain situations make it [more] difficult to apply the strategies and tools I use in my daily communications with those around me."

Moreover, participants emphasized that physical pain's abstract nature and internal presence make it harder to define, explain, and share: "I can never explain my feeling of pain. I try … but do not know how to describe it accurately enough: How much it hurts, where, and what kind of pain it is. How can one take a sensation and translate it to words?" (NC).

This challenge of explaining and defining pain with words may link to difficulties using pain-evaluation tools that translate the pain experience into symbols (faces, numbers, colors, etc.). As manifested in AH's words, this challenge represents the participants' unique desire and stress to be correct and accurate, which is not simple in the pain phenomenon: "I do not know how to use numbered or colored scales to rate pain; they are too complex. How can I know I'm "translating" my pain correctly to another representation? I struggle with this definition and not being able to confirm that my answer is correct, accurate, and reflects what I feel."

Coping Strategies

This study revealed two coping-strategy types: (a) direct strategies to solve the pain situation and (b) indirect coping strategies to ease the pain experience. The latter type was reported as more commonly used.

Direct Coping Strategies

Preference to Cope With Pain by Oneself

Given their significant challenges in communicating pain, it is understandable that all participants (24 citations) reported preferring to cope with pain by themselves, as AH's description demonstrated: "I have difficulties reporting pain… When I tried to reach out for help, … I could not get the response I needed. I realized that I had to get by on my own. Bit by bit, … I simply rule out going to others in the context of pain."

Many participants described depending on others' help when in pain as children. Two parallel processes throughout the years contributed to their preference for coping without external assistance. The first process was maturation, gradually self-learning their pain characteristics and mechanisms and transitioning to more independent coping. For example, NB stated, "As a child, the sole responsibility for solving painful situations was my parents.' Today, I better understand where the pain is coming from, its side effects, and how to treat it."

The second process was a form of mistrust of others' assistance during pain situations. Repeated experiences of being misunderstood and trying and failing to get help created a chasm between the participants and their surroundings: "Because our experiences with trying to get help are painful, we do not want to ask for help from those around us when in pain… The outside is not a place that lends help… Only I understand my pain. Only I can help myself" (BF).

The participants reported asking for help only when they evaluated the pain as severe—intense, long-lasting, or accompanied by external signs of a serious injury. OM described such an experience: "I did not tell anyone … that I fell or was in pain. After several days, my leg swelled a lot, so I said to myself, 'OK, maybe I should tell my parents that I'm feeling pain.'" As reflected in OM's report, participants agreed that seeking others' help would be the last resort.

Asking Others for Help

When participants did ask for help, most (27 citations/12 participants) reported asking family members (mainly parents) or doctors. Several also asked friends, partners, or housing facility assisting staff. Most participants identified their parents as significant figures in pain situations, helping them define the pain situation, look for solutions, and bridge the gap with medical professionals:

> If I need help when I'm in pain and not feeling well, I go to my mother. When I'm not making sense to others or even myself, my parents understand me. They know how to help me understand what's happening to me and solve the problem. They also help me communicate my needs to staff members who will take care of me. (NA)

Although comprehensive agreement on the positive value of approaching parents for help was apparent, asking medical professionals for help was controversial among the participants. Some shared negative interactions with medical staff, which included inadequate assessment and treatment of physical pain, resulting in medical complications. OM's experience is one example:

> I told the doctors in the emergency room that I was in great pain. They did their tests and finally said, "You can go home," like everything was fine. I kept telling them I was in pain, but they discharged me anyway. My mother [took] me back to the hospital several hours later… I had to be hospitalized immediately because of a severe leg infection that already started spreading.

The participants' shared experiences suggested three distinct triggers for inadequate treatment of physical pain. The first they described as *disrespect*, feeling the medical staff did not take their complaints seriously. "When I seek help and say to the doctors, 'I am in pain,' I expect them to pay attention… But what happens is that when I go to the doctors, they do not take me seriously. I had the feeling of being really disrespected" (GM).

The second trigger is the medical staff's *misunderstandings* due to communication difficulties: "They do not get me, do not understand what is happening to me, why I came, and what I need. I go seeking help, but during the appointment, I realize time after time that it is not going to work, and I give up. I know their treatment of me will not be adequate because they do not understand me" (NB).

The last trigger mentioned was *conflicting expectations* regarding the role of each side in the interaction. Whereas the medical staff expects the person with ASD to articulate their complaints and requests, the person with ASD copes with an initiation challenge and expects the medical staff to identify the proper treatment:

> After I broke my leg, I was in a lot of pain but wasn't offered painkillers. I thought it was the doctor's or the nurse's role to offer me medication, but they did not do that. I kept suffering excruciating pain. Today, I realize they expected me to tell them … to ask them. But it's hard to address someone and suggest my own ideas. (AK)

BF described a similar incident. "On the third day of the hospitalization (post-hysterectomy), the nurse suddenly came over and asked, 'What are you getting for the pain?' I told her I was not receiving anything. She asked why I had not asked for anything."

The participants' experiences emphasized the gap between their needs and expectations and the medical staff's prevalent attitude. AK's and BF's words indicating this gap also demonstrated an aspect of the complex relationship of people with ASD to pain medication. They shared that their difficulty initiating communication aimed at receiving care resulted in less or no pain-medication treatment.

Using Pain Relievers (Analgesics)

Participants described asking for analgesics as a challenge stemming from their difficulties initiating communication. Analgesic use appeared to be a broader subtheme (33 citations/13 participants). Participants described preferring to avoid analgesics due to concerns over (1) using chemical substances, (2) masking internal information, and (3) inability to report pain accurately to the medical staff due to the analgesics' influence. Many participants described hesitating to use analgesics because they worried about the chemicals' effects on their bodies. TC shared, "I do not like to put chemical substances into my body. My body chemistry is challenged as it is. I fear the effects that painkillers have on my body."

Another common concern was masking internal sensations (i.e., losing pain input, such as severity, intensity, and location), which might decrease pain awareness. RS said, "The pain from the hernia was getting much worse, so I went to the hospital. I was in a lot of pain but afraid to ask for painkillers. I feared I would lose my awareness of the pain and then lose control over my body."

Participants also mentioned losing internal information after using analgesics in conjunction with their third concern—the inability to communicate with and get help from medical staff. They described fearing situations in which the medical staff would ask about the nature of their pain, and they could not answer because of the analgesic effect—and fearing misdiagnosis as a result. GM shared her emergency room experience after she broke her leg: "I did not want to ask for pain pills. I was afraid that if I took them, then when the doctor came, I would not be able to tell him what I was going through exactly. I have to rely on information from my leg for that. So, I thought to myself, I will not take painkillers … so no misdiagnosis would occur."

Despite their reluctance, a few participants reported using analgesics for intense or unpredictable pain. EK shared her menstruation experience: "For example, when I'm on my period, I cannot control it… I mean, it's strong waves of pain you do not know how or when they'll appear. When I … recognize that unpleasant sensation is beginning, I immediately take pills. I do not wait for it to start hurting."

Indirect Coping Strategies

The participants' reports indicated less prevalent use of direct pain-related coping strategies, including asking for help and using analgesics, than indirect pain-related coping strategies. These included ignoring and resting, engaging in alternative activities, covering/holding the sore area, and self-injurious behavior (SIB).

Ignoring and Resting

Many participants (19 citations/11 participants) mentioned ignoring the pain as a helpful strategy in mild pain situations. They reported continuing their daily routines, hoping their pain would dissipate. AC described, "I try to pass the time and let the pain fade." Many participants also reported resting as an opposite strategy. They described a definite stop in functioning that enabled them to relax their bodies by sitting or lying in bed. NC elaborated, "When I'm in a lot of pain or hurt in a lot of places, … I just lie in bed. I try to relax my body, rest. When my body is relaxed, the pain decreases." Some participants described combining other relaxation techniques with resting, such as meditation, deep or yogic breathing, listening to constructed meditations, and repeating health-focused mantras (e.g., "I feel good," "My body is strong").

Engaging in Alternative Activities

Along with relaxation techniques, participants (26 citations/14 participants) described various alternative activities that served as coping strategies. The common denominator was that these were favorite, preferred distracting activities. The activity reported most often was using a cellphone for gaming, watching videos, and browsing social media. OL shared, "When I am in pain, … the best place to escape to is my phone. There are many activities I can distract myself with—movies, games, and more. It's as if it passes the pain, and you do not think about it." Other activities participants mentioned were talking with someone, reading a book, watching movies, taking a shower, thinking, and daydreaming.

Whereas participants repeatedly described preferring to engage in purposeful activity, a few expressed engaging in emotional activities (e.g., crying or complaining) to cope with pain. Although possible and familiar, such a coping strategy was not prevalent or preferred, as OM's words demonstrated: "I rarely cry because of pain. I tend to complain when I need to unload. When I was sick or went to the ER, I saw many people crying. I guess it's good to cry, but I do not tend to that. It's uncommon for me, but I can remember several times when it happened."

Covering/Holding the Sore Area

Several participants (16 citations/7 participants) reported a specific alternative activity subtype that included covering, holding, or massaging the painful area. These behaviors reflect the spectrum of strategies from ignoring to actively coping with pain. On one side, several participants reported covering the painful area to avoid visual signs that may remind them of their pain. AC gave an example: "A large rock fell on my leg and wounded me. The wound bled. I preferred not to pay attention to the wound; ignore it and keep working. I pulled my pants down to cover the wound so I did not see and think about my pain."

Whereas covering the painful area aimed to ignore the pain, participants described holding the area as deriving from acknowledging the pain's existence. They explained that this behavior aimed to protect the painful area and dampen the pain. AK described, "At the end of the climb on the mountain, my hands were full of scratches. They burned and hurt. I remember holding them close to my body. I wanted them to be protected and no one could touch them. The pressure on them, the contact, lessened the pain." Like AK, several participants referred to touch, specifically deep pressure massage, as a pain-coping strategy. Most reported massaging the painful area to dampen the pain; one described massaging another area simultaneously as a distractive stimulus.

Self-Injurious Behaviors

Several participants (14 citations/five participants) reported another strategy to reduce pain was self-injurious behaviors (SIB), harming oneself while in pain. The SIB severity varied between mildly (e.g., pinching, hair-pulling, and scab-picking) and severely injurious (e.g., head-banging, starting a physical confrontation, and suicide attempts) behaviors. AK's comment manifested mildly SIB at one extreme: "Sometimes, when I am in a lot of pain, I pinch myself somewhere else. Then the other pain distracts me from the sharp pain." At the other extreme, BG described severe SIB: "During high school, when I was in pain, I would bang my head on the wall… One time I was waiting for a doctor's appointment, and my head really hurt, a strong migraine. I came close to my parents and banged my head on the wall next to them. It calmed me." The participants' reports demonstrate varying SIB severity and function. In AK's case, the SIB created a distraction to reduce pain or perhaps served as an unconscious way to induce the "pain inhibits pain" mechanism. In BG's case, the SIB was carried out for emotional relief.

Implications of Pain on Function and Participation

All participants (34 citations) described pain's implications on function, ranging from a complete stop in daily function to full and uninterrupted function. Some participants firmly stated they could not function when in pain because of its intense influence on them. Others reported continuing to function as usual without changing their daily routine. Most participants described more moderate implications of pain on their function. They reported needing to reduce the amount and rate of their daily functions when in pain. "I have to decide what to spend my energy on. I cannot perform all my functions as usual; I must decide which are especially important, and these I do" (NC). Many participants reported skipping or reducing their engagement in daily functions, including work ["Long-lasting pain interrupts my concentration, it will make me miss work" (AK)], education ["On days when I am on my period, I'm in so much pain, I cannot participate in classes" (GM)], and leisure ["I cannot do even things that I really enjoy, like playing music" (AD)].

Another pain-related implication participants described was involvement in bondage and discipline, dominance and submission, sadism, and masochism (BDSM). Being a part of a BDSM community expressed their sexual functioning and social participation. Of the three participants who mentioned engaging in BDSM, two were a couple, and the third was not in a stable relationship. Although these participants differed in their reported pain thresholds (hyper-/hyposensitivity), they all related to the sense of control over pain as a source of enjoyment and pleasure during BDSM interactions.

BG described her feelings from the "dominant" role viewpoint: "I'm on the side that likes to cause others pain… I like that I can hurt others without experiencing pain myself, be in control. It also allows me a chance to see how pain transforms from a bad thing to something good. That pleases me." Her partner, RS, shared his feelings from the "submissive" viewpoint: "I personally enjoy being on the controlled side. The pain I feel … is pleasant… When I choose to engage in a BDSM session, I know I'm about to feel pain… Readying myself for pain and being able to control the pain I am about to feel has some effect." GM also reported satisfaction from the sense of control over the pain she acquires in the submissive role:

> I do not necessarily love pain, but I know I can stop it when it is too much. It's controllable, and no one can hurt me if I do not want it. Suddenly, the pain becomes pleasant. It's mostly giving the other side what it needs… Most times, I find it pleasant for me, too. It provides me a safe place where I can experience pain in a pleasant and controlled way, and I get what I want at the same time—it can be sex, and it can be a hug.

Suggestions for Healthcare Providers

The participants suggested ideas to promote a better-suited healthcare experience in pain situations. The participants' suggestions addressed various needs and challenges they cope with when seeking health care. These suggestions included theoretical issues such as healthcare providers' attitudes and practical ideas, such as visual aids or environmental accommodations. Their ideas are presented in **Table 2**.

DISCUSSION

This study examined the physical pain experiences that adults with ASD shared. Its phenomenological approach captured first-hand accounts of the pain experience through their lens.

TABLE 2 | Suggestions for healthcare providers.

Need	Participant suggestion
Communication Mitigation	"I need the option to communicate differently, not just by speaking. If the doctor had shown me a picture of the human body and told me, 'Show me where it hurts,' it would have been a lot easier to answer compared to just asking, 'Where does it hurt?'" (OK).
Initiation Responsibility	"I do not usually ask for help; I need the doctor to be the one to tell me, 'We have something to give you for the pain' and suggest the option more than once. I am not used to asking for help; it is hard for me to initiate asking for help" (RS).
Emotional Support	"Emotional support, attitude and personal connection are critical to me. I need to feel safe. The doctor wants what is best for me and is attentive to me" (NC).
Sensory Modifications	"The ER is loud; there are screams and bright lights. I cannot speak about my pain or answer questions in such an environment. It would help to have a private room without much light and noise. Then, I would be able to self-reflect, think, and communicate" (BF).
Information Processing	"It would help me if there were booklet with structured sentences and demonstrative pictures so I could understand what I suffer from, what am I going through, what I am experiencing and followed by a description of my situation" (NB).

It spotlights the crucial role of pain awareness and communication in their daily lives beyond the previous literature, which focused on aspects of pain such as neural response (e.g., Failla et al., 2018), sensitivity (e.g., Failla et al., 2020), and behavioral expression (e.g., Nader et al., 2004). Thus, little was known about the pain experience of people with ASD in their daily life contexts.

This study's results suggest a novel theoretical model (**Figure 1**) reflecting the participants' insights into the sequence and implications of the physical pain experience. The sequence begins with physical pain, consisting of pain sensitivity, awareness, emotional aspects, and communication. As a result of this experience, the person with ASD chooses and applies coping strategies. The outcomes of this process manifest in function and participation levels. The model contributes a constructed conceptualization of the pain experience in people with ASD and its consequences.

Pain Experience

Pain Sensitivity

The unique sensory characteristics of people with ASD have many layers, including pain sensitivity. Three aspects of pain sensitivity emerged from the data: (1) its characteristics, (2) the surroundings' input regarding it, and (3) changes in perceived sensitivity across the lifespan. This study revealed variable pain-sensitivity characteristics among participants. Several participants reported a gradual change in pain sensitivity across the lifespan; most described an *increased* pain threshold. Many of those who defined themselves as less sensitive to pain shared that their primary group (mainly parents) told them over the years that they had higher pain thresholds than others.

Sensory sensitivity has long been researched in this population using various methodologies, mostly parental reports (Moore, 2015). Previous research demonstrated inconsistent findings regarding pain sensitivity in people with ASD, often depending on the chosen methodology. Generally, studies based on physiological measurements indicated no pain-threshold difference between people with and without ASD (Allely, 2013). Psychophysics-based studies have indicated hypersensitivity to supra-threshold pain stimuli (Failla et al., 2020). In contrast, studies based on case studies and self- or parental reports pointed to pain hyposensitivity (Allely, 2013). Neuroimaging studies aiming to characterize pain sensitivity in people with ASD also were inconsistent. For example, whereas Gu et al. (2018) reported pain hypersensitivity, Vaughan et al. (2020) reported pain hyposensitivity. The first-hand accounts in this study align with the inconsistent literature, representing diverse pain-sensitivity levels: pain hyposensitivity, pain hypersensitivity, or the same sensitivity as others (neutral).

The literature debated whether pain sensitivity changes across the lifespan. Lu et al. (2007) found that greater age predicted higher pain tolerance, lower pain intensity, and pain unpleasantness in neurotypical children and adolescents. These results align with this study's participant reports about perceived pain sensitivity changing from childhood to adulthood. On the other hand, Riley et al. (2000) found no changes in pain intensity or pain unpleasantness but age-related changes in emotional pain-related distress and pain behaviors in chronic pain adult patients. They attributed the changes to attitudes, beliefs, and life circumstances. These findings may link to this study's third pain sensitivity subtheme—the influence of others' input on the perceived sensory sensitivity. Riley et al.'s study strengthened our hypothesis that external input from the surroundings affects individuals' perceptions of their pain sensitivity by shaping attitudes and beliefs.

Despite the inconsistent literature on pain sensitivity, there is a prevailing belief, frequently based on anecdotal observation or clinical impressions, that pain insensitivity is common among people with ASD (Messmer et al., 2008). Because of this prevalent belief, people with ASD may be subject to mistaken input by their surroundings regarding their pain sensitivity. The study of Nader et al. (2004) provided evidence of misinterpreting the pain experience of people with ASD. They found incongruencies between parents' reports of their children's pain and observed pain responses as interpreted by professionals during an invasive procedure. One cause of the prevailing misconception regarding pain sensitivity in people with ASD is their core characteristic of communication difficulties, manifested as different social-communicative behaviors during pain episodes (Summers et al., 2017). People with ASD also may exhibit confusing behaviors such as SIB, which might be interpreted as pain hyposensitivity (Symons, 2011).

Although pain is subjective by nature (Love-Jones, 2019), participants elaborated on their frequent need to rely on others, especially their parents, to learn and determine their various pain characteristics and did not mention specifically the level of their pain sensitivity.

Pain Awareness

All participants reported challenges in pain awareness as a form of uncertainty regarding the pain's existence and nature (i.e., location, intensity, and type). Their difficulties recognizing, interpreting, and characterizing pain may result from interoception challenges—the afferent signaling, central processing, and neural and mental representation of internal bodily signals (DuBois et al., 2016; Critchley and Garfinkel, 2017). Some models expand the interoception definition to encompass motivationally important physiological signals, including pain (Craig, 2002). Abnormal interoception has been found among people with ASD, with a slight tendency for hyporeactivity in interoceptive awareness (DuBois et al., 2016). Contemporary models differentiate three interoception dimensions: (a) accuracy, the precision of detecting internal body sensation, (b) sensibility, the self-perceived tendency to be internally self-focused and interoceptively aware, and (c) awareness, the metacognitive awareness of interoceptive accuracy (Garfinkel et al., 2015). In this study, participants reported challenges in recognizing, interpreting, and characterizing pain sensations, reflecting difficulties with the first interoception dimension (accuracy). In contrast, their ability to acknowledge those difficulties reflects preserved interoceptive awareness. These findings are congruent with the study of Garfinkel et al. (2016), which indicated impaired interoceptive accuracy alongside intact interoceptive awareness in people with ASD.

The participants' reports may also point to another aspect of interoception, *interoceptive impact*, which was suggested by Dunn et al. (2022). The interoceptive impact is the influence of interoception on everyday life (Dunn et al., 2022). The participants described challenges in pain awareness and accompanied those descriptions with daily function manifestations. For example, some participants described challenges in recognizing pain, which affected their ability to identify the source of their distress and, as a result, to adjust the level of daily functioning (e.g., using a broken limb). The current study strengthens the concept of interoceptive impact and recognizes it as a 4th dimension of interoception.

The participants' reports in this study echoed a significant challenge with pain awareness, ascribing it as the primary source of their difficulty regarding the pain experience. They described the lack of internal information as disturbing, triggering a sense of uncertainty, and depending on external information from people around them or visual input to resolve this internal inconvenience. When external information is congruent with their inner pain experience, it results in reassurance and regulation; incongruences result in confusion and distress.

Emotional Aspects of Pain

The participants addressed two pain categories, physical and emotional, which appear simultaneously or sequentially. The participants elaborated on the significant effect of their emotional state on their pain experience. The International Association for the Study of Pain defined *pain* as involving actual or potential tissue damage or as the individual describes such damage (Raja et al., 2020). A growing body of literature suggests emotional stimuli may provoke pain like that associated with acute physical pain (Frumkin et al., 2020). The emotional responses to pain, particularly fear, might be more critical than physical pain in determining the suffering the pain causes and affect disability and performance levels (Crombez et al., 1999). The findings of Crombez et al. (1999) support this study's results, emphasizing the significant role of emotional aspects in the pain experience. Participants addressed two main factors that affect their fear of pain: (1) the sense of control over the physical pain and (2) the extent of life risk associated with the pain. These factors are cognitive-driven and based on knowledge, familiarity, and awareness.

Interoception enables top-down, predictive, multisensory integration and body ownership (DuBois et al., 2016). Seth (2013) suggested that the gap between incoming interoceptive signals and predictive efferent signals is a base for anxiety. Due to interoception deficits, people with ASD may encounter uncertainty in physical pain experiences and often cope with intolerance to uncertainty. This intolerance motivates them to desire predictability and actively seek certainty. When the uncertainty remains unsolved, it may evoke *uncertainty paralysis* (i.e., a feeling of being stuck; Stark et al., 2021). This paralysis may explain the tendency to stop functioning in pain that participants described in several contexts.

In this study, many participants reported or manifested rational and binary thinking to cope with uncertainty in the pain experience. The participants' evaluation of the extent of life risk associated with the pain prominently demonstrated such dichotomous thinking. Dichotomous thinking expresses cognitive rigidity, an ASD core characteristic (American Psychiatric Association, 2013) associated with anxiety in children with ASD and directly mediated by uncertainty intolerance (Ozsivadjian et al., 2021).

Pain Communication

The participants provided an extensive description of difficulties communicating pain. They attributed these difficulties to (a) core communication deficits, (b) challenges conceptualizing pain, and (c) challenges using prevalent pain-evaluation tools. It has long been recognized that pain is a physical sensation and a complex social experience, and social communication plays a crucial role in its expression (Craig, 2009). People with ASD are likely to encounter challenges reporting pain due to their core difficulties in social communication, including failure to initiate or respond to social interactions and deficits in nonverbal communication (American Psychiatric Association, 2013). These difficulties hinder their ability to accurately report the degree and nature of their pain experience (Failla et al., 2021).

Another potential source of the difficulty participants mentioned is their challenges conceptualizing the abstract pain experience into words or symbols. Prior studies found that people with ASD had weaker conceptual reasoning ability than neurotypicals of similar ages and cognitive abilities (Williams et al., 2014). Moreover, pain conceptualization requires observing oneself and others (Loeser, 1996), which often challenges people with ASD. Two deficits affect their ability to consolidate the pain concept: (1) deficits in empathy and theory of mind, affecting their understanding of another's mental state (Baron-Cohen, 2000) and (2) difficulty in pain interoception, affecting their ability to notice and characterize their pain experience.

The last source of pain communication difficulty specifically affects their ability to express their pain to health care providers—challenges in using pain-evaluation tools. People with ASD may encounter barriers to reliable reporting due to decreased communication or cognitive abilities. Pain typically is measured by verbal self-reports, considered the "gold-standard" pain assessment (Failla et al., 2021). This study's participants specified difficulties related to the facial, numerical, or color pain representations often used to assess pain medically. Pain also is measured by observation-based assessments (Moore, 2015; Failla et al., 2018) that code nonverbal responses (e.g., facial expressions) to stimuli. However, these responses may be atypical in people with ASD (Failla et al., 2018). Previous studies demonstrated mixed findings on facial reactivity in children with ASD undergoing painful procedures compared to non-ASD populations (Nader et al., 2004; Rattaz et al., 2013).

The challenges in pain awareness and core communication symptoms in people with ASD result in major difficulties expressing their pain experience to others, particularly health care providers. Communication difficulties may result in providers misunderstanding the pain characteristics, such as location and intensity, and affect their ability to diagnose the pain source adequately. In this study, several participants described pain mis/underdiagnoses that resulted in severe medical complications.

Coping Strategies

Pain researchers have studied coping with pain thoroughly (van Damme et al., 2008). However, studies of the pain experience in people with ASD focused on understanding pain as a phenomenon in this population and defining its features (e.g., Allely, 2013; Moore, 2015). Little is known about pain-coping strategies among people with ASD.

Direct Strategies

Direct coping strategies reflect a preference to cope with pain by oneself. Participants who preferred to cope with pain without depending on others, as they had in childhood, attributed this change to two main reasons: maturation and independence, including enhanced skills and coping strategies, and mistrust of others. They reported enhanced skills improving their ability to cope with pain. These reports agreed with the longitudinal research of Shattuck et al. (2007) on adolescents and adults with ASD, indicating that most of their sample experienced declining ASD symptoms and maladaptive behaviors. The adolescents exhibited more significantly improved reciprocal social interactions; the adults improved most on restrictive, repetitive behaviors. Such modifications across the lifespan can explain the higher capacity for more independent coping with pain.

Another reason our participants preferred coping with the pain alone was their mistrust of others. Previous studies indicated higher suspicion or mistrust levels in people with ASD (Blackshaw et al., 2001). Repeated adverse social interactions may exacerbate social anxiety (Kuusikko et al., 2008), leading to social withdrawal (Ding et al., 2019). This progression of repeated adverse incidences of disappointment may explain their preference not to get assistance from others.

Concurrent with the notion that people with ASD experience mistrust others, participants reported asking for help as a last resort. They described reaching out, mainly to their parents, for help in evaluating the pain situation, seeking a solution, and mitigating miscommunication with health professionals. Asking health professionals for help was inconsistent, often accompanied by inadequate evaluation and treatment. Similarly, Ely et al. (2016) conducted a qualitative study of pain communication in children with ASD and found the primary support source was the children's parents.

Despite the significance of external support in pain situations among people with ASD, many participants in this study reported negative interactions with health professionals. Negative pain-related interactions constitute adverse social interactions that can detrimentally influence a person's sense of well-being, life stress, supportive networks, and psychological distress in people with chronic pain (Fernández-Peña et al., 2020). Studies have associated satisfaction with support as leading to both adaptive and maladaptive coping, but disappointment to only maladaptive coping (Holtzman et al., 2004).

Previous research reflected the communication gap between people with ASD and health care professionals, resulting in overlooking pain and inadequate treatment for this population (Moore, 2015). Health care professionals reported lacking knowledge and training regarding people with ASD and thus low self-efficacy in managing their medical care (Walsh et al., 2020). Women with ASD reported more significant health care challenges, including anxiety, emotional distress relating to communication, and anxiety about waiting rooms. They also noted self-disclosure of diagnostic status and lack of ASD awareness by health care professionals (Lum et al., 2014).

Using analgesics is a prevalent coping strategy (e.g., Barry et al., 2004). However, the literature has associated it with long-term increased pain, disability, and poorer psychological adjustment to pain (Jensen et al., 1991; Snow-Turek et al., 1996). This study's participants widely shared their challenge in using analgesics, their concerns about consuming chemicals and their fear of masking internal information that may influence their ability to report pain to the medical staff. In the study of Rattaz et al. (2013), neurotypical children received local anesthetic or sedation almost systematically before a medical procedure, but less than half the children with ASD received the same treatment. Rattaz et al. suggested that health professionals might be less attuned to pain alleviation in children with ASD.

These findings indicate that people with ASD have more responsibility for initiating and requesting analgesics than their neurotypical peers. On the other hand, this responsibility clashes with their concerns about using analgesics and core deficits in initiating communication.

Indirect Strategies

Many participants in this study mentioned ignoring the pain—behaving as if there is no pain—as an effective coping strategy (Peres and Lucchetti, 2010). Children with ASD have reported using this coping strategy, avoiding talking about the pain and redirecting the conversation to other interests (Ely et al., 2016). Previous studies with chronic pain patients found inconsistent results regarding whether ignoring or avoiding pain is an adaptive coping strategy. Some studies indicated that ignoring pain sensations predicted lower perceptions of control over pain (Haythornthwaite et al., 1998) and higher depression levels (Haythornthwaite et al., 2003). Others associated it with better pain outcomes, such as more acceptance and lower pain-related anxiety (McCracken and Eccleston, 2003).

Whereas ignoring pain is a form of active engagement and effort, resting represents coping by a complete stop from daily functioning. Resting has been associated with increased pain and disability in people with chronic pain (Jensen et al., 1991; Tan et al., 2001; Samwel et al., 2006). Both ignoring and resting were found to have negative implications. These results suggest that an extreme coping strategy, whether an intense activity or a complete stop, is ineffective and has adverse effects.

Some participants described combining resting with relaxation techniques such as mantras and breathing. Previous research regarding relaxation techniques for pain was insufficient due to methodological inadequacies (Smith et al., 2018). Despite the lack of rigorous evidence regarding the use of relaxation techniques in general, positive pain-related mantras were well established as a subset of the self-statements coping strategy. *Self-statements* are a set of phrases individuals internally rehearse to cope with pain experiences (Fernandez, 1986). Self-statements predict greater perceptions of control over pain and self-efficacy in people with chronic pain (Haythornthwaite et al., 1998). It has been suggested that using self-statements recruits the ASD characteristic of repetitive behavior (American Psychiatric Association, 2013), redirecting it into an effective pain-coping strategy.

This study's participants also commonly reported engaging in alternative distracting activities and thinking to redirect their attention from the pain (Peres and Lucchetti, 2010). Advantages and disadvantages of distracting oneself from pain have been found in people with chronic pain. On the one hand, being involved in an alternative activity is related to lower pain sensations, a more positive mood, and decreased pain catastrophizing. On the other hand, it was associated with more pain-related anxiety and less healthy function (Haythornthwaite et al., 2003; McCracken and Eccleston, 2003; Peres and Lucchetti, 2010).

Involvement in alternative activity as a distractor from pain ranged from active (e.g., taking a bath) to passive (e.g., listening to music) distraction. The study of Dahlquist et al. (2007) showed that both active and passive distractions increased pain tolerance and thresholds relative to the baseline in neurotypical children, but active distraction was significantly more effective.

The participants in this study mentioned several unique behaviors linked to the painful area: holding, massaging, and covering. These behaviors may serve as pain-coping strategies to protect the affected body area or minimize pain through mechanisms associated with tactile stimulation or increased circulation (Sullivan et al., 2004). Covering a sore area has decreased pain ratings (Vijayan et al., 2015). These results demonstrate that pain perception depends on multisensory body representations. Hence, a change in pain-related sensory modality (e.g., vision) might reduce pain and be utilized as a pain coping strategy.

Similarly to reporting behaviors related to the painful area, several participants reported using SIB to reduce pain. Previous studies regarding SIB indicated that SIB might relate to untreated pain caused by a medical condition, such as painful digestive or skin problems (Richards et al., 2016). In addition, researchers and theoreticians suggested that SIB may serve as a pain-coping strategy, proposing that individuals engage in SIB to release endogenous opiates, which results in feeling pleasure (Sandman, 2009) and pain relief (Holden et al., 2005).

Function and Participation

The participants reported a wide span of pain implications on function. The effect can be arranged on an extreme spectrum from "freeze" to "function." Some participants described a complete break from their daily routine, whereas others reported full function alongside the pain. The most affected functions were work, education, and leisure.

Previous research in children with ASD revealed that increased pain sensitivity affects other physiological functions (e.g., sleep and gastrointestinal function) and decreases participation in daily activities (Riquelme et al., 2018). Research among people with chronic pain demonstrated vast implications for their social participation and daily function, including family life, leisure, and work (Dueñas et al., 2016).

Participants described engaging in BDSM activity and being a part of the associated community as another implication of the pain experience for participation. They related to the feeling of controlling pain as a source of pleasure. These reports align with the qualitative study of Dewinter et al. (2017) of BDSM in ASD, describing a sense of agency relating to sexual interest and arousal.

Suggestions for Healthcare Providers

During the interviews, the participants themselves suggested ideas may promote a better-suited healthcare experience in pain. These suggestions were various, practical, and theoretical. The first-hand accounts and the suggestions deriving from them may help build a bridge for healthcare providers toward a more adequate, efficient, and accurate assessment and intervention in pain situations of people with ASD.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material; further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

This study involved human participants. It was reviewed and approved by the University of Haifa Ethics Committee of the Faculty of Social Welfare and Health Sciences. The participants in this study provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

MK-L contributed to conceptualizing, collecting data, analyzing, interpreting, and writing the original draft. NS contributed to conceptualization, consulted regarding the qualitative methods, reviewed, edited, and assisted in interpreting the results. YG, TB-S and IW-F administrated the project, reviewed and edited. TH assisted in sample recruitment. EG supervised, contributed to conceptualization, reviewed, edited, and assisted in interpreting the results. All authors contributed to the article and approved the submitted version.

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The Need for Sensory-Friendly "Zones": Learning From Youth on the Autism Spectrum, Their Families, and Autistic Mentors Using a Participatory Approach

Marc-André Clément[1,2†], Keven Lee[1,2,3†], Melissa Park[1,2,3*†], Anabel Sinn[4] and Natalie Miyake[5]

[1] School of Physical and Occupational Therapy, Faculty of Medicine and Health Sciences, McGill University, Montreal, QC, Canada, [2] Centre de Recherche Interdisciplinaire en Réadaptation, Montreal, QC, Canada, [3] Lady Davis Institute, Montreal, QC, Canada, [4] addtothenoise, Los Angeles, CA, United States, [5] WIAIH, Pointe-Claire, QC, Canada

Introduction: Differences in sensory processing were linked to a diagnosis of autism spectrum disorder (ASD) before its inclusion as a core characteristic in the revised DSM-V. Yet, research focused on sensory processing and meaningful participation of children and youth with ASD remains relatively scarce. Although refinement of the International Classification of Functioning and Disability (ICF) relies on first-person accounts, longitudinal studies that foreground sensory experiences and its impact on involvement in a life situation from first-person perspectives are largely missing from this body of research.

Objectives: In this sub-study, we drew from a longitudinal participatory research project consisting of two separately funded studies with children and youth with ASD and their families between 2014 and 2021. The participatory project used photovoice (PV) methods to identify the primary concerns related to socio-spatial exclusion (PV-1) and the action steps needed to redress them (PV-2). The objective of this sub-study was to understand what really mattered to children with autism, their parents, autistic youth and an adult mentor to consider how their experiential knowledge could deepen understanding of meaningful participation.

Materials and Methods: We used an overarching narrative phenomenological and aesthetic theoretical framework to focus data analysis on the bodily sensing experiences related to significant moments or events, followed by an inductive thematic analysis of what mattered about those moments.

Results: The topical areas of concern that emerged from analyses were: (1) the relationship between sensory experiences and mental health (*motion madness*); (2) the indivisibility or layering of sensory and social experiences (*squishing and squeezing*); (3) the impact when "tricks" to stay involved are categorically misunderstood (*When*

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Reviewed by:
Evan Dean,
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Claudia Hilton,
University of Texas Medical Branch
at Galveston, United States

***Correspondence:**
Melissa Park
melissa.park@mcgill.ca

† These authors share first authorship

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you don't respond in the correct way), and (4) how care and consideration of others can lead to innovative solutions for inclusion (*I can't be the only one*). Listening to the bodily-sensing experiences of children with ASD, autistic youth and adults, and their families in their own terms has implications for remapping the ICF and envisioning sensory curb-cuts to access, initiate and sustain occupational participation for all.

Keywords: autism, occupational participation, photovoice, experience, universal design (UD), built environment, bodily-sensing, sociality

INTRODUCTION

Sensory processing, such as hyper- and hypo-reactivity to sensory stimuli in the environment, is included as a core characteristic of autism spectrum disorder (ASD) in the revised Diagnostic and Statistical Manual of Mental Disorders (DSM-V) under the category of restricted, repetitive patterns of behaviors, interests, or activities (APA, 2013). Early on, research with specific attention to hyper-responsiveness to sensory input demonstrated that infants, toddlers, and children diagnosed with ASD—aged between 5 and 83 months—have different sensory processing patterns (Baranek et al., 2007). More recently, a meta-analysis of over five decades of research demonstrated that persons with ASD have significant differences in patterns of sensory responsivity than other comparison groups, such as typically developing or other neurological diagnoses (Ben-Sasson et al., 2019). Since the publication of the revised DSM-V and the focus on the sensory processing of persons with ASD, research demonstrates a steady increase of 1.2% of the diagnosis for children and youth between 1 and 17 years of age (Diallo et al., 2018). Yet, surprisingly, there is relatively little research focused on the sensory processing of children and youth with ASD and participation.

The research on children and youth with ASD and participation is also relatively scarce. For example, Askari et al. (2015) found only 16 articles in their scoping review of ASD and participation in leisure activities outside of school. Although the scoping review used the domains in the International Classification of Functioning, Disability, and Health (ICF) to categorize results, only three quantitative cross-sectional studies mentioned sensory processing (Tomchek and Dunn, 2007; Hochhauser and Engel-Yeger, 2010; Reynolds et al., 2011). In contrast, a systematic review (Ismael et al., 2018) that explicitly used Dunn's sensory processing framework (Dunn, 2001; Dunn, 2007) to focus on the participation of children with ASD yielded seven studies that found that sensory processing had a significant impact on participation in everyday life.

Participation, defined as "involvement in life situations" (World Health Organization, 2002), is conceptualized in the ICF as being restricted by body functions and structures (impairment), activities (limitation), and environmental and personal factors. Although the ICF was ground-breaking in bringing together the terms of biomedicine and the social model of disability, it has long been critiqued for its absence of ways to conceptualize agency, intentionality, subjective meaning, and the dynamic interaction between persons and environments, as well as how the ICF can support actual interventions (Jahiel, 2015). Both Jahiel's (2015) structural reformulation of the ICF and Askari et al.'s (2015) scoping review of participation intersect in a mutual critique of the static nature of the ICF from two different perspectives. From a conceptual perspective, the ICF is only a "snapshot" of what its codes/qualifiers can capture at a given moment of time (Jahiel, 2015, p. 19), while methodologically, the quantitative, cross-sectional studies of participation underscore the need for more longitudinal studies (Askari et al., 2015). Further, as Jahiel (2015) astutely pointed out, "Very few [research discussions] have dealt with the "how" question" (p. 19); that is, how can research on participation support its actualization?

Jahiel (2015) also marked how interviews and focus groups contribute to the development of instruments to measure the subjective meaning of participation, while also noting that first-person perspectives on how the environment significantly impacts on participation has not yielded the same results. For example, autists' autobiographies describe how their "extraordinarily heightened senses" are intimately related to experiences of what the geographer and critical autism studies scholar Davidson (2010) called barriers to "socio-spatial inclusion" that are further exacerbated by lack of understanding by non-autistic others (p. 309). Yet, research on sensory processing and participation has rarely included the experiences of children and youth with ASD from their first-person perspectives (e.g., see Kirby et al., 2015 as a rare exception). Instead, qualitative studies on the participation of children and youth with ASD have primarily relied on parental perspectives (Rios and Scharoun Benson, 2020, see also Howell and Pierson, 2010; Lam et al., 2010; and Thompson and Emira, 2011 in Askari et al., 2015), and only one study focused on the impact of the sensory environment on the participation of children with ASD (Pfeiffer et al., 2017).

Thus, in this article, we draw from a longitudinal, participatory research project that consisted of two separately funded studies with children and youth with ASD and their families that took place between 2014 and 2021. We used photovoice methods, with the overarching aim to identify the primary concerns (barriers and facilitators) to socio-spatial inclusion (Photovoice-1) and action steps to redress them (Photovoice-2). In the sub-study that we report on here, our objective was to understand what really mattered to autistic youth about their bodily-sensing experiences to consider how their experiential knowledge could deepen understanding of participation from first-person perspectives.

MATERIALS AND METHODS

This qualitative sub-study draws key exemplars from a longitudinal participatory project, consisting of two studies funded through separate mechanisms across a 7-year period. Participatory research is an approach in which key stakeholders who become co-researchers identify key concerns and develop actions to address those concerns (Jagosh et al., 2015). In our project, we used photovoice, an approach to participatory research in which persons use and-or make images (typically photographs, mini-videos) to share experiences in response to a question of direct concern to them (Wang and Burris, 1997). Although participatory approaches originate in social critical approaches, researchers' underlying epistemologies and conceptual or theoretical frameworks often shape the actual process (e.g., see Asaba et al., 2014). Arguably, as Asaba and Suarez-Balcazar (2018) point out, participatory approaches "gained momentum in times when scholars were examining methodological approaches to address participation and health disparities," although there remain differing levels of community or participant engagement (p. 309). We describe the conceptual frameworks and differing levels of engagement of autistic persons and their parents in the two studies below.

Recruitment and Participants

For recruitment of the first photovoice study (PV-1), a parent who was a key stakeholder (NM) informed families in her network about the project. If they were interested in participating, researchers met them, and completed a formal consent process. Six children between the age of 5–12 years old (1 female:5 males) and their parents (5 females:1 male) were recruited. Recruitment for the second photovoice study (PV-2) consisted of re-engaging families from PV-1 who were still interested and through personal networks for older autistic youth. In total, 10 autistic persons (3 females:7 males) along with four parents were recruited. In PV-2, the youth, older youth and adult identified their own gender. Three of the youth with autism and two parents were in both studies (see **Table 1**).

Sensory processing questionnaires were used in both studies to foster discussions around sensory experiences. We report on them here to situate their experiences. In PV-1, we used the Short Sensory Profile (SSP) (McIntosh et al., 1999), a 38-item caregiver questionnaire that describes children's sensory processing patterns. The scoring from the SSP is expressed as a range from "typical performance" to "definite difference" across seven sensory subscales (see **Table 2**). In PV-2, we used the Adolescent and Adult Sensory Profile (AASP) (Brown et al., 2001). Based on Dunn's Model of Sensory Processing, the AASP is a self-reported sensory processing pattern questionnaire in which the scores describe the individual's neurological threshold and behavioral response continuum across four quadrants (Brown et al., 2001). The scoring within each quadrant ranges from "much less than most" to "much more than most people" (see **Table 3**).

The research settings were based in community centers for youth with disabilities in the greater Montreal area in Québec, Canada. Both studies were approved by a university ethics review board.

Conceptual Framework

The longitudinal participatory photovoice project used narrative phenomenological and aesthetic conceptual frameworks. The narrative phenomenological framework focused data collection and analysis on significant experiences or events from first-person (i.e., I, we) and multiple perspectives (Mattingly, 2010). Events are the memorable moments that stand out in experience (Dewey, 1934; Jackson, 2005), which often emerge during intersubjective moments in which there is something at stake (Jackson, 1998). The aesthetic conceptual framework heightened attention to the tight entanglement of bodily-sensing experiences, the narrative forms used to represent them (e.g., metaphor), and considerations of the good (Park, 2010). Further we integrated Mattingly's (2019) critical phenomenology 2.0 during data analysis of this sub-study on sensory processing and participation to mark "perplexing particulars". A perplexing particular is "an encounter that not only surprises in the sense of striking unexpectedly, but also eludes explanation" (p. 429). As a form of experience, perplexing particulars provide a critical edge by asking researchers to reconsider established categories or assumptions from the first-person perspective of those with whom they conduct research. Finally, during the representation of data, we used philosophical-literary terms, such as bodily-sensing, to foreground the *experiences* related to sensory processing from a first-person perspective rather than positivist-biomedical terms that focus attention on sensory processing from a neurological perspective (modulation, regulation) and-or categories (auditory, olfactory, vestibular-proprioceptive, visual, and etc.) (i.e., see Park, 2008).

Data Collection/Analysis

The primary method for data collection across the longitudinal participatory project was the group meeting to discuss images taken. These meetings were structured as "collective narratives," a method in narrative phenomenology in which each person has a chance to speak without interruption (Mattingly, 2010). We also conducted individual narrative interviews (Mattingly and Lawlor, 2000) when persons were unable to attend the groups. All collective narratives were held in the meeting rooms of community-based organizations familiar to the families, and recorded, de-identified, and transcribed verbatim.

Photovoice 1

The first study emerged from a small research project initiated by researchers at a local children's hospital to understand the resources needed by parents of children with ASD. However, the parents' primary concerns were more related to their exclusion from—and lack of awareness about the sensory challenges in—their local communities. Subsequently, the first photovoice study was a pilot project using ethnographic methods and participatory approaches to understand what really mattered to families with children with ASD, sensory experiences and social-spatial exclusion from their first-person perspectives using photovoice (Park, 2014–2016). All families were compensated for their time.

TABLE 1 | Recruitment results for PV1 and PV2.

Participant	Gender	Role	Participation in PV1	Age at time of PV1	Participation in PV2	Age at time of PV2
Leo	M	Participant	✓	6		
Phillipe	M	Participant	✓	6		
Marco	M	Participant	✓	7		
Karl	M	Participant	✓	11		
Breanna	F	Participant/Co-researcher	✓	10	✓	15
Paul	M	Participant/Co-researcher	✓	11	✓	17
Victor	M	Participant/Co-researcher	✓	12	✓	17
Keith	M	Co-researcher			✓	17
David	M	Co-researcher			✓	17
Cassandra	F	Older youth consultant			✓	22
Sophie	F	Older youth consultant			✓	26
Joshua	M	Older youth consultant			✓	24
Samuel	M	Older youth consultant			✓	27
Casey	M	Adult mentor			✓	42

TABLE 2 | Scores from the Short Sensory Profile (SSP) of the autistic individuals implicated in the participatory photovoice project through 2014–2016 (PV1).

	Scores from the short sensory profile							
	Tactile sensitivity	Taste/smell sensitivity	Movement sensitivity	Underresponsive/Seeks sensation	Auditory filtering	Low energy/weak	Visual/auditory sensitivity	Total score
Leo	PD	TP	TP	DD	DD	TP	DD	DD
Philippe	TP	DD	TP	DD	DD	TP	PD	DD
Marco	DD	TP	DD	DD	DD	DD	DD	DD
Breanna	DD	DD	DD	DD	DD	DD	DD	DD
Paul	DD	DD	TP	DD	DD	DD	PD	DD
Victor	PD	PD	TP	DD	PD	DD	PD	DD

TP, Typical Performance; PD, Probable Difference; DD, Definite Difference.

We conducted two collective narratives to understand what really mattered to the parents and children, using the following questions: "What are your favorite activities, including any that take place in public spaces?" and "What would you like to do with your children in public spaces that you cannot do at this time?" (120 min/group). We then organized a collective narrative in which photographs and videos were shared in response to the question, "What are barriers to doing what they would like to do in public spaces?" (180 min/group). The children (including the youngest at age 6) and their parents contributed photographs. Most of the stories were told by the parents, with two of the older children sharing their experiences at the third group. We conducted one interview (90 min/interview) (Total: 480 min).

Photovoice 2

The second study explicitly used a participatory approach in which the initial grant application included a parent of a youth with autism from PV-1 who was the project leader, a sustainable designer who guided the public facing initiatives, and a researcher who guided pragmatics related to academia, such as the grant writing/submission, ethics, and management of data collection/analysis (Park et al., 2018–2021). All autistic youth and parents who engaged in the study were considered co-researchers and compensated for their time. The aim was to collaboratively develop mechanisms to create more inclusive social-spatial communities by starting with the everyday places frequented by the youth—either those in which they felt excluded or those they identified as being "ideal" from a sensory perspective.

We organized four collective narratives (120 min/group). The participatory process consisted of the following steps. First, the youth contributed photographs and stories about their experiences in the specific places they envisioned change, with parents adding occasional anecdotes. Second, action steps emerged during and from these shared experiences. For example, at the first collective narrative, shared stories about sensory experiences in spaces they had recently frequented led to discussions about what objective measures could be used for others to understand their sensory challenges in those spaces. Third, individuals in the group found tools which they vetted and modified to map and measure the actual sound levels and sensory experiences in those spaces. Thus, each action step emerged from and determined the topic of subsequent meetings. Due to the various school schedules of the youth, these collective narratives were held on weekends, with lunch being provided. Fourth, after all youth had shared their experiences, the groups discussed resources needed and next steps. This led to the invitation of a guest researcher who showed them technologies that could augment their data collection. This phase was disrupted and then

TABLE 3 | Scores from the Adolescent and Adult Sensory Profile (AASP) of the autistic individuals implicated in the participatory photovoice project 2018–2021 (PV2).

	Low registration	Sensation seeking	Sensory sensitivities	Sensory avoiding
Breanna	++	=	+	+
Paul	=	−	=	++
Victor	+	=	++	++
Keith	+	− −	++	++
David	−	−	=	+
Cassandra	+	+	++	++
Sophie	U/A	U/A	U/A	U/A
Joshua	U/A	U/A	U/A	U/A
Samuel	=	=	=	+
Casey	++	−	++	++

=, similar to most people; +, more than most people; ++, much more than most people; –, less than most people; – –, much less than most people; U/A, data unavailable.

ended prematurely by the social distancing requirements and dramatic changes in the routines of the families during COVID-19. During the 1st year of social distancing, we contacted nine of the autistic co-researchers or consultants by phone or in-person to follow-up, asking: (1) How does the sensory environment impact you; and (2) What do you hope will come out of this project? Four youths provided written responses, two youths provided video-clip responses, and field notes were taken of phone call or web interviews with two youth and one adult (Total feedback: 180 min) (Total: 660 min).

Sub-Study on Sensory Experiences and Meaningful Participation

For the sub-study, we identified significant experiences across PV-1 and PV-2 transcripts. Significant experiences are those moments which stand out from the everyday flow of experience and can be identified by shifts to present tense, use of metaphor, and heightened emotionality (Mattingly and Lawlor, 2000). KL provided the key analysis for PV-1 and MAC provided the key analysis for PV-2. MP conducted analysis alongside KL and MAC for coherency and triangulation of results. KL, MAC, and MP then conducted an inductive thematic analysis of significant experiences related to sensory experiences and their articulated strategies within specific contexts. Finally, we examined the significant experiences related to sensory experiences, mental health and participation, using the participants' descriptors (*stress, anxiety, meltdowns, drained*), heightened emotionality (*hate*), and/or language (*insane*). Pseudonyms were used for all participants, apart from the adult autist who is an advocate. Exemplary quotes were chosen by consensus and the final themes emerged during the iterative analysis between the three academic researchers, with a lead co-researcher providing critical feedback (NM). The results are presented to keep the first-person perspective intact to keep specific experiences situated within specific contexts.

RESULTS

As much as possible, we used the self-identifiers used by the children and youth when they shared experiences (e.g., person-first or identity-first). These self-identifiers did shift back and forth during and between collective narratives and interviews and, thus, we use both terms within the manuscript. In addition, we use the concept of bodily-sensing (e.g., see Park, 2008) to foreground the situated and embodied nature of the autists' experiences. We've used the autistic youth and adult own bodily-sensing terms that represent their topical areas of concern that emerged from analyses to structure the results.

"Motion Madness": Bodily-Sensing Experiences and Participation

The autistic children, youth, and adult shared bodily-sensing experiences of hurt and pain that occurred in every space of their lives, whether in institutional spaces (schools, universities, hospitals), everyday civic ones (shopping malls, restaurants), or private homes.

"Hurt" and "Pain"

The autistic youth in the participatory projects described sensory experiences in terms of pain. These painful experiences are as Breanna (age 10, PV-1) indicates, *whenever* they go somewhere: "Whenever we go somewhere, if there's a really bright light, it hurts my eyes and my brain really can't focus." Kathy adds how her son, Karl (age 11, PV-1), would wear sunglasses at the Children's Hospital "because the lights were too bright and they were hurting [his eyes]." For Breanna, the hurt is not limited to bright lights, but also comes with the smells in a local mall's bath and body shop: "The perfume and the smell, it really hurts, like, it goes up to my brain and it really hurts me in my brain." Victor (age 17, PV-2) adds, "Dogs barking or howling, it's like glass shattering in my head. As for vacuum, it's like shaking my brain multiple times because of the sound." These painful experiences are an inescapable part of everyday life. They are, as Breanna underscores, "always something in the back of my mind, in every place I visit."

For Cassandra (age 22, PV-2), an older youth mentor, the technology-related sounds that pervade her classroom at university are painful:

> *Everybody is on their laptops typing at the speed of light and that tikatik noise, which drills into my ears to the point where I could not focus on anything the teacher was saying 'cause all I could hear was the noise of the other students around typing, and I would have [panic] attacks. I would walk outside of the class because that sound of people typing on their keyboards.*

The incessant sound of typing on keyboards is a *drill* so intense that she has *panic attacks* and must leave class. For Casey, an adult mentor (PV-2), it's all the sounds in outdoor public spaces:

> *I get overstimulated very easily. Like, just on the street with the cars, sirens, people, just the sound of everything. Especially awful noises, I am extremely sensitive and [. . .] very high and low frequencies that other people can't even hear are often really painful for my ears.*

As an adult mentor in the group, he offers a nuanced explanation of how the frequencies that others cannot hear causes the pain.

"Motion and Commotion"

For the children in the first photovoice study (PV-1), the biggest barrier was neither articulated in terms of discrete sensory systems nor multiple sensory systems. Rather, as the parents discovered in one conversation, it was the overall experience of *too much* of everything going on that was one of the biggest barriers to their children's involvement in a life situation. For example, one of the parents described how her son Karl (age 11) would sit in the top near the handles of the grocery cart:

> Kathy: Karl has to be in a cart because he can't have anyone touch him. And he has to sit on the top because if he sits on the bottom, people might bang into him as we're grocery shopping. And there's just way too much motion and commotion going on. If everyone walked in a clockwise motion, I think maybe we'd be better, but-. . .
>
> Saul**:** (a father of a preschooler with autism) -He fits?
>
> Kathy**:** Oh, yeah. Trust me, we fit. Trust me, we even get our feet in there too. And what Karl does, if there's too much motion and commotion going on? He shuts down and goes to sleep. Gone. Done.
>
> Nina: It's funny. Do you say, "motion and commotion," or does he?
>
> Kathy: I call it "motion and commotion."
>
> Nina: Okay. Because Victor calls it "motion madness" [. . .] that's when Victor would say, "that's motion madness. I'm not going there, it's motion madness." He made it up.

Kathy continues saying that Karl will not go on the city bus either, because of the sound, smells, and "all the motion and commotion of people."

More recently (PV-2), Victor found that online platforms used to learn during COVID-19 helped alleviate school's motion madness, stating, "I like the gallery view so I can see everyone instead of the screen changing every time someone talks. It's too much change." Yet, eating out remains a challenge since "restaurants with multiple TV screens are stressful and distracting," adding that "There is too much going on." Casey (PV-2) is quite articulate about how the bodily-sensing experiences that Victor links to *madness* not only impacted his involvement in his work internship at a laboratory in the pathology department of a hospital, but also his mental health: "There were so many noises and the talk and other people. [. . ..] it just like drove me insane."

"All of a Sudden"

Victor's motion *madness* and the layering of sounds and frequencies that drive Casey *insane* are amplified with the unexpected nature of sensory aspects of and in the built environment. This additional barrier to participation was reflected in a conversation between parents when their children were younger. Nina, Victor's mother, remembers the challenge of public restrooms when Victor was about 8 years old:

> *It isn't that he doesn't like toilets, but he hates the automatic flushers. He can't stand that because some of them [motion detectors] are too sensitive. If he has to sit, he'll jump up because he—and he's not afraid he's gonna get flushed down or anything—he just hates the element of surprise. 'Cause some of them [motion detectors] are too sensitive and at the Theme Park, they have them. When we went to the Theme Park, he held his business for so long, 'cause he's like, "I'm not going in those [public restrooms]." And I said, "You just gotta go," and sure enough, he did it and I heard him go, "Ah!"*
>
> A researcher asks, "Oh, he screams?"
>
> *Yeah, you heard him outside. He screamed. It scared him. And that was, like, three years ago. Now, he just avoids it. If he sees it, he avoids it. He'll go somewhere else. He can't stand it. He just doesn't like these things.*

Two other families also concurred that they had the same experience, with Paul (age 11, PV-1) and Breanna (age 10, PV-1) underscoring the automatic nature and sound of hand dryers.

Cassandra, in a separate interview, links sensory sensitivities to the added impact when something happens *all of a sudden*:

> *Especially with sensory sensitivities. I used to notice a lot of the time, if it happens all of a sudden-, if I'm not expecting this place to be really loud or I'm not expecting this smell, it will affect me to such a great degree. [. . .] Obviously, the thing with sensory sensitivities is the more overwhelmed you are, the more anxious you are, depressed or frustrated.*

When the level of sound or smell exceeds Cassandra's expectations or *overwhelms* her, the ultimate impact is on mental health (*anxiety, depression,* and *frustration)*. The experiences of the autistic youth and adult underscore the tight entanglement between bodily-sensing experiences of hurt and pain, mental health (*madness, insane, overwhelm, anxiety, depression, and frustration*) and any semblance of participation or involvement in a life situation.

"Squishing" and "Squeezing": The Layering of the Sensory-Social

Casey's (PV-2) experience of being *driven insane*, situated within a work internship in a pathology department at a hospital, also underscores how painful bodily-sensing experiences are inextricably linked to social and built environments.

> *There were so many noises and the talk and other people and then for certain chemical reactions, they had these alarm clocks, and then the buzzers went off and then the telephone, and then on top of all the machines-, on top of that, people really like to turn on the radio-, yeah the radio. It just like drove me insane.*

The layering—*and then, and then, and then, and then on top of all*, *on top of that*—drives Casey insane. For the youth and their parents, the layering of the sensory-social was described as the source of stress, pressure, and feeling trapped.

Stress

Nina (PV-1) described the challenges she faced when she had to take Victor, when he was younger (∼age 12), to the drop-in clinic for a recurring illness:

> *Every time he has strep, which is, like, every month, we have to go to a drop-in clinic. Often a lot of public waiting rooms have these things where you're face to face, like you're sitting so close together. So he doesn't like it because everyone is just staring at each other, so you're trying to look away. He can't stand that.*

When he is older, Victor (age 17, PV-2) more fully describes what he could not stand from his first-person perspective:

> *Hospital waiting rooms are the worst [. . .]. You are forced to be in the tiny room with many people, lots of smells, noises, babies crying, kids jumping everywhere, too much. I get really stressed.*

Ultimately, it is not just having to look directly at others, but the additional layering of smells, noises, and the motion madness of *kids jumping everywhere* that leaves him *really* stressed. The stress of the sensory-social layering also occurs when he uses public transportation:

> *. . .very busy and crowded transport, you have many people squishing and squeezing you. It's noisy and smelly and way too many people. It's stressful. I cannot handle the busy of people. It gets so bad sometimes I cannot get off the bus or metro and I can miss my stop.*

The *squishing and squeezing* from, what he calls, *the busy of people* creates so much stress that Victor remains, literally, frozen.

> *Many times, I have to get off at a different stop and walk because it's too busy. I often leave 1–2 hours before and get up really early so I don't need to be with so many people.*

He either ends up walking further or leaving one to two hours earlier. However, there is a price.

> *But then I need to wait in the cold outside until I can go [in] to school. It's too early, and they don't let us in that early, and it is freezing outside. But it's better than a stressful squished metro ride.*

Having to choose between a *stressful squished* metro ride and walking further or waiting in the cold, Victor bears with the latter. Not going to school is not an option. As Sophie (age 26, PV-2) explains, she often has "no choice" but to wait at the bus stop, despite the smell of someone smoking and "It's not easy." Casey's experience of public transportation provides some additional details:

> *If you're in a metro and you don't like to be touched? Well sorry, you're never going to be on there at rush hour. It's like sardines, right? So, it's really hard. If you can at least get a chair, it's going to help, because you have less people and their bags squishing you.*

Casey describes being squished during rush hour in terms of a can of sardines and the sense of touch as unavoidable. He tries to describe this experience for the non-autists in the group using sensory processing terms:

> *Especially in the summertime there's a lot of smells on the busy metro and the buses and so on. The sound and just the visual, it's chaos. It really is like-, for you who don't have autism or sensory processing [challenges] that don't even feel that stress-, it's like I get stressed out every time I go in public transit. I just kind of suck it up, but I hate it and I'm drained.*

In the end, Casey just has to *suck it up,* an effort that is tied to intense emotions (*hate*) and leaves him feeling empty (*drained*). This experience of public transportation is so overwhelmingly shared by the others that it leads to one of their hoped for actions (described in section "I Can't be the Only One: From Individual Tricks to Universal Design").

Pressure

Among the autistic youth and adult, the everyday pressure of time and crowds amplified the sense of pressure in their bodily-sensing experiences. For example, Paul (age 17, PV-2) recalls his experience of getting around crowded hallways at his high school as *hell time*: "For me, getting around the hallway was an absolute hell time because you have 5 min to maneuver up to halfway across the building, ending up being in crowded hallways." Victor also describes how the mix of *too much going on*, the press of others in the small space of a locker room and time constraints adds to the experience of stress:

> *Locker rooms are really busy, noisy. There is very little space-, very stressing, too busy, too much going on. It is a small place and we are pressured to rush and get dressed fast for gym. Lots of noises, weird smells, and people pressing against you.*

This double sense of "pressure" and "pressing" also occurs in situations in which time is not a factor:

> *Bathrooms are really busy, like a stadium. It's really stressful, there are too many people and too much noise from hand dryer, faucets, toilet flushing, line up people are too close.*

Like Paul and Victor's description of the pressure, Casey's experience of the layering of noise and crowds augments situations that are *already* inherently stressful:

> *It's already stressful having to go get a blood test, but with all the noise and crowd-, it's too much, I cannot take it. It's really chaotic. And then you have to go to this desk to talk about that and then standing-, standing in line, I always find it excruciating.*

This doubly stressful situation is experienced as *excruciating*. Yet many of these situations—public transportation to get to school, walking from class to class, locker rooms for gym class, and blood tests–are not really optional.

"Trapped" or Opt-Out

Casey, reflecting further, questions if the experiences of *excruciating* might be attributed to his own lack of patience before interrupting himself: "I think it also has to do with patience-, with also feeling trapped standing in line in the crowd-, here it is . . . the more difficult it is to find." In the end, Casey reasons that it is the experience of being trapped in a situation that makes it hard for him to *find* patience. For Cassandra, it's often better to leave:

> *I will leave early sometimes-, have to take a shampoo bottle, unscrew the top and like smell the shampoo bottle just to get the smell away*

> *or I'll have to leave the house because the smell [of cooking] will be overpowering.*

Cassandra and Casey first interpret their response to the sensory aspects of a hospital and a home in terms of their own characteristics or choices (*patience, leaving*). Yet, they both interrupt themselves. Casey reflects on how *standing in line* leaves him feeling *trapped,* while Cassandra interrupts herself to reflect on all the times she has first tried to stay in place by smelling something stronger than the smells that bother her. Still, the smell of cooking is, ultimately, so *overpowering* that she ends up leaving her home. As Cassandra astutely points out, the sensory and social cannot be separated:

> *You can't separate the social problems from sensory problems because if you're already stressed out because of a social situation, you're going to be more susceptible to sensory overload.*

The spiraling effect of the stress of a social situation increases Cassandra's susceptibility to *sensory overload,* making it difficult for Cassandra to envision what she can do in the future:

> *I don't think I'd ever be able to have a job. You know, like in food places, because I'm so sensitive to smell, or you know stuff like that. Or-, you know, I'm sure that whatever job I ended up having, involved in dealing with other people my age, it would stress me out because of the whole social aspect of things too.*

Having to deal with the social aspect of things and her sensory sensitivities raises important implications for what kind of work Cassandra believes will be possible. For the autistic youth and adult, the entanglement between, and spiraling effect of, the social and the sensory often left them with no other options than to feel *trapped* or opt-out prior.

"When You Don't Respond in the Correct Way": Categorical Misunderstanding of Individual Strategies

The autistic youth and adult shared stories in which their actions were grossly misunderstood, often explicitly linked to others placing them in denigrating categories and barely tenable positions. For example, Victor recalls an event in the hallway outside the cafeteria of his school at one of the meetings that receives an immediate response from a peer:

> Victor: Recently, someone called me the R [retarded] word. . .
>
> Keith: (age 17) Ohhhh [expressing empathy]
>
> Victor: Yeah. . .-, right in the hallway during lunch, where I don't like it because [showing photograph of the hallway] everyone is like scootched together like a bunch of prison mates.
>
> Keith: Ouff
>
> Victor: I'm like waiting here and everyone's behind me. Every time I try to back away from them, to stay far, they come closer to me.

Victor then tries to *stick up* for himself.

> *So, then I decided it's time to just stick up for myself. So when they were starting to get too close to me, when I was trying to have some room, I just turned around and said politely, "First of all, I would greatly appreciate it if you would give me some space, thanks." They did, but then they did it [come close] again. I was like, "Ahem," just to tell them to "go away." Well, after as they continue to bother me, it's like, "Man, I got to think of some other ideas."*

He then tries another approach by standing next to the line while sharing his discomfort with the students to the side and behind him.

> *When I got into the line, it was impossible because the line was already fully lined up. So, I just stood next to it [the line]. But when I tried to get in, they wouldn't allow me. They said I have to go in [the line] and I told them, "I don't want to! [. . .] It feels uncomfortable. It's like being in a prison cell." So then they told me, "It's that or no lunch." So, I did not eat lunch that day.*

Despite all his efforts—the polite request and thank you, the cue (*ahem*), standing next to the line and explaining the situation to his peers—Victor's experience of being caught in a situation amplifies. Between enduring being called something unnamable (*the R-word*) and being in *prison* or not eating lunch, he feels he has no option but to take the latter.

Like Victor, Cassandra tries to find ways to remain in places she would like to be. Yet, often, these individual attempts are not enough. She gives an example of being in the classroom in which her attempt to remain in class is misunderstood:

> *Sometimes I would wear noise-canceling headphones in class. The teachers look at me like, "Are you not listening to me?" or something like that. "No, on the contrary, I'm wearing the noise-canceling headphones so that I can listen to you!"*

Her actions are not just misread. They are grossly misunderstood and criticized. Such experiences are not limited to public spaces such as schools, but also at home with her parents.

> *I would say, for me, my biggest sensory sensitivities are sound and smell. So the visual doesn't bother me as much. Obviously, if there is a lot of like flashing lights and a lot going on, it will bother me. But definitely not to the point where sound and smell will, for example, when I'm at home and my mom's doing something as simple as, you know, cooking a meal. Sometimes, it will cause a panic attack and my parents will not understand, "What's the big deal we're just cooking something in the oven."*

The critique from persons in authority at university (*Are you not listening to me*?) along with intimate others at home (*What's the big deal. . ..?*) underscores the impact that occurs when the very intentions underlying actions to stay in place are misrecognized. For Cassandra, this also includes being categorically misunderstood by her peers:

> *The combination of loud music and the smell of alcohol and the smell of people smoking or whatever people are doing and the smell of food-, . . . the smell of this-, this sound-, people talking, you know, I have to put my foot down and I have to say, "Yeah, you know, I'm that weird girl who's never gone to a party." I will never go to a party, and that's just something that I do because' I don't want to end up running out of the party and having a panic attack.*

Even when the youth attempt to stay in a place, like Victor and Cassandra, their actions were categorically misunderstood (*R-word, weird*).

Victor and Casey both speak about their sensory strategies in terms of *tricks*. Yet, Casey further delineates that such tricks can only be used in situations in which they are *socially accepted.*

> *In public transportation, I have my tricks and listen to music or my mp3 player. But if you're traveling with someone, then it's not really socially accepted to be listening to music. When [I'm] communicating.... I can deal with it, but it would like drain me really fast and it's everywhere. It's everywhere I go. It has an effect. It doesn't matter where you go, it's everywhere.*

In order to be socially accepted, Casey must forgo using his *tricks* (listening to music) and communicate, an experience that *drains* him *really fast*.

For Casey, this double-bind experience is *everywhere* and can have even more dire implications:

> *I was being accused of stealing something. And then-, when you don't respond in the correct way or so according to them, then you've come across as even more of a threat. Then, I lose my ability to communicate in stressful situations like that and so-, so I cannot really tell them I am autistic. I just lose that ability.*

As an adult, *not responding in the correct way* can be perceived as a *threat* and lead to accusations that could put one in an actual prison. Worse, the stressful situation makes Casey lose the very ability to speak, by which he could alleviate misunderstanding and defend himself. Even more, he loses his identity as an autist, which is integral to his advocacy work.

The apparent choice between being categorically misunderstood when one doesn't respond in the right way (*R word, weird, threat*) or foregoing lunch, having a panic attack, or being drained by the effort to be socially accepted is not really an option. In the end, the autistic youth and adult's intentions to stay involved in a life situation using individual tricks (wearing noise-canceling headphones, standing next to the line, and listening to music in the presence of others) were categorically misunderstood.

"I Can't Be the Only One": From Individual Tricks to Universal Design

During PV-2, the youth co-researchers and autistic adult also shared experiences about what was or could be useful in their everyday environments. They envisioned actions that could be taken toward a more hopeful future that, as they underlined many times, could also benefit others.

A "Quiet" Place

The youth and adult expressed the need to have a place to retreat. Cassandra voices that sometimes just a bit of preparation in a quiet room would be useful:

> *But if I'm in a quiet room, getting ready, and I tell myself, "Listen, I'm going to be faced with sounds," that "I'm going to be faced with smells" and I mentally prepare myself beforehand. Then, you know, it'll be more effective.*

She continues that the quiet room or retreat could also help her recover from meltdowns caused by sounds and smells:

> *I remember so many times having meltdowns. And if there was-, if there was that opportunity to have a room that I could sit there, even if it's just a tiny room where I could close the door and be with myself and it would drown out the sound a little bit.*

Any space could be useful, even a *tiny* one. Any time could be useful, even for just *a little bit*. Such a space would not necessarily be devoid of any sounds or smells:

> *I like it [the music room] because my music teacher has a pet bird, two guinea pigs and two rabbits, There are live animals. I love animals and they make me feel calm. The room itself is quiet, except noises from the animals (Victor).*

What Victor's experience delineates is that it is the social and built environment rather than a natural one that is often the cause of stress and that connecting with animals brings a sense of *calm*. Ultimately, it is also the unpredictability of the sensory-social that concerned the autistic youth and adult. As David (age 17, PV-2) underlined, its more about knowing in advance the type of environment and how one can prepare in advance. He longed for an app that "if it existed, to be able to use when we plan an outing."

Sensory Friendly "Zones"

To be able to prepare for a sensory-social environment using a quiet room or an app, however, would not fully rectify barriers to participation. The autistic youth and adult agreed that designated zones were needed across all everyday spaces. As David (age 17, PV2) best expressed, "more research [is needed] to continue to learn more and find ways to help and to advocate [....] talk to these commercial places, like restaurants, to let them know about sensory friendly zones." The term, *zones,* emerged during the discussions during PV-2 as a critical modifier to the more common phrase of sensory friendly. After debating the relative merits of space or zone, they agreed that not only were *zones* within institutional and everyday public spaces a more achievable aim but one that would not separate them from others. They also reasoned that a *zone*, integrated into already existing spaces with proper signage, could also include others seeking a similar sense of quiet.

For Cassandra, a publicly accessible sensory friendly *zones* would align with her desire to educate others about autism:

> *I always dreamed of, you know, putting myself in a place where I know there's a lot of students and just handing out like things educating people on what autism is, you know? People that work in places like restaurants or even, you know, police officers, the security guards in malls, for example.*

She imagines that if others understand the relationship between the sensory experiences in social, built environments and mental health, then others would also benefit:

> *I can't be the only one who has meltdowns in malls or meltdowns in a train station. Sometimes all it needs is, you know, one security or two tops that has some knowledge and some awareness of-, they*

> *can make a training, they can train people, it'll take them maybe two hours to explain to them. This is, you know, this is autism, this is mental illness, this is what you do, this is what you don't do.*

Cassandra's words, "I can't be the only one," stress the inclusive nature of her reflection. If the staff of different public services such as transportation, restaurants, police forces, and policy makers were trained to understand *what you do* and *what you don't do,* many others would benefit.

"People Just Know"

The autistic youth, their parents, and autistic adult all indicated across both studies that training or educating others was not enough. Although there were many stories of when someone who was educated or understood made all the difference for their experiences—whether a police person, a hostess at a restaurant or staff at a water park—what was needed was a universal sign. They all desired that such a universal sign could, for example, be placed in all public transportation vehicles to designate a sensory friendly *zone*, whether actual seats or just a place to stand. For Cassandra, such signage could help with the process of training: "I feel that the use of a new disability symbol with help with that process immensely since it will show that there are more disabilities than just physical ones." For Casey, such signage would also help others understand his actions:

> *I wouldn't mind that something would be there that you can-, like, it's in your card, or where people just know that you have autism. And I also find, at least, like dealing with cops, and security guards, they noticed something about me that's unlike-, more on edge or a bit nervous or maybe. It will be nice if I add something on my card and I can point to in order that, "Oh, this person is autistic, is not a threat."*

Although Casey is talking about having a card that he could point to so that others *just know,* the youth wanted a symbol and a sign to do this work. A public, universally recognized symbol would not only alleviate being immediately labeled as a *threat* on an individual level, but could also become inclusive of and provide a sensory friendly *zone* for others.

In the end, the youth with ASD and their parents agreed that a universal sign should neither categorize them as disabled nor suggest they be protected (*safe*), ultimately opting to use an existing phrase in the public sphere of sensory friendly and modifying that by *zone.* They envisioned a symbol that would not segregate persons but one that could be used within and include others in already existing spaces. Victor best articulated the inclusive nature of their shared vision, stating, "I hope all the mayors learn from this so they can make their cities more sensory friendly." Victor imagines what could happen if all mayors understood the impact of social built environments on bodily-sensing experiences and how the creation of sensory friendly *zones* could create more inclusive cities.

DISCUSSION

In the following section, we discuss how close attention to the experiential knowledge of autistic youth, their parents, and autistic advocates of their own bodily-sensing could inform concepts about participation used in rehabilitation and approaches to mental health while opening up new areas for relational approaches to research and social transformation.

Remapping the International Classification of Functioning, Disability, and Health: First-Person Perspectives of Bodily-Sensing and Participation

Taking the first-person perspectives of autistic children and their families (PV-1) as well as autistic youth and adult (PV-2) into account clearly illuminates how the sensory-social is indelibly and inextricably linked in experience and impacts on involvement in life situations. Yet in third-person perspective research, social and sensory constructs are often examined as separate factors. Further, third-person perspective research still locates deficits within the individual. For example, Askari et al.'s (2015) scoping review notes how participation of children with ASD is impacted by "the core deficits of an ASD [diagnosis] (i.e., communication impairments, social deficits, and abnormal restrictive, repetitive, and stereotyped behaviors) as well as other characteristics associated with the disorder (e.g., maladaptive behavior)" (p. 112) with only a relatively scant amount of research suggesting that social support and negative attitudes were central factors. In contrast, a focus on sensory processing leads to different implications. For example, Dunn (2007) suggested that her model of sensory processing could be used to adapt everyday life situations—particularly activity contexts—to support the needs and participation of children with different patterns of sensory processing. Ismael et al.'s (2018) systematic review, which specifically focused on research that used Dunn's sensory processing framework (Dunn, 2001), found that the sensory processing of children with ASD impacted their participation and concluded by suggesting that the sensory environments of activities are critical factors for participation.

In our participatory project, we used the Short Sensory Profile (SSP) (McIntosh et al., 1999) and the Adolescent and Adult Sensory Profile (AASP) (Brown et al., 2001) to focus on sensory experiences rather than as a measurement. However, the scores did show that the children with ASD in PV-1 presented higher scores in the visual/auditory filtering categories with patterns of under-responding/sensory seeking. The sensory sensitivities of the autistic youth in PV-2 who had participated in PV-1 remained the same in the AASP. Yet their scores in PV-2 also showed changes in their related sensory patterns (from *sensory seeking* to *sensory avoiding*). On one hand, this suggests that sensory sensitivities alone did not impact participation. For example, they shared experiences that clearly demonstrate that they had all developed individual *tricks* to stay in or travel to spaces in which they wanted to do valued activities that were meaningful. Instead of individual deficits as barriers to participation—related either to the diagnostic criteria of autism or sensory processing—the most incalcitrant barriers to meaningful participation were the social responses (or lack thereof). Based on specific, situated and embodied experiences, the autistic youth and adult's individual *tricks* led to being categorically misunderstood (*R-word, weird*) or *drained* by their attempts to *respond in the correct way*. On the other hand, this also suggests that being categorically misunderstood and drained by efforts to do what is *socially accepted* could also shift sensory processing patterns from seeking to that of avoiding.

Making the Layering of the Sensory-Social Visible

The autistic youth and adult experienced the social and built environment in homes and institutions (*smells, bright lights*, enclosed spaces, and placement of chairs) and it's layering in everyday objects (*alarms*, *vacuums, buzzers*, *sirens, telephones*, *televisions*, and *machines*) as *excruciating, overwhelming,* and the cause of *hurt* and *pain*. Their concrete suggestions for change, such having a quiet space, mirrored those of the autistic authors in Davidson's (2010) review who suggested "toning down 'toxic' stimuli – such as fluorescent lights" (p. 305). Yet the domains of the International Classification of Functioning and Disability (ICF) as currently mapped could neither lead to such existential perspectives nor capture such concrete suggestions for social-spatial inclusion.

Rather, the ICF domains constrain research to a limited range of, and very different, causal factors impacting on participation. For example, no studies in the scoping review of sensory processing and participation of youth with ASD investigated a comprehensive range of determinants (Askari et al., 2015). What the studies did cover were different domains, such as: environmental factors (family support, social attitudes), body functions (sensitivity and behavioral challenges), and activity limitations (communication and interpersonal relationship problems). However, the environmental domain only focused attention on material, natural and social environments without any explicit indication of its sensory aspects. In addition, no interrelationships between domains were explored.

In the sub-study of the participatory project, the autistic youth and adult shared experiences in which bodily-sensing was inseparable from both social attitudes and the social built environment. However, it is their bodily-sensing experiences from their first-person perspectives that so clearly illustrates how the layering of the sensory-social limits their participation to feeling *trapped* with the only options being to *suck it up or leave*. In a similar vein, Davidson's (2010) review of 45 autobiographical texts showed how autistic authors' "extraordinarily heightened senses" were barriers to social-spatial inclusion (p. 305). Davidson used the term "sensory geographies" to illuminate how persons must navigate physical environments that are also social spaces that contain, what she calls, "sensory furniture." She notes that even though sensory furniture could easily be moved, it is not. This inflexibility decreases the possibility of access as well as the sustainability of participation across time. Like Davidson's sensory furniture, the autistic youth and adult in the participatory project underscored how it was the social built environment which led to *hurt* and *pain* and eventually, their leaving (even home) or opting out entirely. Davidson's background as a social geographer, however, points out the potential and universal implications of the autistic youth's participatory project in their directives for what new furniture to add—in the form of signage (sensory friendly *zones*)—and what to dismantle entirely.

Threading (Agentic) Meaning Throughout

The focus of the participatory project on bodily-sensing experiences supports an ongoing discussion about how the ICF could be restructured to better map subjective experiences of participation. As Mitra and Shakespeare (2019) note, keeping health conditions at the top of the diagram and positioning personal factors below and separate from environmental factors raises critical questions, such as: "What about the agency of the individual?" and "What if the activities under consideration are not those that are valued?" (p. 338–339). Thus, Mitra and Shakespeare (2019) suggest moving personal factors to the top of the diagram and moving health conditions below. The bodily-sensing experiences of being *squished*, *squeezed*, and *trapped* in everyday spaces by the children with autism and youth co-researchers underscore how their choices are limited and constrained by the layering of the sensory-social. One simple example is how, from a third-person perspective, Casey, Sophie, and Victor use public transportation to participate in things that matter to them. Yet, on closer inspection, the layering of the sensory-social limits their sense of agency by determining when they can travel if they want to avoid such experiences (Victor) or resign themselves to being drained entirely (Casey). The third option, of course, is to simply opt out. Although only descriptive, it is notable that the sensory processing patterns of the three youth who participated in PV-1 and PV-2 do show a shift from sensory seeking to sensory avoiding.

Jahiel's (2015) reconceptualization of the ICF marks how focus groups and interviews led to the development of subjective measures of meaning and values while ethnographic accounts of the experiences of disabled persons that highlighted the significant impact of environmental factors on participation did not subsequently lead to new measures. Jahiel attributes this gap to the separation of the personal from environmental domains in the model, arguing for the reformulation of the personal-environmental as more interactive and dynamic than depicted. The autistic youths and adult's bodily-sensing experiences of the impact of the *sensory-social layering* on their participation certainly buttress this argument. In Jahiel's reformulation, one new domain of "intent" is created with all the domains moving to the same level to visually emphasize the interactional or even transactional quality between them. Placing all the domains on the same level, while also making intentionality a distinct domain, places the environment on equal footing as agency. This could also highlight the important work that parents already do to facilitate their children's agency and control over their environments through modifications and-or advocacy (Pfeiffer et al., 2017).

Two concepts, "scene setters" (Badley, 2008) and "scene setting" (Jahiel, 2015) could accentuate how the value-laden aspects of the environment impact on existential experiences tied to participation. For Badley (2008), scene-setters refers to societal contextual elements that influence participation, which could account for and make visible the constraints of sensory-social layering on persons' full involvement in a life situation. By extension, the "scene-setting aspect of the environment determines what certain aspects of functioning mean, what is relevant to us in a particular context, how we do things, and what [. . .] options we have at our disposal" (p. 2,337). For Casey, the layering of the sensory-social in his work internship strips him of any sense of agency (*drives him insane)* and determines its meaning (*hate),* which provides nuance. Persons may appear to be fully involved in a life situation from a third-person perspective but may be doing so in spaces where the societal-contextual elements negatively impact on their experience. This has important ramifications for, as will be pointed out below, mental health.

The longitudinal nature of the participatory project also provided an embodied, situated and temporal view of participation from first-person perspectives. As it has been pointed out, the ICF is static and understanding participation and developing adequate measures will require much more than cross-sectional research (Askari et al., 2015) that rely on snapshots in time (Jahiel, 2015). Victor's experience in the lunch line and Cassandra's experience at school, for example, provide rich descriptions of how what may look like involvement in a life situation can change from minute to minute. From a third-person perspective it may appear to a casual observer that both Victor and Cassandra are participating in school and university activities respectively. Yet, despite their efforts to stay in line (explaining to peers) or class (wearing noise cancelling headphones) both opt-out in the end (not eating lunch, leaving class).

A recent definition of *occupational* participation could prove useful to help delineate the range of entry points toward evaluating participation temporally. In occupational science, the concept of occupation is defined as the ordinary things that persons do that really matter to them, and in which "the meaning or lack of meaning to occupations" (Yerxa, 1990, p. 9) can only be revealed by an individual's experience of them. Thus, to some degree *occupational* participation provides another way of conceptualizing meaningful participation, albeit from a first-person perspective. Further, occupational participation is defined as "accessing, initiating, and sustaining valued occupations within meaningful relationships and contexts" (Egan and Restall, 2022). Although Victor and Cassandra are able to access and initiate valued activities, the categorical misunderstanding of their actions on top of the layering of the sensory-social is just too much. They are unable to sustain their participation across time.

Socio-Spatial Inclusion: The Mental Health Costs of Being Socially Acceptable

The autistic youth and adult in the participatory project made clear links between their lack of control over the layering of the sensory-social and their mental health. They reported on how the painfulness of the sounds, smells, sights, and motion-commotion—and its unexpected nature—in the social and built environment was, as Victor explains, *madness.* However, these metaphorical descriptions have real implications. In her ethnographic study, Bagatell (2007) described how the layering of the sensory-social leaves Ben, a 21-year-old college student with Asperger's, more and more depressed until one day he finds himself sitting on a windowsill with his feet dangling over the edge:

> *They're feelings [panic] that just get too powerful. It's not so much feelings like emotional feelings but it's like physical, physiological. [. . .] It's like outward pressure. [. . .] It makes me crazy sometimes. I just don't know what to do (p. 423).*

The panic attacks that Ben experiences in his struggle to orchestrate the voices from, what he calls, the "Aspie" world with the everyday one are less about being an emotional state than a physical and physiological one. His bodily sense of *outward pressure* aligns with the autistic youth's experiences in the participatory project of the *pressing* of others and *pressure* of time. For Ben, the outward pressure *makes* him *crazy*, much like the layering of sounds and their frequencies *drives* Casey *insane*. For Ben, this sensory-social experience reaches an existential breaking point in which he can only envision a life alone, which leaves him questioning, "What kind of a life is that?"(p. 424).

Despite the extensive neuroscience research on the relationship between atypical sensory processing and psychopathology (e.g., see the review by Bailliard and Whigham, 2017), there is a surprising lack of attention to the relationship between actual pain, unexpected or unanticipated aversive input, lack of agency in particular contexts, and mental health. In their research of sensory processing patterns in the general population, Dean et al. (2018) found that sensory seeking was negatively correlated with depression, suggesting that sensory seeking could be a positive predictor of resilience and adaptability. More specifically, children who actively engage in their environment demonstrate fewer signs of depression and are more likely to be resilient. They also suggest that children who, on the contrary, are more avoiding would gain from interventions that would assist them in developing self-regulation strategies viewed as "appropriate to their peers, parents, and teachers" (p. 6) to support participation. Yet, the autistic youth and adult in the participatory study underscored that it is the double sense of pressure—navigating the sensory geographies and the social expectations of what is acceptable—that left them *drained* and categorically misunderstood in their schools, communities and workplaces. Their continuous efforts to *respond in the correct way* ultimately empty them in ways that are, as Ben's experience also hints at, potentially world ending.

How Does One Proceed?

Speaking of her own experience, the autist and anthropologist Prince (2010) says:

> *Since I can remember—and that is from my own beginning—I have been pierced and pained by the intensity of life. There were many times as a child I believed I would crumble in on myself, my emotional skeleton finally eaten away by the screaming and clutching of a modern society that dissolved me—normal life, other people call it (p. 56).*

The intensity of the "normal life" *crumbles* and *dissolves* her much like the layering of sensory-social (*on top of, on top of)* renders Casey speechless, taking away his ability to disclose who he is as an autist—and, thus, his own identity as an advocate and activist. For Prince, the *piercing* and *pain* are too much, and she quits school at an early age, becoming homeless for several years. She explains, however, that opting out was not about not caring but precisely the opposite. As a "naturally connected person" (p. 56), she cares (almost) too much, a characteristic that she observes in her son's interactions moving bugs that are so tiny they are barely perceptible to a place where they would not drown in their back yard.

His natural connection to everything around him not only left him vulnerable to others' judgements but also the to the lights that start to hurt his eyes and "the normal noise of conversation [that] hurt his ears[. . .]" (p. 65). Prince's descriptions of her son's experiences are also reflected in the *hurt* and *pain* that the children with ASD, autistic youth and adult in the participatory project attributed to bright lights, sounds of buzzing, alarms, music, talk, engines, hand dryers—especially when they occurred *all of a sudden.* Prince's son, ". . . would cover [his ears] with his hands and rock, trying to get under the table," what she calls, being "contextually autistic" (p. 66). When she took him out of school and provides home schooling, he flourishes.

In addition to its impact on participation, the pressure to *respond in the correct way* and be the person one "should" be to "fit in" (Bagatell, 2007, p. 417) or to "pass as normal" (Prince, 2013, p. 329) has larger repercussions for mental health. For Cassandra, the navigation of her sensory sensitivities coupled with the *social aspect of things* raises critical implications for what she believes might be possible for her. When individual strategies fail, are dismissed and-or categorically misunderstood, what are the real options?

Although the anthropologist Prince (2013) points attention to how societal contextual factors come to define the kind of person one is, she is also making a larger claim as an autist: Any attempts for autists to *pass as normal* create barriers to three universal desires held by all people:

> *The ways we pass as normal keep us from having any of our three deepest wishes granted like heaven; we can't be loved for who we are, because we hide ourselves, knowing we are freaks; we can't give, because we are often too afraid; and because no one knows who we are or what we can give, we are afraid to die, knowing we can't truly be remembered (p. 329).*

If one is only something unnamable (*R-word*), *that weird girl,* a *threat,* or a *freak* than one has not existed at all. As Prince profoundly points out, the very actions that allow one to *pass as normal* are also the very actions that do not allow one to be fully seen. The very actions that allow one to pass as normal are also the existential barriers to participation at the deepest levels, in which social expectations and standards about what is normal render one virtually invisible where *no one knows who [one is] and what [one] can give*.

This shifts the question from "how does *one* proceed" to "how do we, as a society, proceed?"

A Relational Approach to Sensory Curb-Cuts

In geographer and critical autism studies scholar Davidson's (2010) relational approach, she draws on an aggregate of autistic authors' insights about social-spatial exclusion. Such first-person perspectives are necessary, Davidson suggests, to re-imagine sensory geographies since sensory experiences are often hidden from and inaccessible to others. The concept of "relational" is used in a commonsense way as based on mutual understanding (p. 306). A relational approach foregrounds being sensitive to others' ways of being and the reciprocal responsibilities toward one another when occupying spaces together. Thus, re-imagining sensory geographies in such a relational approach entails listening deeply to what autists share and taking responsibility, as a society, to redesign the spaces we inhabit together.

The autistic youth and adult of this participatory study give a clear vision of what can be done. For them, the space that is needed is simply a *zone*. A place not just where they can participate, but one that is equally friendly to others. As Cassandra reflects, "I can't be the only one who has meltdowns." In universal design principles, the curb-cut in sidewalks is the most common exemplar. Once cuts were made in sidewalks to support the accessibility of persons in wheelchairs, they also immediately became useful for a variety of others—whether for baby strollers, toddlers, older adults, those with visual impairments or simply those who prefer to shuffle. Cassandra also alludes to the potentiality of not just considering physical barriers in her reminder that there are "more disabilities than just physical ones." Listening deeply to persons with ASD and autistic persons could expand sensory accessibility for all.

Dunn et al. (2012) proposed a "contextually relevant" reflective guidance for occupational therapy interventions linking sensory processing principles to a family's routines and settings so that parents can learn about how their children's sensory processing patterns might affect their participation. The parents, then, become responsible for helping creating spaces for meaningful participation for their children. With this approach to modifying activity contexts and informing parents about sensory processing principles, the participation of children with autism aged between three and 10 years old increased. Pfeiffer's (2017) research showed how parents support their children's sense of agency and control over the environment in ways which increase their participation. The focus of these studies align with the relationship-centered focus in occupational participation (Restall and Egan, 2021). However, the weight of responsibility remains on children, their families and the health professional who work with them.

Cassandra's vision, however, expands the potentiality of these efforts by shifting the responsibility to other social sectors. She suggests that it would only need "one security [personnel] or two tops that has some knowledge and some awareness of [autism], [so] they can make a training, they can train people." Her vision could materialize, an approach in which we, as a society, "are willing to take relational responsibilities seriously and really hear" what autists have to say (Davidson, 2010, p. 311). When *the busy of people* becomes *too much*, having a space to go while not necessarily being alone is something that the autistic youth desired. For Cassandra, avoiding meltdowns is as simple as a quiet place, even a *tiny* one, where she can prepare herself. For Victor, it is a space to be *calm*, and even better if there are the sounds and presence of animals. Yet, what the autistic youth, their parents and the autistic adult mentor collaboratively agreed upon in their meetings was not a demarcated or separate space but integrated *zones* that are sensory friendly.

On several occasions, Nina brought attention to the book *Designing for Autism Spectrum Disorders* which aims to explain "how architecture and interior spaces can positively influence individuals who are neurodivergent by modifying factors such as color, lighting, space organization, textures, acoustics, and ventilation" (Gaines et al., 2016, p. 3). Creating social-spatial inclusive spaces on an even larger scale is best exemplified, in turn, by Victor's response to the question, "What do you hope will come out of this project?" His answer gets right to the heart of a relational approach: "I hope all the mayors learn from this [project] so they can make their cities more sensory friendly." Victor imagines what could happen if the mayors (plural) could learn from the experiential knowledge they shared. It's a vision where others know who they are and what they can give. It is not just inclusive cities that they envision, but "mutually 'inclusive' societies" (Davidson, 2010, p. 311) that is Cassandra's and Victor's wish.

STUDY LIMITATIONS

The sensory experiences are limited to the urban area in which the participatory project was situated. Future studies would benefit by listening to the experiences of autistic persons from multiple areas. In addition, the regulations associated with the COVID-19 pandemic interrupted group gatherings in March 2020, constraining our ability to take action steps as well as conduct thorough member-checking on the themes reported here.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article and any further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Research Ethics Office (IRB) of the Faculty of Medicine and Health Sciences. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

MP designed PV-1. MP, KL, and the families collected and analyzed the PV-1 data. MP, NM, and AS designed PV-2, and collected and analyzed the data along with the youth and M-AC. M-AC, KL, and MP are co-first authors of the sub-study, contributing to the analyses of results and representation of the data. KL and MP revised and wrote the final manuscript. All authors read and approved the final submitted version.

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ORIGINAL RESEARCH
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Oral Sensory Sensitivity Influences Attentional Bias to Food Logo Images in Children: A Preliminary Investigation

Anna Wallisch[1], Lauren M. Little[2], Amanda S. Bruce[3,4] and Brenda Salley[3]*

[1] Juniper Gardens Children's Project, University of Kansas, Kansas City, KS, United States, [2] Department of Occupational Therapy, Rush University, Chicago, IL, United States, [3] Department of Pediatrics, University of Kansas Medical Center, Kansas City, KS, United States, [4] Center for Children's Healthy Lifestyles and Nutrition, Kansas City, MO, United States

Background: Children's sensory processing patterns are linked with their eating habits; children with increased sensory sensitivity are often picky eaters. Research suggests that children's eating habits are also partially influenced by attention to food and beverage advertising. However, the extent to which sensory processing influences children's attention to food cues remains unknown. Therefore, we examined the attentional bias patterns to food vs. non-food logos among children 4–12 years with and without increased oral sensory sensitivity.

Design: Children were categorized into high ($n = 8$) vs. typical ($n = 36$) oral sensory sensitivity by the Sensory Profile-2. We used eye-tracking to examine orientation and attentional bias to food vs. non-food logos among children with high vs. typical oral sensory sensitivity. We used a mixed model regression to test the influence of oral sensory sensitivity to attentional biases to food vs. non-food logos among children.

Results: Results showed that children with high oral sensory sensitivity showed attentional biases toward non-food logos; specifically, children with high oral sensory sensitivity oriented more quickly to non-food logos as compared to food logos ($p < 0.05$), as well as spent more time looking at non-food logos as compared to food logos ($p < 0.05$). Findings were in the opposite direction for children with typical oral sensory sensitivity.

Conclusion: Sensory sensitivity may be an individual characteristic that serves as a protective mechanism against susceptibility to food and beverage advertising in young children.

Keywords: food advertising, sensory processing, picky eating, eye tracking, attentional bias

Edited by:
Catana Brown,
Midwestern University, United States

Reviewed by:
Cynthia Lau,
Touro University Nevada,
United States
Martin Yeomans,
University of Sussex, United Kingdom

****Correspondence:***
Anna Wallisch
annawallisch@ku.edu

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INTRODUCTION

Evidence shows that children's sensory processing patterns impact their eating habits, as children with sensory sensitivity are described as picky eaters and often refuse novel foods [for a review see Dunn et al. (2016)]. Extensive research also demonstrates that increased food and beverage advertising is positively associated with children's consumption of unhealthy foods [for a review see Boyland et al. (2016)]. While investigators have examined the influence of individuals' weight and age on differential patterns of attention to food advertising (e.g., Carters et al., 2015), research has not yet addressed how children's sensory processing patterns may be associated with attentional bias to food advertisements. For children with sensory sensitivity, food advertisements may not be particularly rewarding, contributing to decreased attention to advertising cues. Therefore, this study examined the extent to which sensory processing sensitivity influenced children's attentional bias to food logos. This is important because findings from this study may contribute to an understanding of how specific sensory processing patterns serve as a protective factor against the effects of unhealthy food and beverage advertising.

According to the *Reactivity to Embedded Food Cues in Advertising Model*, individual susceptibility factors influence physiological and psychological reactivity to food cues, which leads to a reciprocal relationship with eating behavior (i.e., incentive-sensitization process) (Folkvord et al., 2016). This model is supported by studies which show that children's individual characteristics (e.g., impulsivity, attention) are related to their food choices. For example, Folkvord et al. (2014) showed that children with higher impulsivity were more susceptible to food marketing than children with lower impulsivity. Another study revealed that children who showed increased attention (e.g., gaze duration, number of fixations) to food cues were more likely to eat unhealthy snacks (Folkvord et al., 2015). Velazquez and Pasch (2014) found that children's preferences for unhealthy food were associated with their maintenance of attention to food logos; however, associations were no longer significant after controlling for demographic characteristics. Lastly, Spielvogel et al. (2018) found that unhealthy food cues attracted children's visual attention to a greater extent than healthy food cues, although, children's initial visual interest (i.e., latency to first fixation) did not differ between unhealthy and healthy food cues. We propose that the way children experience food and marketing based on their sensory processing patterns may underlie attentional biases to food cues, and may serve as an individual factor that can help clarify the mixed findings related to children's attention to food cues.

Emerging evidence suggests that sensory processing may be an individual characteristic that influences individuals' attention to food cues and subsequent eating behavior. Sensory processing refers to the ways in which individuals detect and behaviorally respond to sensory information. According to Dunn's Framework of Sensory Processing (Dunn, 2014), individuals demonstrate behaviors that reflect underlying neurological thresholds. Children that have high neurological thresholds require more intense or an increased amount of sensory stimulation to notice aspects of their environments (i.e., these children are considered *underresponsive*). Conversely, children that have low neurological thresholds notice environmental stimuli very quickly and can easily become overwhelmed by environmental stimuli (i.e., these children are *sensory sensitive*). Sensory processing patterns may differ across systems (e.g., tactile, auditory) and individuals may show both high and low neurological thresholds based on sensory system (Dunn, 2014).

Studies show that children with sensory sensitivity demonstrate greater physiological reactivity [for review see Aron et al. (2012)], while other literature suggests those with sensory sensitivity show highly selective eating patterns (e.g., Farrow and Coulthard, 2012). Conversely, children with high sensory thresholds (i.e., underresponsive) are more likely to be obese (e.g., Davis et al., 2013). Additional research shows that sensory sensitivity is associated with picky eating (Steinsbekk et al., 2017). However, many studies have linked overall sensory sensitivity and/or a combination of visual, auditory, and tactile stimuli with selective eating (e.g., Wildes et al., 2012; Nederkoorn et al., 2015). It is unclear if children's sensory patterns, however, are related to their attention to environmental food cues; it may be that the reactivity among children with increased sensitivity results in negative experiences with food, which in turn contributes to overall decreased attention to food cues in the environment. In other words, the association between oral sensitivity and attention to food cues has not been investigated. In the current study, we investigated the following research question: To what extent does oral sensory sensitivity impact attention to food vs. non-food logo images among typically developing children ages 4–12 years old? We hypothesized that children with high oral sensory sensitivity would show different patterns of attention to food vs. non-food logos. Specifically, we hypothesized that children with high oral sensory sensitivity would demonstrate increased duration of attention to non-food logos as compared to those with typical oral sensory sensitivity.

MATERIALS AND METHODS

Participants

We recruited 44 children ages 4–12 years through local community organizations. We obtained approval from the institutional review board at the University of Kansas Medical Center and children's legal guardians provided informed consent. Children were excluded if they had a history of a developmental diagnosis, vision/hearing/physical impairments, uncontrolled seizure disorder, and/or history of traumatic brain injury. We also excluded children with a gastrointestinal condition (e.g., gastroesophageal reflux, dysphagia). The sample included children aged 49–148 months (M = 93.95 months, SD = 26.27 months). The sample was 52.3% female, and the average body mass index (BMI) was 17.12 (SD = 2.46, range = 12.38–23.27).

Procedures

Stimuli

We presented a paired preference paradigm with 31 slides; each slide showed 2 images on opposite corners of the screen of a food logo and a non-food logo. All images were based on a paradigm of logo image presentation (see Bruce et al., 2012), which showed familiar food and non-food logos to children. The logos that were included in the current study were child appropriate and culturally familiar (e.g., common fast food chains, popular television streaming networks). While the original Bruce et al. (2012) study validated 120 images, our team used 62 logos (31 food, 31 non-food) that had not been altered by companies or corporations since the original study and may be most familiar to young children. Please refer to the Bruce et al. (2012) study for a full description of how the images were validated and rated according to familiarity, valence, and arousal as well as a full list of the images.

The images were presented on a white background, which was split into four equal quadrants. Each quadrant measured 8 in × 6 in (20.32 cm × 15.24 cm), and was presented full-screen on a 16 in × 12 in (40.64 cm × 30.48 cm) monitor. The two images within each stimulus were matched for size; each picture was confined to a space of 4 in × 4 in (10.16 cm × 10.16 cm). Each picture was centered within its quadrant, leaving a 4-inch (10.16 cm) gap between each picture horizontally, and a 2-inch (5.08 cm) gap between each picture vertically.

Eye Tracking Research Technology System

We presented images on a 16 × 12 in. computer monitor. Responses were recorded using Applied Science Laboratory (ASL) E6 eye-tracking system, Model 504 (Applied Science Laboratories [ASL], 2008) with the GazeTracker interface program (Eye-Gaze Response Interface Computer Aid [ERICA], Inc, 2010) in a darkened interior room. The pan/tilt module, a component of the ASL system, uses near infrared technology to illuminate the eye and telephoto an image of the eye onto a camera. The E6 control unit then extracts the pupil and reflection of the light source on the cornea to compute gaze location at a 120 Hz sampling rate. Each child was seated in a hydraulic chair that was adjusted to the child's eye height with the mid-point of the stimulus monitor (124.5 cm). We used a 5-point standard calibration in which dynamic cartoons were presented individually at each of the target points. Once accurate calibration was achieved, the experimental paradigm proceeded and we monitored calibration throughout the session. If calibration was inaccurate, we paused the testing session, recalibrated, and resumed the session.

Data Extraction and Reduction

We used the GazeTracker interface program to extract variables of interest within each defined look zone (i.e., food logo, non-food logo). All data was transferred to excel and each trial by variable was extracted per participant. We calculated the below variables of interest for *each trial* within *each participant*.

Fixation Count

Fixation count is the number of times an individual stops to examine each stimulus; the minimum time of each stop was set to 0.250 s, which includes return fixations (i.e., the number of times an individual looks at a stimulus on a slide, then returns attention to that stimulus again).

Latency to First Fixation

This variable represents the duration (in seconds) from the start of a trial until the participant visually fixates on either image.

Number of Times in Zone

Each image fell within an outlined zone (food logo, non-food logo) and this variable represents the number of times that each participant showed fixation counts within each zone.

Percent Time Spent in Zone

This variable represents the percent of total look duration within each zone (food vs. non-food logo zones), relative to overall looking time.

Measures

The *Sensory Profile-2* (SP-2; Dunn, 2014) is a standardized parent-report tool used to evaluate a child's sensory processing patterns in the context of everyday life. It consists of 86 questions which are scored using a 5-point Likert Scale. Parents indicate the extent to which each item describes their child's experience and/or functioning (almost always to almost never). A variety of summary scores are generated reflecting patterns in three domains: Sensory Modalities (auditory, visual, touch, movement, body position, oral), Behavior (attention, conduct, social-emotional), and Sensory Processing Pattern (registration, seeking, sensitivity, avoiding). In the oral processing domain, $n = 5$ items are categorized as "oral sensitivity" and $n = 5$ items are categorized as "oral seeking"; we used the mean of the 5 items within the oral sensitivity domain to create a mean score.

We calculated an oral sensitivity score based on our hypothesis that oral sensitivity would influence children's eye gaze to food vs. non-food logo stimuli. According to norm-referenced data, children are categorized as "*much less than others/less than others*," "*similar to others*," or "*more than/much more than others*"; such categorizations help practitioners understand individual's scores as they relate to peers and to determine if they meet cut-off scores to show clear sensory differences. When children show 'much less/less than others' scores, they scored at least 1 SD below the majority of peers and are showing *decreased* responses to sensory stimuli in that domain. When children show "more than/much more than others," scored at least 1 SD above the majority of peers and they are showing *increased or exaggerated* responses in that sensory domain.

Data Analysis

As the *Sensory Profile*-2 scoring was standardized in the general population, we categorized children's oral sensitivity scores into "much less than others/less than others"; "similar to others"; or "more than/much more than others" based on normative data. For the oral sensitivity score, we considered any score equal to or above 2.4 as "*more than/much more than others*" because in the normative scoring, a mean score on the sensitivity overall score above 2.4 (on a 5 point likert scale) is considered as such [refer to Dunn (2014)]. We then used SAS 9.2 (SAS Institute, 2015) to analyze data and used hierarchical linear modeling, also referred to as mixed model regression, to test research questions. The repeated administration of stimuli presentation to each participant introduces dependence in the measurement of outcomes, as responses are nested within individuals (Raudenbush and Bryk, 2002). Therefore, the estimation of random effects accounts for such dependence. We tested four models with the following as dependent variables: (1) fixation count; (2) latency to first fixation; (3) number of times in zone; and (4) percent time spent in zone. We treated each trial as repeated measures within child; we included sensory group (more/much more than others, similar to others, less than others) and condition (food logo, non-food logo) as independent variables. We also tested the interaction between sensory group × condition. This analytic approach allowed us to test the extent to which children with high vs. typical oral sensory processing may orient and attend to food vs. non-food logo images.

RESULTS

Main Effects

In the current sample, $n = 8$ children showed high (i.e., "much more/more than others") and $n = 36$ children showed typical (i.e., "similar than others") oral sensitivity processing scores. The mean oral sensitivity score for the high (i.e., "much more/more than others") group was 3.88 (SD = 0.80), while the mean oral sensitivity score for the typical (i.e., "similar than others") group was 2.09 (SD = 0.25). Using a t-test, results showed that the high oral sensitivity group significantly differed from the typical oral sensitivity group ($p < 0.001$).

We then used a t-test to examine whether there was a significant difference in the chronological age between those with high vs. typical oral sensory sensitivity. Results showed that those with high oral sensory sensitivity were younger (mean age = 77.63 months) than those with typical scores (mean age = 97.58 months), but this did not reach significance ($t = 2.011[42]$, $p = 0.051$). While not significant, we still controlled for age group in all subsequent analyses, as research shows a positive association between age and visual attention in children (Dye and Bavelier, 2010). We also used a t-test to examine differences in BMI between groups; results showed no significant differences ($t = -1.09$ [41], $p = 0.914$).

Significant main effects were not found; however, significant interactions between condition and group were found for fixation count ($p < 0.05$), latency to first fixation ($p < 0.01$), number of times in zone ($p < 0.01$), and percent time spent in zone ($p < 0.001$). See **Table 1** for results. Given the significant main effects found for latency to first fixation, number of times in zone, and percent time spent in zone, we conducted follow up comparisons. See **Figure 1** for mean scores across group.

Fixation Count

Children with typical oral sensory sensitivity showed a significantly higher fixation count for food vs. non-food logos (Estimate = 0.76, SE = 0.19, DF = 1984, t-value = 4.02, $p < 0.0001$). Children with high oral sensory sensitivity did not show a significant difference in fixation count between stimuli type.

Latency to First Fixation

Latency to first fixation refers to the amount of time before participants visually oriented to either the food or non-food logo stimuli. Mean scores showed that children with typical oral sensitivity first looked at food logo images in 0.81 s (SD = 0.97 s), vs. those with high oral sensitivity first looking at food within 1.28 s (SD = 1.19 s). Children with typical sensory oral processing oriented significantly more quickly to food ($M = 0.81$ s; SD = 0.97) vs. non-food logos ($M = 0.90$ s; SD = 0.97 s) (Estimate = −0.09, SE = 0.04, df = 2195, t-value = −2.08, $p < 0.05$). Conversely, children with high oral sensitivity oriented significantly more quickly to non-food ($M = 1.09$; SD = 1.18 s) as compared to food logos ($M = 1.28$; SD = 1.19) (Estimate = 0.10, SE = 0.09, df = 195, t-value = 2.05, $p < 0.05$).

Number of Times in Zone

Children with typical oral sensitivity looked more to the food logo image zone ($M = 3.36$; SD = 2.65) compared to those with high oral sensitivity ($M = 2.5$; SD = 2.5) (Estimate = 1.04, SE = 0.44, DF = 47.1, t-value = 2.49, $p < 0.05$). Children with typical oral sensory sensitivity showed no significant difference in the number of times in the food logo zone ($M = 3.36$; SD = 2.66) vs. non-food logo zone ($M = 3.30$; SD = 2.30) (Estimate = 0.12, SE = 0.14, $D = 1970$, t-value = 0.89, $p = 0.37$). However, children with high oral sensitivity looked more to the non-food zone ($M = 3.28$; SD = 3.13) vs. the food zone ($M = 2.5$; SD = 2.5) (Estimate = −0.71, SE = 0.28, $D = 1969$, t-value = −2.58, $p < 0.01$).

Percent Time Spent in Zone

Children with typical oral sensitivity spent a significantly higher percentage of looking time in the food zone ($M = 34.71$; SD = 23.45), compared to those with high oral sensitivity ($M = 23.31$; SD = 22.29) (Estimate = 9.87, SE = 4.49, df = 43.2, t-value = 2.20, $p < 0.05$). Children with typical oral sensory processing spent a significantly higher percentage of time looking at food logos ($M = 34.71$; SD = 23.45) vs. non-food logo images ($M = 29.78$; SD = 21.29) (Estimate = 5.49, SE = 0.97, df = 2195,

TABLE 1 | Type 3 tests of fixed effects.

	DF	*F* Value	*p*
Fixation count			
Condition	1977	1.83	0.176
Group	38.2	0.35	0.555
Age_Group	38.6	0.16	0.688
Condition × Group	1977	4.69	0.031
Latency to first fixation			
Condition	2195	0.96	0.326
Group	37.9	1.52	0.225
Age_Group	38	0.03	0.864
Condition × Group	2195	7.47	0.006
Number of times in zone			
Condition	1973	3.62	0.057
Group	34.4	2.82	0.102
Age_Group	35.2	0.05	0.833
Condition × Group	1973	7.31	0.007
Percent time spent in zone			
Condition	2195	0.24	0.626
Group	37.7	1.29	0.262
Age_Group	37.7	0.11	0.745
Condition × Group	2195	18.50	<0.0001

Condition, food logo vs. non-food logo; group, oral sensory sensitivity high vs. oral sensory sensitivity typical.

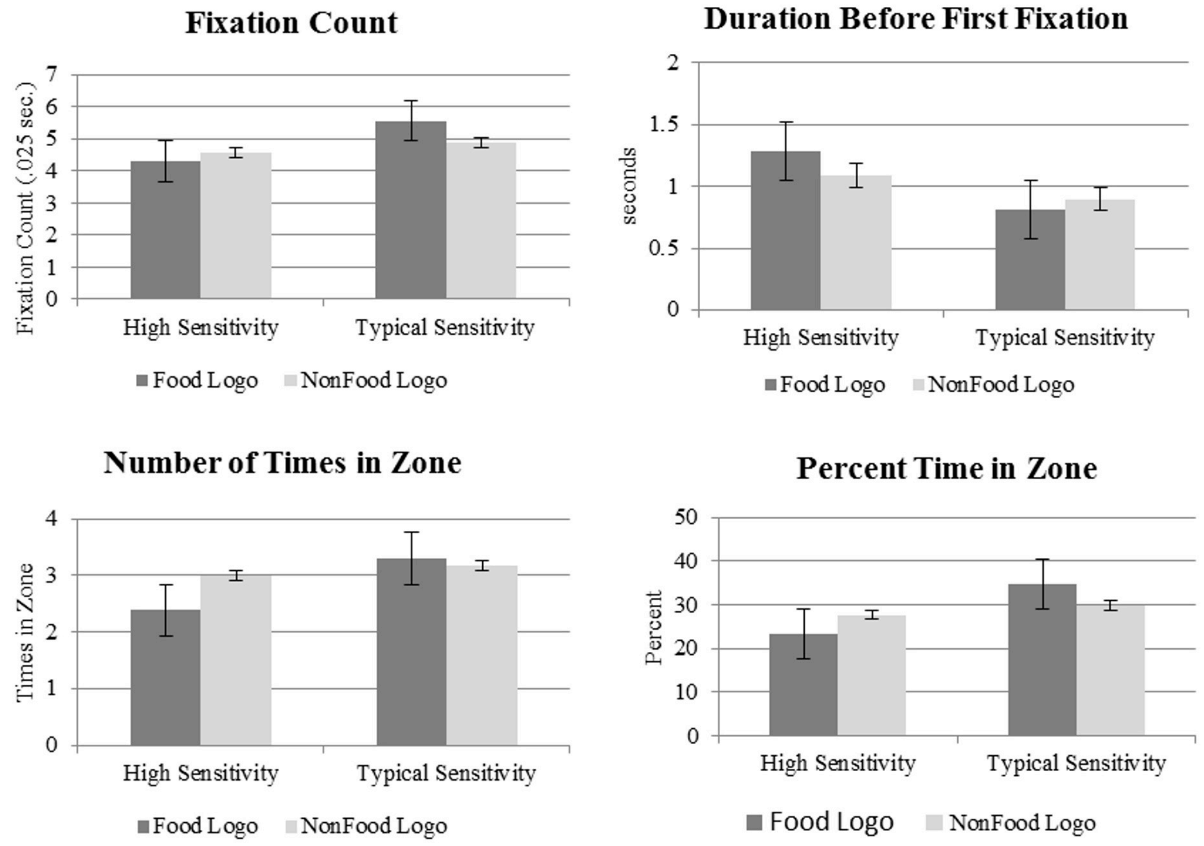

FIGURE 1 | Mean scores on eye tracking variables of interest between the high oral sensitivity and typical oral sensitivity groups.

t-value = 5.68, $p < 0.0001$). However, children with high oral sensitivity spent a significantly greater percentage of looking time in the non-food zone (M = 27.69; SD = 25.18) vs. food (M = 23.31; SD = 22.29) (Estimate = −4.38, SE = 2.08, df = 2195, t-value = −2.10, $p < 0.05$).

DISCUSSION

Findings from the current study suggest that oral sensory sensitivity influences children's patterns of attention to food vs. non-food logo stimuli. Regardless of chronological age or BMI, results show that children with high oral sensory sensitivity display an orientation bias toward non-food logos and an overall attentional bias to non-food logos. Children with typical oral sensory sensitivity, however, show orientation and overall attentional biases toward food logos. Results from the current investigation show that oral sensory sensitivity may be a child characteristic that serves as a moderating factor in attentional bias to food advertising.

The current study's findings highlight the important role of sensory sensitivity in children's cue reactivity, which in turn may influence their eating habits. While high oral sensory sensitivity has been associated with picky eating (e.g., Nadon et al., 2011), it has previously been unclear if attention may play a pivotal role in this relationship. According to the *Reactivity to Embedded Food Cues in Advertising Model,* cue reactivity results in physiological responses to food cues in one's environment (Folkvord et al., 2016). Children with high sensory sensitivity have been shown to have increased physiological arousal as compared to those with typical sensory sensitivity and/or sensory under-responsivity (e.g., Schaaf et al., 2010). Additionally, sensory sensitivity has been linked with increased sensitivity to disgust (Schienle and Schlintl, 2019). High oral sensory sensitivity may be a person characteristic that predisposes children to a negative physiological response to food cues, which then contributes to decreased attention to food cues. Taken together, our findings suggest that even in the absence of a diagnosed clinical eating disorder or difference in BMI, children with high oral sensory sensitivity show significant attentional differences to food advertising as compared to those with typical oral sensory sensitivity. While previous studies have uncovered the eating behavior differences among those with high sensory sensitivity, the current investigation points to the underlying role of attentional bias to non-food logos among those with such high sensory sensitivity. It may be that the motivation that drives attentional bias toward food in many children is not similar among those with increased oral sensory sensitivity.

This study provides novel information related to the link between attentional biases to food logos and oral sensitivity patterns. Specifically, children with higher oral sensory sensitivity demonstrated less attentional bias toward food logos; whereas, children with typical oral sensitivity patterns showed attentional biases toward food logos. This means that children with higher oral sensitivity patterns may show less motivation to look at images associated with food. Picky eating is often associated with higher oral sensitivity, and this means that picky eaters may attend less, and be less susceptible, to food and beverage advertising cues.

Limitations and Future Directions

The limitations of the current study include our relatively modest sample size and a wide age range. Additionally, the paradigm that was used to elicit attention must be replicated and validated in a larger sample of children. Specifically, while our study utilized logos familiar to children and logos used in previous studies with children (e.g., Bruce et al., 2012; Boyland et al., 2016), certain logos may have been more or less arousing than others (e.g., toy logos vs. phone company logos). Thus, future studies may match food and non-food images based on the degree to which an image is exciting to children. Further, we did not capture the child's level of hunger prior to viewing the eye tracking paradigms, and future studies should examine how hunger states may influence attentional biases. Children's oral sensitivity may be associated with their overall sensitivity scores as well as other sub-domains (e.g., touch processing) that fall within the sensitivity score. In this study, we limited analyses to testing the influence of oral sensitivity on attention to logos. Lastly, we used a parent report measure of sensory processing, and while a validated measure, parent report may differ from individual child experiences. Future studies should include a larger sample with a narrower age range as well as include a behavioral measure of sensory processing.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Kansas Medical Center Institutional Review Board. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

AW and LL designed the study, collected the data, analyzed the data, interpreted the data, and wrote this manuscript. AB and BS supported the design of the eye tracking paradigms, as well as the interpretation of findings. All authors contributed to this manuscript, reviewed drafts of the manuscript, provided critical feedback, and approved the final version.

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Characterizing Sleep Differences in Children With and Without Sensory Sensitivities

Amy G. Hartman[1]*, Sarah McKendry[1], Adriane Soehner[2], Stefanie Bodison[3], Murat Akcakaya[4], Dilhari DeAlmeida[5] and Roxanna Bendixen[1]

[1] Department of Occupational Therapy, University of Pittsburgh, Pittsburgh, PA, United States, [2] Department of Psychiatry, University of Pittsburgh, Pittsburgh, PA, United States, [3] Department of Occupational Therapy, University of Florida, Gainesville, FL, United States, [4] Department of Electrical and Computer Engineering, University of Pittsburgh, Pittsburgh, PA, United States, [5] Department of Health Information Management, University of Pittsburgh, Pittsburgh, PA, United States

Objectives: Individuals register and react to daily sensory stimuli differently, which influences participation in occupations. Sleep is a foundational nightly occupation that impacts overall health and development in children. Emerging research suggests that certain sensory processing patterns, specifically sensory sensitivities, may have a negative impact on sleep health in children. In this study, we aimed to (i) characterize sleep in children with and without sensory sensitivities and (ii) examine the relationship between sensory processing patterns (using the Sensory Profile-2) and sleep using validated parent- and child-reported questionnaires. We hypothesized that children with sensory sensitivities will exhibit more difficulties with sleep.

Methods: We recruited 22 children (ages 6–10) with sensory sensitivities (SS) and 33 children without sensory sensitivities (NSS) to complete validated sleep and sensory processing questionnaires: the Children's Sleep Habits Questionnaire (CSHQ), Sleep Self-Report (SSR), and Sensory Profile-2.

Results: Children with SS had significantly more sleep behaviors reported by both parents ($p < 0.001$, $g = 1.11$) and children ($p < 0.001$, $g = 1.17$) compared to children with NSS. Specifically, children with SS had higher frequencies of sleep anxiety ($p = 0.004$, $g = 0.79$), bedtime resistance ($p = 0.001$, $g = 0.83$), and sleep onset delay ($p = 0.003$, $g = 0.95$). Spearman's ρ correlations indicated significant positive correlations between parent- and child-reported sleep. Children with SS showed a larger association and greater variability between sleep and sensory processing compared to their peers. Significant positive correlations between parent-reported sleep behaviors and sensory sensitive and avoiding patterns were identified for both children with SS and NSS. Child-reported sleep behaviors were most strongly associated with sensitive and avoiding patterns for children with NSS and seeking patterns for children with SS.

Conclusion: We present evidence that sleep is impacted for children with SS to a greater extent than children with NSS. We also identified that a child's sensory processing pattern may be an important contributor to sleep problems in children

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****Correspondence:***
Amy G. Hartman
agh38@pitt.edu

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with and without sensory sensitivities. Sleep concerns should be addressed within routine care for children with sensory sensitivities. Future studies will inform specific sleep intervention targets most salient for children with SS and other sensory processing patterns.

Keywords: sensory processing disorder, sleep, children, routine, participation, sensory sensitivity

INTRODUCTION

Sensory processing, or multisensory integration, occurs in specific areas of the brain as sensory input from the external environment is transformed into usable data, supporting our ability to act in the world (Bundy and Lane, 2019). Epidemiological studies estimate that 5–16% of children in the general population experience sensory processing patterns that impact their daily life (Ayres, 1971; Ahn et al., 2004; Dunn et al., 2016; Galiana-Simal et al., 2020; Mulligan et al., 2021).

Using Dunn's Sensory Processing Framework (2014), sensory processing patterns can be characterized in four quadrants: (i) low registration, (ii) sensory seeking, (iii) sensory sensitivity, and (iv) sensory avoiding. The low registration and sensory seeking patterns are characterized by their high neurological thresholds for sensory input. Children with higher thresholds often tolerate busy environments more easily than those with low thresholds. They can miss sensory information like verbal cues during school or details in a more complex activity. Children with sensory sensitivity and sensory avoiding patterns have lower neurological thresholds and tend to register and attend to more sensory input than others. They can be very detail-oriented and can flourish with consistent routines that allow them to predict the sensory input they will experience. Each of these sensory processing patterns influence participation in many areas of occupation, such as activities of daily living, play and leisure, and education (Koenig and Rudney, 2010; Cohn et al., 2014; Schaaf et al., 2015; Dunn et al., 2016).

Sleep is an area of occupation that is of interest in healthcare and occupational therapy science. Emerging research suggests that certain sensory processing patterns, specifically sensory sensitivities, may have a negative impact on sleep health for typically developing children (Rajaei et al., 2020), children with attention-deficit hyperactivity disorder (ADHD; Mimouni-Bloch et al., 2021), and children with autism (Tzischinsky et al., 2018). However, the literature has yet to assess sleep in children with predominate sensory sensitivities, which is necessary to begin to disentangle sensory processing difficulties from other neurological differences in special populations and uncover its impact on sleep.

We hypothesize that children with a low neurological threshold, that is, children who are sensory sensitive or sensory avoiders, will exhibit more difficulties with sleep processes. Sleep requires a shift from awake and alert to a relaxed state that allows one to transition to sleep. This process involves complex processes involving biological (Jones, 2020), psychological (Carskadon, 2002), social (Belísio et al., 2010), environmental (Caddick et al., 2018), and family factors (Gregory et al., 2005; Meltzer and Montgomery-Downs, 2011). Children with lower neurological thresholds can experience high sensitivity to sensory information and are more prone to hyperarousal (McIntosh et al., 1999; Lane et al., 2010; Koziol et al., 2011). It is our hypothesis that children who experience these sensory processing patterns find it difficult to calm down to fall asleep at night, or sleep-onset.

We chose to focus on children with predominate tactile (touch) and oral-tactile sensory sensitivities for our study because emerging evidence has identified tactile sensitivity as a potential key contributor to the reported sleep problems in children with autism (Tzischinsky et al., 2018), fetal alcohol spectrum disorder (Wengel et al., 2011), and typically developing children (Shochat et al., 2009).

The goal of this study was twofold. First, we aimed to characterize parent- and child-reported sleep in children (ages 6–10 years old) with reported sensory sensitivities (SS) compared to children without sensory sensitivities (NSS). Using data from validated parent- and child-reported questionnaires, we identified differences found between groups in common bedtime experiences. We specifically investigated reported sleep-onset difficulties for both groups using parent- and child-reported questionnaires and expected to see higher rates of sleep problems reported for children with SS.

Second, we aimed to examine the association between sleep behaviors and sensory processing patterns (sensitivity, avoidance, low registration, seeking) for each group. We specifically hypothesized that there would be a significant association between sleep behaviors and the lower neurological threshold patterns in both groups. Further, we expected to see a greater association between each sensory processing pattern and sleep behaviors for children with SS compared to peers with NSS.

MATERIALS AND METHODS

Study Design

This cross-sectional, observational study utilized validated parent-, and child-reported questionnaires to characterize sleep in children with and without sensory sensitivities. All procedures and consent forms were approved by the University of Pittsburgh's Institutional Review Board (STUDY20050082).

Participants

Children between the ages of 6 and 10 years old in the United States and their families were recruited to take part in this remote research study. An *a priori* sample size calculation using the Children's Sleep Habits Questionnaire (CSHQ) total score indicates a total sample of 17–20 participants in each group would achieve at 95% power to capture important differences between groups. Interested families were screened and consented by the PI (first author) over the phone. Caregivers (all identifying as parents) reported participating in at least 4 nights of their child's bedtime routine each week. All participating children did not have known sleep disorders and had not engaged in behavioral sleep intervention in the past, or while participating in this research study.

Two groups of children were recruited for this study: children with sensory sensitivities (SS) and children without sensory sensitivities (NSS). Children recruited for the NSS group reported no diagnoses or sensory processing difficulties that impact their daily life. Children recruited for the SS group reported tactile and oral-tactile sensitivities, established by answering "yes" to 6 of the 8 tactile and oral-tactile sensitivity questions posed in the screening process (taken from the Sensory Profile-2 Questionnaire, see **Supplementary Appendix A**). Children with a diagnosis of autism, ADHD, or Down's syndrome were excluded from this study as these diagnoses have different components (e.g., neurological, medical) that may impact sleep.

Protocol

Upon enrollment in the study, all parents and children completed sleep and sensory processing related questionnaires reflecting on the past month: Children's Sleep Habits Questionnaire (parent-report, CSHQ; Owens et al., 2000a), Child's Sleep Self-Report (child-report, SSR; Owens et al., 2000b), and the Sensory Profile-2 (parent-report, SP2; Dunn, 2014). Questionnaires and a demographics survey were sent electronically using REDCap software (Clinical and Translational Sciences Institute at the University of Pittsburgh Grant Number UL1-TR-001857). Study data were collected and managed using REDCap, an electronic data capture tool hosted at the University of Pittsburgh (Harris et al., 2009, 2019). REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies. Prior to completing the questionnaires, parents were instructed to allow their child to complete the Sleep Self Report on their own, helping only if their child needs help reading or understanding the questions.

Outcome Measures

All questionnaire data were reviewed by the study team for completeness. Participants who missed questions were contacted to complete these items.

Demographic Questionnaire

A parent-reported demographics survey was developed by the study team to capture important characterizations for each participant. Age, sex, race, ethnicity, and geographic location (e.g., rural, suburban, urban) information was collected for both the parent and child. Parents were asked if their child was currently taking medication and the timing of medication and if any medications or supplements were being taken to aid sleep.

School information was collected, specifically the child's grade and if school was virtual, hybrid, in-person, homeschool, or another form of schooling. Parents also reported if this year's school situation was different than what is typical for their child (e.g., before the pandemic) in order to understand if a significant change in schooling could impact sleep.

Children's Sleep Habits Questionnaire

The CSHQ is a parent reported questionnaire that includes 33 unique items reflecting on a child's sleep over the past month. Questions are scored on a 3-point Likert scale (Rarely, Sometimes, Usually) with higher scores indicating worse sleep. Six items are reverse scored (items 1, 2, 7, 9, 10, 28). The data produce 8 subscale scores: bedtime resistance (6 items), sleep duration (3 items), night waking (3 items), sleep onset delay (1 item), sleep anxiety (4 items), parasomnias (7 items), sleep disordered breathing (3 items), and daytime sleepiness (8 items). Two questions are found in both the bedtime resistance and sleep anxiety subsections, creating a total of 35 questions in the questionnaire. A total score on the CSHQ consists of the sum of 33 unique items. Internal consistency coefficients of the CSHQ are near (0.68) or above (0.78) acceptable standards for the community and clinical samples, respectively (Owens et al., 2000a). A cut-point of 41 correctly identifies 80% of children with clinically significant sleep problems (Owens et al., 2000c).

Sleep Self-Report

The Sleep Self-Report (SSR) is a 26-item, 1-week retrospective survey designed to be administered to school aged children between 6 and 12 years (Owens et al., 2000b). This questionnaire is designed to capture domains similar to the CSHQ (parent-report). This tool produces three subscales: bedtime behavior (12 items), sleep behavior (7 items), and daytime sleepiness (4 items). Each item is rated on a 3-point scale (Usually, Sometimes, Never) with a higher score indicating more disturbed sleep. All items are summed for a total score. Internal consistency coefficient is acceptable (0.88) (Owens et al., 2000b).

Child Sensory Profile-2

The Child Sensory Profile 2 (SP-2) is a newly updated caregiver-reported questionnaire that evaluates the child's neurological threshold and self-regulation continuums (Dunn, 2014). The original Sensory Profile has an over 90% discrimination rate between neurodivergent (e.g., children with ASD, ADHD) and neurotypical children (Ermer and Dunn, 1998). The updated SP-2 is found to significantly discriminate between vulnerable populations at a similar rate as the original version (Dunn, 2014). National normative data for clinical and population-based samples are available (Dunn, 2014). The SP-2 uses 86 items scored on a 5-point scale of "Almost Always" (5 points), "Frequently," "Half the Time," "Occasionally," and "Almost never" (1 point). A "Does not apply" option (0 points) is also available in the instances that parents have not observed the behavior in question. Items can be summed to produce *quadrant* subsections (seeking, avoiding, sensitivity, and registration) or *sensory* subsections (auditory, visual, touch, movement, oral, and behavior).

For this study we utilized the *quadrant* scores as measurements of four distinct sensory processing patterns. Within each quadrant, higher scores indicate more frequent sensory behaviors. The sensory sensitivity quadrant characterizes the degree to which a child detects sensory input.

Statistical Analysis

Data were exported from REDCap and analyzed using Stata/SE (version 17.0; StataCorp 2021). We examined the data for influential outliers and adjusted statistical testing to accommodate for non-influential outliers. No influential outliers were identified.

Demographics Analysis

Participants were separated by group (SS and NSS) based on screening questions. Student's t-test or Chi-squared tests were used to compare groups on the demographic variables of age, sex, race, ethnicity, and geographic location to ensure these variables were similar across groups. Additionally, we examined rate of general medication use, medication or supplement use to aid sleep, and frequency of special education services (school based and outpatient) to further characterize our groups.

Characterizing Sleep by Group

Means and standard deviations of total scores and subsection or quadrant scores of each questionnaire were calculated and compared by group. To understand the significance of the differences between groups, Student's t-tests or the non-parametric alternatives and Hedges' g effect size estimations for unequal groups were computed. Hedges' g is an effect size that is better suited for our small sample and unequal group sizes. Effect size interpretation for the social sciences when comparing group differences typically indicates $g > 0.41$ as a minimum effect size representing practically significant effect, $g > 1.15$ as a moderate effect, and $g > 2.70$ as a strong effect (Ferguson, 2009). Considering our multiple variables and comparisons, a probability level of $p < 0.01$ was set *a priori* to indicate significance.

TABLE 1 | Demographics.

	SS group (n = 22)	NSS group (n = 33)	p-value
Parent age (*SD*)	38.36 (3.57)	37.33 (4.59)	0.487
Child age (*SD*)	7.46 (1.44)	7.46 (1.65)	0.999
Child sex†			0.375
Male (%)	14 (64%)	17 (52%)	
Female (%)	8 (36%)	16 (48%)	
Child race and ethnicity			
Black/African American, Hispanic	2 (9%)	0 (0%)	0.078
Black/African American, Non-Hispanic	4 (18%)	0 (0%)	0.011*
White/Caucasian, Hispanic	1 (5%)	0 (0%)	0.216
White/Caucasian, Non-Hispanic	12 (55%)	30 (91%)	0.002**
Other/multiple	4 (18%)	3 (9%)	0.322
Geographic location			
Urban	9 (41%)	3 (9%)	0.005*
Suburban	9 (41%)	24 (73%)	0.018*
Rural	4 (18%)	6 (18%)	0.999
Child use of melatonin for sleep (%)†	7 (32%)	3 (9%)	0.032*
Special education services†			
Children receiving special education services (%)	10 (45%)	5 (15%)	0.013*
Children receiving outpatient therapy services (%)	8 (36%)	2 (6%)	0.004**

Student's t-test performed unless otherwise indicated.
†Chi Squared test performed.
**p < 0.05, **p < 0.01.*

Examining Relationship Between Sensory Processing Patterns and Sleep Problems

For the second aim of this study, we examined the relationship between each sensory processing pattern and reported sleep behaviors for each group (SS and NSS). Sensory processing pattern scores were calculated using the SP-2 scoring criteria and correlated with the sleep questionnaires total scores. All variables were correlated using Spearman's ρ with the probability level of $p < 0.05$ set *a priori* to indicate significance. We used Mukaka's guidance of correlation coefficient magnitude in medical research of 0.70–1.00 indicating high correlations, 0.50–0.70 indicating moderate correlations, 0.30–0.50 indicating low correlations, and < 0.30 indicating negligible correlations (Mukaka, 2012). Scatter plots were used to visualize the data for each group and a fitted line was drawn to represent the magnitude and direction of the relationship between each sensory processing pattern (quadrant) and sleep total score. Due to our small sample size, we were unable to quantify the amount of variance in reported sleep each sensory quadrant explained in each group, however, we can visualize the data to inform future larger studies.

RESULTS

Demographics

A total of 57 parents and children were consented for this study, 23 in the SS group and 34 in the NSS group. Prior to the completion of the study, one participant asked to be withdrawn due to a family move and one participant was lost in follow-up, resulting in 22 participants in the SS group and 33 in the NSS group. All participants were recruited between September 2021 and December 2021 when families were transitioning into the school year during the COVID-19 pandemic. Children were reported to have had at least 2 weeks of school prior to starting our study with hopes that they have at least begun to adjust to the new schedule.

The groups were similar in child age, parent age, and child sex, but differed on racial and ethnic diversity (see **Table 1**). The SS group also had more diversity in location (urban, suburban, and rural). Additionally, the majority of both groups were living in the mid-west or eastern areas of the United States; however, the SS group did have one participant in the south and two participants in the west.

Parents of children with SS reported diagnoses of anxiety (13%), trauma (13%), behavior-related diagnoses (e.g., Oppositional Defiance Disorder; 8.6%), and developmental delay (4.3%). While none of the children in this study had a diagnosis of ADHD or Autism, two children with SS were reported to take Strattera or Ritalin daily (common ADHD medications). Additionally, two children were reported to take Prozac and Zoloft (common antidepression medication) however, no children were reported to have a diagnosis of depression. Within the group of children with NSS, one child was reported to have a diagnosis of anxiety (3%) and one was reported to have asthma (3%). The only medications reported to be taken for children with NSS were allergy medication, multivitamins, magnesium and Vitamin D supplements, and melatonin. All other children with NSS did not report a diagnosis that impacts their daily life.

Another key difference between the groups was the number of children using medications or supplements to support sleep. Melatonin was used significantly more often by children with SS (n = 7/22, 32%) when compared to children with NSS (n = 3/33, 9%, $\chi^2 = 4.58$, $p = 0.032$). Parents who reported use of melatonin used small doses (ranging from 0.5 to 2.5 mg) between 30 and 60 min prior to bed.

While we did not directly ask about adoption during our study, 5 children with SS were reported to have been adopted. No children with NSS were said to have been adopted, however, parents were not directly asked. Additionally, more children with SS received special education services at school (SS = 45%, NSS = 15%, $\chi^2 = 6.11$, $p = 0.013$) and outside of school (SS = 36%, NSS = 6%, $\chi^2 = 8.15$, $p = 0.004$). These services included occupational therapy, physical therapy, speech therapy, and therapies from psychologists and psychiatrists. Parents did not specify the goal areas of these services; however, it was indicated that all children had not received interventions related to sleep in the past or currently.

Characterizing Sleep

Child's Perception of Sleep

A total score of the SSR was also compared between groups to characterize a child's perception of their sleep (**Table 2**). These data met all assumptions for parametric testing and therefore were compared using Student's t-test. Children with SS scored significantly higher (i.e., indication of increased difficulties) in overall sleep scoring compared to children with NSS [$Mean_{\mathrm{SS}} = 42.18$, $SD_{\mathrm{SS}} = 8.26$, $Mean_{\mathrm{NSS}} = 33.55$, $SD_{\mathrm{NSS}} = 6.71$, $t(53) = -4.26$, $p < 0.001$, $g = 1.17$]. When examining subsection scores, we found a statistically significant difference between the bedtime [$t(53) = -3.68$, $p < 0.001$, $g = 1.01$] and sleep behavior ($U = -3.63$, $p < 0.001$, $g = 1.23$) subscales. In addition to the questions included in the total score, children were asked "*do you have trouble sleeping?*" as part of the SSR. For children with SS, 64% (14/22) indicated that they had trouble sleeping. For children with NSS, only 21% (7/33) indicated that they had difficulty sleeping ($\chi^2 = 6.49$, $p = 0.011$).

Parent's Perception of Child's Sleep

To characterize a parent's perception of their child's sleep, we calculated and compared the total score of the CSHQ by group. Due to the non-normality of these data, we used non-parametric Mann-Whitney U-tests to compare groups (**Table 2**). Parents reported a statistically significant difference in overall sleep, with children with SS ($Mean_{\mathrm{SS}} = 54.91$, $SD_{\mathrm{SS}} = 10.00$) scoring higher (i.e., indication of increased difficulties) than children with NSS ($Mean_{\mathrm{NSS}} = 45.12$, $SD_{\mathrm{NSS}} = 7.27$; $U = -3.41$, $p = 0.001$, $g = 1.11$). Further analysis of subsections indicated that parents of children with SS identified higher frequencies of bedtime resistance, sleep onset delay, sleep anxiety, night awakenings, and parasomnias. Both groups scored similarly on sleep duration, sleep disordered breathing, and daytime sleepiness subsections. Ninety-one percent of total scores for children with SS exceeded the cut-point of 41, indicating clinically significant sleep problems (Owens et al., 2000a). Interestingly, 67% of total scores for children with NSS exceeded the cut-point, a higher rate than what is reported in the literature (Markovich et al., 2015).

Correlations Between Parent and Child Reported Sleep

In a *post hoc* analysis, we correlated parent and child reported sleep total scores by group to see the relationship between both perspective of the child's sleep. Interestingly, we found that children with SS and their parents had very low, non-significant correlations between their reported of sleep ($\rho = 0.14$, $p = 0.526$). Children with NSS and their parents showed a small and significant positive correlation between their total scores ($\rho = 0.40$, $p = 0.020$).

TABLE 2 | Comparison of groups.

	SS group (n = 22)	**NSS group (n = 33)**	***p*-value**	**Hedges' *g***
Sleep self-report total score†	42.18 (8.26)	33.55 (6.71)	<0.001**	$1.17^{\ddagger\ddagger}$
Bedtime†	22.45 (4.78)	12.97 (4.19)	<0.001**	$1.01^{\ddagger}$
Sleep behavior	12.68 (3.05)	9.64 (2.01)	<0.001**	$1.23^{\ddagger\ddagger}$
Daytime sleepiness†	7.05 (1.84)	5.94 (1.58)	0.021	$0.66^{\ddagger}$
Children's sleep habits Questionnaire total score	54.91 (10.00)	45.12 (7.27)	<0.001**	$1.11^{\ddagger}$
Bedtime resistance	9.64 (2.66)	7.61 (2.32)	0.001*	$0.83^{\ddagger}$
Sleep onset delay	2.09 (0.81)	1.45 (0.56)	0.003*	$0.95^{\ddagger}$
Sleep duration	5.05 (2.01)	4.12 (1.39)	0.095	$0.56^{\ddagger}$
Sleep anxiety	7.41 (2.40)	5.64 (2.12)	0.004*	$0.79^{\ddagger}$
Night waking	4.82 (1.87)	3.70 (0.92)	0.018	$0.81^{\ddagger}$
Parasomnias	10.68 (2.42)	8.42 (1.52)	<0.001**	$1.17^{\ddagger\ddagger}$
Sleep disordered breathing	3.59 (1.01)	3.39 (0.70)	0.493	0.24
Daytime sleepiness	11.64 (3.90)	10.79 (2.70)	0.557	0.26
Sensory profile 2				
Seeking†	55.41 (20.99)	31.36 (11.61)	<0.001**	$1.50^{\ddagger\ddagger}$
Avoiding	57.00 (18.04)	32.24 (11.47)	<0.001**	$1.72^{\ddagger\ddagger}$
Sensitivity	50.14 (16.00)	27.76 (9.15)	<0.001**	$1.81^{\ddagger\ddagger}$
Registration†	49.45 (16.09)	30.88 (10.16)	<0.001**	$1.45^{\ddagger\ddagger}$

Means presented with standard deviations in parentheses with higher scores indicating higher frequencies of problem behavior. Non-parametric Mann-Whitney U-test used until indicated. Hedges' g corrected for uneven groups was used to calculate effect size.

†*Student's t-test was used.*

‡*Effect size interpretation for social sciences typically is as follows (Ferguson, 2009).* ‡*$g > 0.41$ minimum effect,* ‡‡*$g > 1.15$ moderate effect.*

**$p < 0.01$, **$p < 0.001$.*

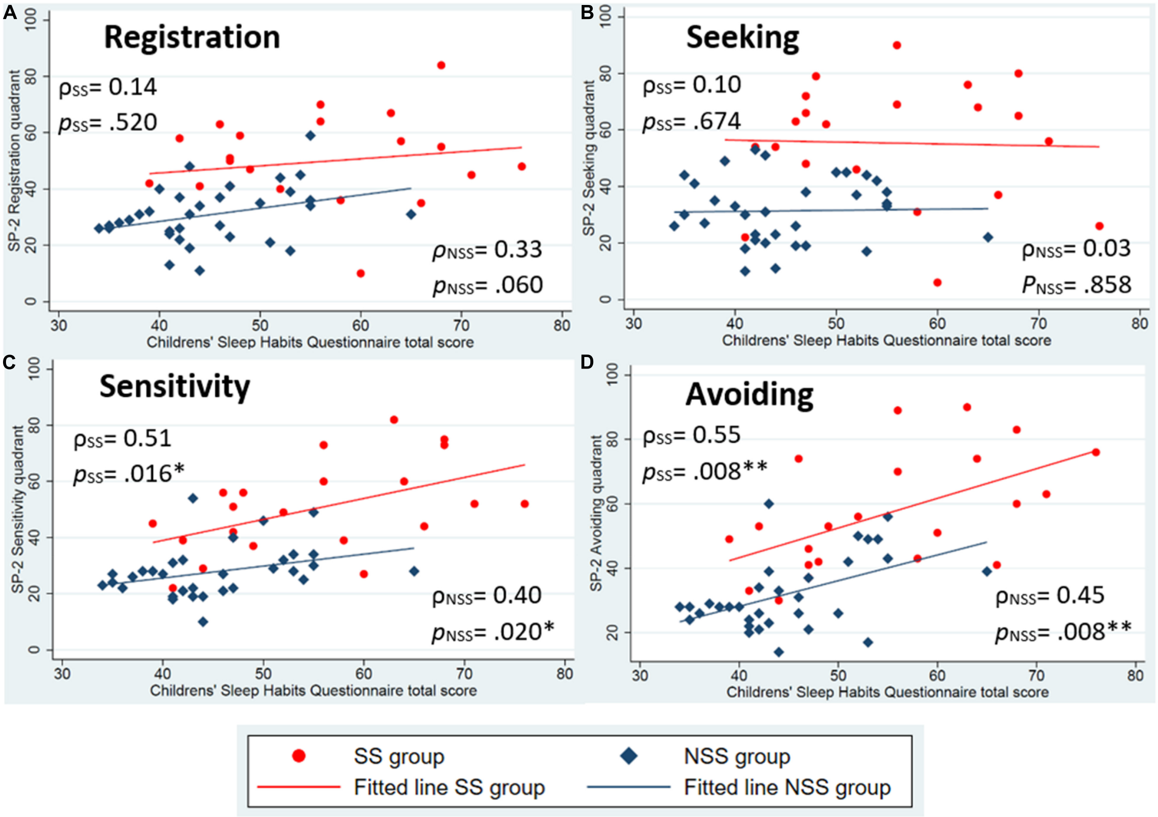

FIGURE 1 | Scatter plots of parent-reported sleep (Children's Sleep Habits Questionnaire) and sensory processing patterns (Sensory Profile-2 quadrant scores). **(A)** Is the registration pattern, **(B)** is the seeking pattern, **(C)** is the sensitivity pattern, and **(D)** is the avoiding pattern. Spearman's ρ correlations and *p*-values presented for each group. $^{*}p < 0.05$, $^{**}p < 0.01$.

Relationship Between Sleep and Sensory Processing Patterns

Characterizing Sensory Processing Patterns in Each Group

Children with SS and NSS differed significantly on the four quadrant scores of the SP-2, with children with SS scoring significantly higher for each quadrant score (**Table 2**). Twenty (91%) children with SS scored higher than at least 1 standard deviation (or "More than others" on the tool) from the mean on one of the quadrants, and 11 (50%) scored 2 standard deviations (or "Much more than others") from the mean on at least one quadrant.

On average, children with NSS scored within one standard deviation from the mean in all sensory quadrants. However, 8 children (24%) with NSS had at least one quadrant score falling one standard deviation above the mean, and 2 participants (6%) scored higher than 2 standard deviations above the mean on a quadrant score.

Correlations Between Sleep and Sensory Processing Patterns

We then examined the correlations between sleep and sensory variables by group. Two compilations of scatter plots are presented in **Figures 1**, **2**. **Figure 1** represents the correlation of parent-reported sleep by each sensory quadrant score by group and **Figure 2** presents the correlations between child-reported sleep and each sensory quadrant score. From these scatter plots and fitted lines, potential differences in the magnitude and significance of the relationship between reported sleep problems and sensory processing patterns can be explored.

Aligning with our hypothesis, both groups had statistically significant associations between parent-reported sleep and low neurological threshold patterns (**Figures 1C,D**). For child-reported sleep, a significant association was found in low neurological threshold patterns for only children with NSS (**Figures 2C,D**). Contrary to our hypothesis, children with SS did not identify statistically significant associations with low neurological threshold patterns. Rather they identified sensory seeking as a significantly associated pattern related to sleep (**Figure 2B**).

Additionally, we compared the magnitude of the associations within each sensory processing pattern by group. Using parent-reported sleep behaviors, larger correlations were found for children with SS compared to children with NSS for all sensory patterns except the low registration pattern. This aligns with our hypothesis and suggests that sensory processing is slightly more strongly associated with sleep behaviors in children with

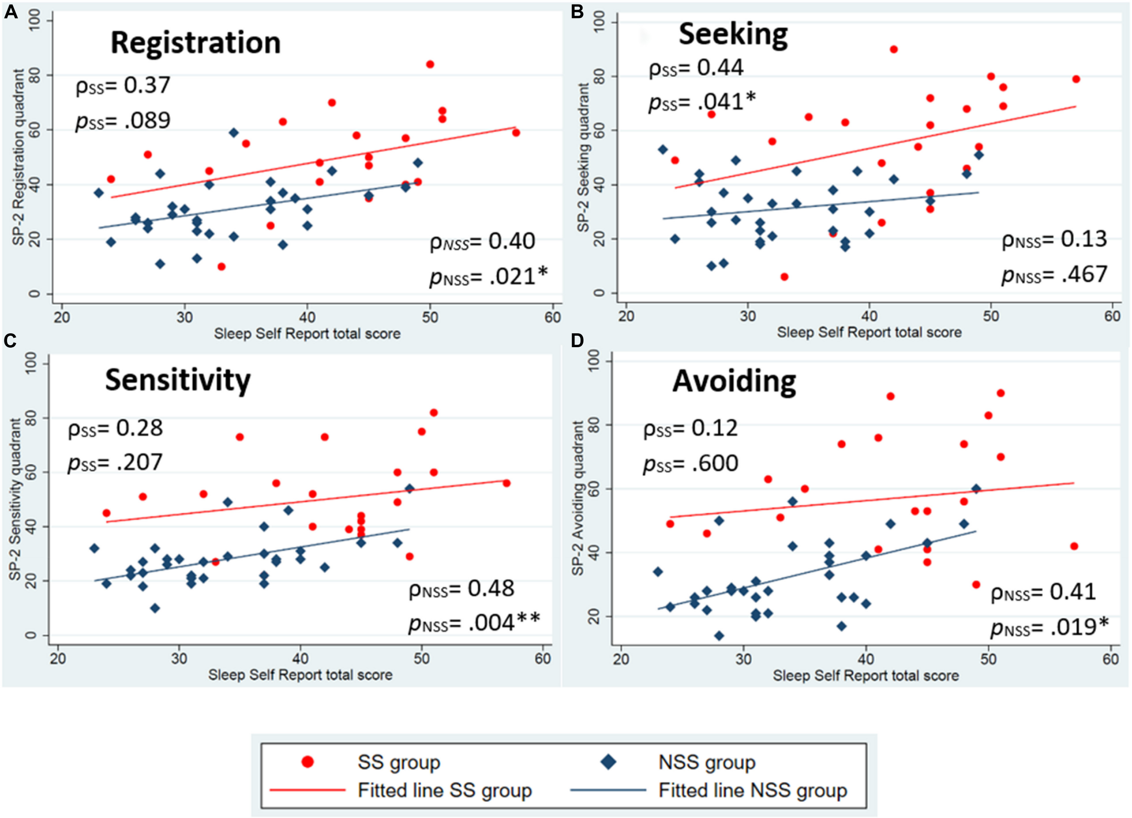

FIGURE 2 | Scatter plots of child-reported sleep (Sleep Self Report) and sensory processing patterns (Sensory Profile-2 quadrant scores). **(A)** Is the registration pattern, **(B)** is the seeking pattern, **(C)** is the sensitivity pattern, and **(D)** is the avoiding pattern. Spearman's ρ correlations and *p*-values presented for each group. $^*p < 0.05$, $^{**}p < 0.01$.

SS compared to peers. Child-reported sleep, however, was found to be more strongly associated with high neurological threshold patterns for children with SS (**Figures 2A,B**) and low neurological threshold patterns for children with NSS (**Figures 2C,D**).

Additionally, a larger variability can also be seen in children with SS compared to children with NSS, as evident by the larger spread of data in this group. We see a shift toward higher scores on both of the sleep variables and each of the sensory processing pattern scores for children with SS in these plots, indicating that children with SS more frequently endorse the sensory and sleep behaviors noted in these questionnaires.

DISCUSSION

First, this preliminary cross-sectional, observational study adds to the science by characterizing sleep behaviors in a novel group: children with sensory sensitivities who do not have a diagnosis of autism or attention-deficit hyperactivity disorder. We compare these data to children without sensory sensitivities (NSS) to understand the areas in which these groups differ. We found significantly increased sleep difficulties (e.g., more frequent bedtime resistance, parasomnias, sleep anxiety) for children with SS compared to children with NSS. The current results align with previous findings in neurodiverse children; studies have found higher prevalence of sleep problems in children with ADHD (Langberg et al., 2020; Mimouni-Bloch et al., 2021) and autism (Souders et al., 2017; Manelis-Baram et al., 2021). Both of these groups have high rates of co-occurring sensory processing patterns that impact daily life (Ghanizadeh, 2011; Ausderau et al., 2016; Kadwa et al., 2019; Dellapiazza et al., 2021).

Second, we noted that parents reported a small to moderate and significant correlation between the lower neurological threshold patterns in both groups. Parents of children with SS reported slightly larger correlations than parents of children with NSS, aligning with our hypothesis that sensory processing patterns are more strongly associated with sleep difficulties for children with SS. When examining child-reported sleep correlations, we found that only children with NSS report similar small, significant, and positive correlations between sleep behaviors and low neurological threshold patterns. Children with SS, on the other hand, report negligible correlations between sleep behaviors and low neurological threshold patterns and small-moderate correlations between sleep behaviors and the higher neurological threshold patterns, a finding that opposed our hypothesis.

As other sleep research has found, we see interesting discrepancies between parent and child reported sleep

(Owens et al., 2000a; Short et al., 2013). As research continues to explore sleep in pediatric populations, it is critical to incorporate both parent and child reported perspectives of sleep to construct a more complete picture of the components of sleep. Using these two methods, we can see that while both parents and children identify higher rates of sleep difficulties for children with SS compared to children with NSS, parent and child reports correlate with different sensory processing patterns.

Relationship Between Sleep and Sensory Processing

Characterizing the relationship between sleep and sensory processing patterns has been of recent interest in the pediatric sleep research community. Rajaei et al. (2020) recently published a large, cross-sectional study with typically developing children in Tehran correlating the Persian version of the CSHQ with Sensory Profile quadrant scores. They found small but highly significant correlations between CSHQ total scores and all sensory process patterns.

Recent studies have also identified similar findings in other diagnostic populations. Manelis-Baram et al. (2021) highlight similar significant correlations between parent-reported sleep (CSHQ) and sensory processing patterns in young children with autism prior to the pandemic. More frequent endorsement of sensory processing behaviors has also been correlated with more frequent parent-reported sleep problems for children with ADHD (Mimouni-Bloch et al., 2021).

While research continues to home in on specific relationships between sensory processing patterns and sleep in children, our findings of higher reported sleep difficulties for children with SS compared to peers suggests that a sensory sensitive pattern could be a key component to understanding the high rates of sleep problems in children (Hollway and Aman, 2011; Reynolds et al., 2011; Mazurek and Petroski, 2015; Deliens and Peigneux, 2019).

The Impact on the Occupation of Sleep

Sleep is a critical occupation that requires a skilled transition from wakefulness to sleep (American Occupational Therapy Association, 2020). Our results indicate that children with sensory sensitivities struggle with independence in this transition. More specifically, there is emerging evidence that children with low neurological threshold patterns, or those with sensory sensitivities and sensory avoidance, show the largest relationship with poor sleep outcomes (Shochat et al., 2009; Thomas et al., 2015; Rajaei et al., 2020). Being that sleep is foundational to a child's health, growth, and development, sleep should routinely be part of care for children with sensory sensitivities.

Strengths, Limitations, and Future Directions

An important strength of this study was the comparison of children with SS to a peer group with NSS. This allows us to account for some of the current historical (e.g., COVID) and temporal (e.g., time of year) factors that otherwise might influence our outcomes of interest. We also used validated questionnaires that are widely used to characterize sleep and sensory processing patterns, a strength to consider when applying our findings with the larger body of literature.

Our study does have limitations that are important to consider. Our study uses a small sample size that lacked racial and ethnic diversity to mirror the United States' demographic make-up. A larger, more diverse sample in future research will further uncover the relationships between sleep and sensory processing patterns. Our groups also were significantly different in their geographic location and urbanicity. These variables can lead to differences in exposure to a myriad of environmental sensory stimuli like nighttime light and environmental noise that could negatively influence sleep in children who are more attune to sensory stimuli.

Our groups also differed in their use of medications or supplements to support sleep. We found a significantly higher rate of melatonin use for children with SS compared with children with NSS. This could be reflective of the significantly higher rates of sleep behaviors noted for children with SS. Parents and children who identify higher rates of sleep behaviors may turn to medication and supplements more readily to address these problems. It is interesting that despite the higher rates of melatonin use, children with SS still report higher sleep behaviors. Future research could examine melatonin use and its perceived effects for children with SS compared to children with NSS.

It should be noted that four children with SS were taking medications that may impact their sleep (Strattera, Ritalin, Prozac, and Zoloft). There were also a similar number of children in both groups taking allergy medication which may impact sleep for these children. Future research should document more information regarding medication timing and effects parents and children note regarding their daily medication.

Additionally, in this study we purposefully sampled children who were reported to have sensory sensitivities. While this allows for a strong sample of children with lower neurological threshold, children with predominately high neurological thresholds may have been excluded, biasing our findings. Future research should include children with a variety of sensory processing patterns to better understand correlations with sleep.

An important consideration with this study is the timeline of data collection, which took place between September 2021 and December 2021, during the COVID-19 pandemic (Delta variant predominance) in the United States. All but one of our participants were attending school in person at the time of data collection, however, some reported having to recently quarantine at home due to COVID exposure or infection. While the effects of COVID on child sleep is still being explored, some studies conducted at the beginning of the pandemic show an increase in overall sleep duration and sleep quality during the early pandemic (Sharma et al., 2021). However, in our data, we show high rates of sleep problems reported in both children with SS and NSS at this time, which may be a result of the higher level of stress and schedule variabilities due to COVID exposure or illness and quarantine restrictions.

Children's sleep habits do not occur in a vacuum, but in a dynamic family context; this context is critical for pediatric sleep researchers to remember (Dahl and El-Sheikh, 2007;

Meltzer and Montgomery-Downs, 2011). Children with poor sleep often impact the family functioning, just as family functioning can impact a child's sleep (Meltzer and Montgomery-Downs, 2011). In this study we did not measure family functioning, parental stress, or overall feelings of burden related to child sleep problems. Future research may consider the family dynamic and parental stress and the impact of poor child sleep on family functioning.

This is one of the very few studies characterizing sleep in children with SS who do not have a diagnosis of autism or ADHD, and lays the groundwork for future studies characterizing sleep using objective sleep measures like actigraphy or polysomnography for children with SS. These measurement tools can provide additional information that can support development of targeted sleep intervention for children with each sensory processing pattern. Additionally, exploration of circadian rhythm timing for children with each sensory processing pattern would be an interesting aspect to consider for future research.

CONCLUSION

Good sleep is critical for childhood development and overall health. We have found evidence that children with sensory sensitivities experience higher rates of sleep difficulties that can be captured by parent- and child-reported questionnaires. Further, we show positive correlations between parent-reported sleep behaviors and low neurological threshold patterns (e.g., sensitivities and avoiding) in both groups. These data indicate children who are reported to have more frequent sensory-related behaviors endorse more frequent bedtime problems. We believe our study provides a step toward uncovering specific sleep intervention targets and will contribute to improvement in everyday care for children with sensory sensitivities.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the University of Pittsburgh's Institutional Review Board. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

AH developed the original study concept, completed the data analysis, and wrote the first draft of the manuscript. RB, AS, SB, MA, and DD contributed to the study development and analysis plan. AH and SM completed the data collection. All authors approved the final manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.875766/full#supplementary-material

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Prevalence Models to Support Participation: Sensory Patterns as a Feature of All Children's Humanity

Evan E. Dean[1*†], *Lauren Little*[2†], *Scott Tomchek*[3†], *Anna Wallisch*[4†] and *Winnie Dunn*[5†]

[1] Kansas University Center on Developmental Disabilities, University of Kansas, Lawrence, KS, United States, [2] Department of Occupational Therapy Education, Rush University, Chicago, IL, United States, [3] Department of Pediatrics, University of Louisville, Louisville, KY, United States, [4] Juniper Gardens Children's Project, University of Kansas, Kansas City, KS, United States, [5] Department of Occupational Therapy Education, University of Missouri, Columbia, MO, United States

Purpose: Research about children tends to consider differences from expected patterns problematic, and associates differences with disabilities [e.g., Autism, attention deficit hyperactivity disorder (ADHD)]. When we focus on disabilities and consider differences automatically problematic, we miss the natural variability in the general population. The International Classification of Functioning, Disability and Health (ICF 11) acknowledges that the experience of disability results from interactions between "environmental" and "personal" factors which determine the person's capacity to participate. The purpose of this study was to examine sensory patterns across a national sample of children in the general population and samples of children with disabilities to investigate the extent to which differences in sensory processing are representative of natural variability rather than automatically problematic or part of a disability.

Materials and Methods: We employed descriptive statistics and chi-square tests to examine sensory processing patterns in children in the general population and autistic children and children with ADHD. We used standardization and validity data from the Sensory Profile 2 to conduct analyses.

Results: Consistent sensory patterns exist across all groups. Children in all groups had different rates of certain patterns.

Conclusion: Since children in all groups have certain sensory patterns, we cannot associate differences with problematic behaviors. Children participating successfully with all sensory patterns might provide insights for universal design that supports participation of all children.

Keywords: sensory processing, ASD, ADHD, general population, children, sensory profile, participation, environment

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Pamela Bryden,
Wilfrid Laurier University, Canada

Reviewed by:
Rosa Angela Fabio,
University of Messina, Italy
Carrie Ballantyne,
University of the West of Scotland,
United Kingdom

***Correspondence:**
Evan E. Dean
edean2@ku.edu

†These authors have contributed equally to this work

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INTRODUCTION

Research describing children frequently focuses on maladaptive behaviors, associating these behaviors with meeting diagnostic criteria. The International Classification of Function model (ICF 11) (World Health Organization, 2013) invites us to think differently. The ICF makes it clear that "activities" and "participation" are critical features of health. In addition, the ICF acknowledges that disabilities result from an interaction between the "environmental" and "personal" factors which determine the person's capacity to participate. Consistent with the ICF view, Willis et al. (2017) conducted a scoping review to identify the elements of meaningful participation for children with disabilities and identified "person-based elements" and "environment-focused elements" as substantial factors. Egilson et al. (2017) added to this alignment when they report that autistic children participate less in community activities, and parents report that social and physical environmental features create barriers.

Sensory processing is a factor that bridges personal and environmental factors. Pfeiffer et al. (2018) consider autistic people and describe the lack of fit between personal characteristics such as sensory processing and environmental characteristics (e.g., sensory stimuli) as critical factors in limited or satisfying participation. Other authors have also described lack of fit between individuals' sensory processing patterns and the sensory environment as instrumental to performance of activities of daily life (Hochhauser and Engel-Yeger, 2010; Reynolds et al., 2011). Chien et al. (2016) found that children with differences in sensory processing, when compared to national norms, had lower participation overall and enjoyed themselves less than children with expected patterns of sensory processing even though both groups participated the same amount. DaLomba et al. (2017) demonstrated a relationship between toddler behavior patterns (using parental perceptions) and patterns of sensory processing. Additionally, Booth et al. (2015) linked high sensitivity to lower satisfaction with life. Therefore, sensory processing, in particular the interaction between the person and the sensory environment, may be an area to inform a more adapted and integrated view about children's behavior and our approach to supporting their participation.

In this introduction we review the evidence-based concepts of sensory processing and examine how sensory processing has emerged as a critical factor in understanding the person/environment interaction. We propose there is a need to examine our use of sensory processing patterns in light of the ICF's conception of health and disability so we can support all children to participate successfully in their everyday lives.

Sensory Processing

Sensory processing refers to how an individual detects and responds to environmental and body stimuli. An individual's sensory preferences and aversions can both support and inhibit activity participation (Dunn, 2001, 2014; Little et al., 2015). In this way, particular behaviors may reflect adaptive responses based on individuals' sensory needs even when those behaviors are challenging in a particular context.

Based on Dunn's Sensory Processing Framework (DSPF; Dunn, 2014), children may exhibit clusters of behaviors that reflect underlying sensory detection thresholds (how quickly one detects) and self-regulation strategies (how one manages input). Sensory patterns include Sensitivity (low threshold, passive self-regulation); Avoidance (low threshold, active self-regulation); Seeking (high threshold, active self-regulation); and Registration (high threshold, passive self-regulation). These patterns were identified from a national sample of children (Dunn, 1999) and have been validated in other studies examining people across the life span (e.g., Daniels and Dunn, 2000; Brown et al., 2001; Dunn et al., 2002; Pohl et al., 2003; Dunn, 2006, 2014).

Sensory Patterns in Disability Groups

Research about children's sensory patterns has investigated the ways in which children with various disabilities show higher rates of sensory responses when compared to their peers without conditions (Dunn et al., 2016). For example, studies show that autistic children show higher rates of sensory responses compared to typically developing peers (Baranek et al., 2006; Tomchek and Dunn, 2007). Studies have shown variability in findings with Registration (failing to detect sensory information) (Ben-Sasson et al., 2007) and Seeking (Miller et al., 2007) reported as pronounced sensory patterns in autistic children; however, other research suggests that Avoidance and Sensitivity are highly characteristic of autistic children (Baranek et al., 2007). Sensory processing patterns can also define distinct profiles of autistic children (Lane et al., 2010, 2011, 2014; Ausderau et al., 2014; Tomchek et al., 2018). These studies have consistently identified four subtypes characterized by the overall intensity of sensory patterns within multisensory systems.

Children with ADHD also show sensory sensitivities and avoidance to sensory input (Reynolds and Lane, 2008). Using the Short Sensory Profile (SSP; McIntosh et al., 1999), Mangeot et al. (2001) found that children with ADHD demonstrated higher variability in sensory responses compared to typical peers on all scales of the SSP. Sensory sensitivity and avoidance have been a consistent finding (Mangeot et al., 2001; Lane et al., 2010; Reynolds et al., 2010). Dunn and Bennett (2002), using the Sensory Profile (Dunn, 1999), found that children with ADHD differed from typically developing peers on sensory seeking, emotional reactivity, and inattention-distractibility. In partial support of these findings, Yochman et al. (2004) found that preschool aged children with ADHD differed from those with typical development on Seeking; however, the ADHD group did not significantly differ on Registration. Additionally, Pfeiffer et al. (2015) using the Sensory Processing Measure (Parham and Ecker, 2007), found that children with ADHD demonstrated increased overall sensory processing scores as compared to those without ADHD. These findings are consistent with reports that children with ADHD have reduced processing and scanning linked to cognitive functions (Capri et al., 2020; Mohammadhasani et al., 2020); low threshold sensory patterns (i.e., sensitivity and avoiding) are also associated with high detection paired with low capacity to process sensory input.

Group vs. Individual Patterns

In group comparisons such as those described above, we may lose sight of the extent to which individual children have differences in sensory processing that affect their everyday routines and activities. Do just some of the children contribute to the statistically significant differences, or are the group findings characteristic of the entire sample? Additionally, because the focus of the above-mentioned studies was to identify patterns that are prevalent in children with specific disabilities such as

Autism and ADHD, we lack an understanding of children in the general population. There has been a paucity of research on the extent to which children in the general population may also show particular sensory patterns. If we apply the ICF broadly, we need to understand how sensory processing helps us understand all children's participation.

Researchers have begun to focus on the variability of sensory processing in children from the general population (Meredith et al., 2015; Little et al., 2018). Emerging evidence suggests that some children in the general population might also display high rates of sensory-related behaviors (e.g., avoidance or sensitivity patterns). For example, researchers have found that avoidance is related to anxiety (Farrow and Coulthard, 2012; Lane et al., 2012; Kotsiris et al., 2020) and associated with sleep difficulties (Shochat et al., 2009) in typically developing children. Similarly, another study found relationships between all four sensory patterns and sleep habits across school-aged typically developing children (Rajaei et al., 2020). Additionally, Registration relates to both easy going approaches and delayed responding to intense situations in typically developing children (DeSantis et al., 2011). Recognizing the variability in sensory processing patterns in the general population, this research encourages researchers and practitioners to think beyond identifying and ameliorating "individual deficits" of sensory preferences and instead focus on environmental and activity features that support participation. In the book *Saving Normal: An Insider's Look at What Caused the Epidemic of Mental Illness and How to Cure It,* Frances (2013) succinctly sums up the dilemma between identifying individual deficits and supporting participation as:

> We must reconcile to there not being any simple standard to decide the question of how many of us are abnormal. The normal curve tells us a great deal about the distribution of everything from quarks to koalas, but it doesn't dictate to us where normal ends and abnormal begins. Human difference was never meant to be reducible to an exhaustive list of diagnoses. It takes all types to make a successful tribe and a full palette of emotions to make a fully lived life. We shouldn't medicalize difference and attempt to treat it away (p. 8).

Finally, most previous research has considered each sensory pattern in isolation. It is unclear how many children have 2 or more sensory patterns that are different from the expected "just like others" range (i.e., −1 standard deviation to +1 standard deviation), and whether these children have disabilities (e.g., Autism, ADHD) or are from the general population. If children in the general population who are successfully participating in their lives have two or more sensory patterns in the difference range (i.e., more than 1 standard deviation from the mean in either direction), then we cannot attribute participation challenges of children with disabilities such as Autism and ADHD solely to their sensory pattern differences.

Sensory Processing and Participation

Dunn et al. (2016) conducted a scoping review about the relationship between sensory processing and participation in everyday activities. They reviewed 261 articles from 122 different journals and included children with (e.g., Autism, ADHD) and without conditions (general population). They reported an increasing pattern of studying the impact of sensory processing on everyday life across a 10-year period. The studies demonstrated a clear relationship between sensory processing and activities of daily living (ADL's) such as eating (e.g., Coulthard and Blissett, 2009; Marquenie et al., 2011; Nadon et al., 2011) and sleeping (Wengel et al., 2011; Reynolds et al., 2012), instrumental ADL's (IADL's) such as school learning (e.g., Brown and Dunn, 2010) and socialization (e.g., Cosbey et al., 2010; Robertson and Simmons, 2013) as well as other aspects of cognition (e.g., Nardini et al., 2008) and temperament (Reynolds and Lane, 2009; DeSantis et al., 2011) that mediate participation outcomes. For example, autistic children who had enhanced perception (i.e., sensory hyperacuity and attention to details) were more likely to have increased activity participation, and children with a high Seeking pattern participated in more adult/child play with family (Little et al., 2015). In ADHD, researchers have shown that children have reduced development of automatic processing, which can impact school learning (Capri et al., 2020; Mohammadhasani et al., 2020). Additionally, in the general population Avoiding and Seeking patterns seem to negatively affect resiliency while Avoiding also negatively affects adaptability. The authors concluded that professionals may need to provide more support for children with Avoiding patterns to overcome obstacles or adjust to changes in routine (Dean et al., 2018). These findings illustrate that all children participate in distinct ways that reflect their sensory patterns, pointing out the need to understand how sensory processing distributes across the population.

The purpose of this study was to examine sensory patterns across a national sample of children in the general population and samples of children with disabilities to investigate the extent to which differences in sensory processing are representative of natural variability in all children rather than automatically problematic or part of a disability.

Research Questions

This study addressed the following research questions:

(1) What is the distribution of sensory pattern scores among children ages 7 months to 14 years 11 months in the general population?
(2) What is the distribution of sensory pattern scores among autistic children and children with ADHD when compared to the general population?

MATERIALS AND METHODS

Sample

For this study, we used the standardization sample for the Sensory Profile 2 (Dunn, 2014); specifically, we used the data from 1,065 children who were part of the standardization (n = 805, 76% of the sample) and children included in validity studies that compared children with conditions to their peers without conditions (n = 260, 24% of sample) for the Toddler Sensory Profile 2 (TSP2) and the Child Sensory Profile 2 (CSP2).

TABLE 1 | Summary of the study sample.

Child groups	*N*	%
General population	805	76%
Children with conditions:		
Developmental delay (DD), Intellectual disability (ID), Down syndrome (DS)	25	2%
Autism	70	7%
Autism + ADHD*	22	2%
ADHD*	85	8%
Learning disability	40	4%
Gifted	18	2%
Total	1,065	100%

n, number of children in each group; %, percentage of total sample.
**Attention deficit hyperactivity disorder.*

Table 1 provides a summary of the children's demographic characteristics.

Design

We employed a descriptive design to characterize the patterns of sensory processing in the children included in this study.

Data Collection Process

The Pearson testing company used their national sites to obtain informed consent for the data for this database. We obtained a de-identified data set for analyses and documented this with our human subject's office.

Measures

We used the data from the TSP2 (7–36 months) and the CSP2 (3–14 years, 11 months) measures. These measures are parent reports of the frequency their children respond to sensory events in everyday life. The TSP2 contains 54 items and the CSP2 contains 86 items. Both measures produce scores that align with the four sensory processing patterns described in DSPF (i.e., Avoiding, Registration, Sensitivity, and Seeking). Parents respond to statements about sensory experiences in everyday life by recording how frequently the children engage in that behavior on a 6 point Likert Scale (i.e., 5 = almost always, 4 = frequently, 3 = half the time, 2 = occasionally, 1 = almost never, 0 = does not apply). There is strong validity and reliability for these measures (Dunn, 2014).

The Sensory Profile measures yield category scores based on the bell curve. Expected scores (i.e., "just like others") include 68% of any group and fall between −1 standard deviation (SD) and +1 SD. Scores reflecting more frequent behaviors are considered "more than others" scores (i.e., scores higher than +1 SD). Scores reflecting less frequent behaviors are considered "less than others" scores (i.e., scores lower than −1 SD). The "more than others" and "less than others" categories each represent approximately 15% of a sample.

Data Analysis

We used descriptive statistics, chi-square tests, and visual displays of the data to characterize sensory processing patterns of the groups.

RESULTS

Research Question 1

The first research question was: "What is the distribution of sensory pattern scores among children ages 7 months to 14 years 11 months in the general population?" We graphed the findings for this question in **Figure 1**. As you can see, 53% (*n* = 565) of the sample have all 4 of their sensory processing pattern scores in the expected range, 31% (*n* = 327) have one or more sensory processing pattern scores in the "more than others" range, and 16% (*n* = 166) have one or more sensory processing pattern scores in the "less than others" range. Seven children had missing data and could not be included in this analysis.

Research Question 2

The second research question was: "What is the distribution of sensory pattern scores among autistic children and children with ADHD when compared to the general population?" (**Figure 2**). As you can see, 13% (*n* = 8) of autistic children, 32% (*n* = 28) of children with ADHD and 53% (*n* = 565) of children in the general population group have all 4 of their sensory processing pattern scores in the expected range. Additionally, 34% (*n* = 21) of autistic children, 22% (*n* = 18) of children with ADHD and 8% (*n* = 85) of children in the general population group have all

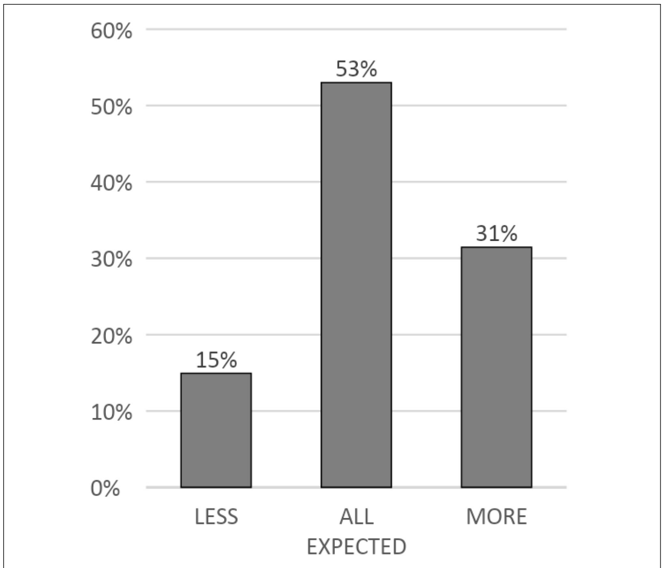

FIGURE 1 | Distribution of "expected," "more than others," and "less than others" scores in the general population. Less, all children who had 1 or more sensory pattern scores in the "less than others" categories; More, all children who had 1 or more sensory pattern scores in the "more than others" categories. All Expected, all children who had all 4 sensory pattern scores in the "just like others" category.

4 of their sensory processing pattern scores in the "more than others" range. Fewer children had all 4 scores in the "less than others" range; 2% ($n = 1$) autistic children, 2% ($n = 2$) children with ADHD and 5% ($n = 52$) children in the general population.

To examine if the distribution of scores between autistic children, children with ADHD, and those in the general population was significantly different, we used chi-square analyses. Results showed significant differences in the number of sensory patterns that fell within the "expected" and "more than others" range. We did not use a chi-square to examine the distribution of those that showed sensory processing patterns in the "less than others" range because there were 4 children or less in each cell in the autistic and ADHD groups. First, the three groups (autistic, ADHD, general population) were significantly different in the number of children that had all sensory patterns within the "expected" range, X^2 $(2, N = 1065) = 80.99$, $p < 0.001$. Using follow up tests with Bonferroni corrections, results showed that children in each group significantly differed from one other (see **Figure 2**). Second, the number of sensory response patterns that fell within the "more than others" range significantly differed by group, X^2 $(8, N = 1065) = 241.26$, $p < 0.001$. Using follow up tests with Bonferroni corrections, results showed that children in the general population were significantly different from the autistic and ADHD groups in showing 3 and 4 sensory processing patterns in the "more than others" range. However, the three groups were not different in showing 1 or 2 sensory processing patterns within the "more than others" range. This means that children in the general population and those with autism and ADHD show similar rates of differences in 1 or 2 sensory processing patterns, while autistic children and children with ADHD show higher rates of differences that fall within 3 or 4 sensory processing patterns.

To examine the "more than others" groups in more detail, we investigated which patterns were most prominent within the groups (see **Table 2**). For the children in the general population group, 27 (3% of total general population group) had only "Seeking" in the "more than others" range, 24 (3% of total general population group) had all 4 sensory processing pattern scores in the "more than others" range.

For the children in the autistic group, 22 (31% of total autistic group) had all 4 sensory processing pattern scores in the "more than others" range, and 11 (16% of total autistic group) had 3 pattern scores (i.e., Registration, Sensitivity, Avoiding) in the "more than others" range.

For the children in the ADHD group, 18 (21% of total ADHD group) had all 4 sensory processing pattern scores in the "more than others" range, and 8 (9% of total ADHD group) had 3 pattern scores (i.e., Registration, Sensitivity, Avoiding) in the "more than others" range. Other groups (Learning Disabilities, Gifted, Developmental Delay) had small numbers and so were excluded from the "more than others" analysis.

DISCUSSION

This study is the first to examine the prevalence of sensory patterns in the general population. The findings illustrate that children in the general population, as well as children with disabilities, exhibit differences in expected sensory patterns. Therefore, we cannot associate those patterns solely to disability groups. Additionally, many children with disabilities scored within the "expected" ranges based on the standardization sample on all four sensory processing patterns. These results demonstrate the importance of considering individual responses to sensory stimuli instead of generalizing based on particular conditions. We will discuss key points here.

Implications for Supporting Participation

As detailed below, evidence from this study indicates that children with and without identified conditions have sensory processing scores both within the expected range and ranges outside of the expected range. This suggests that participation

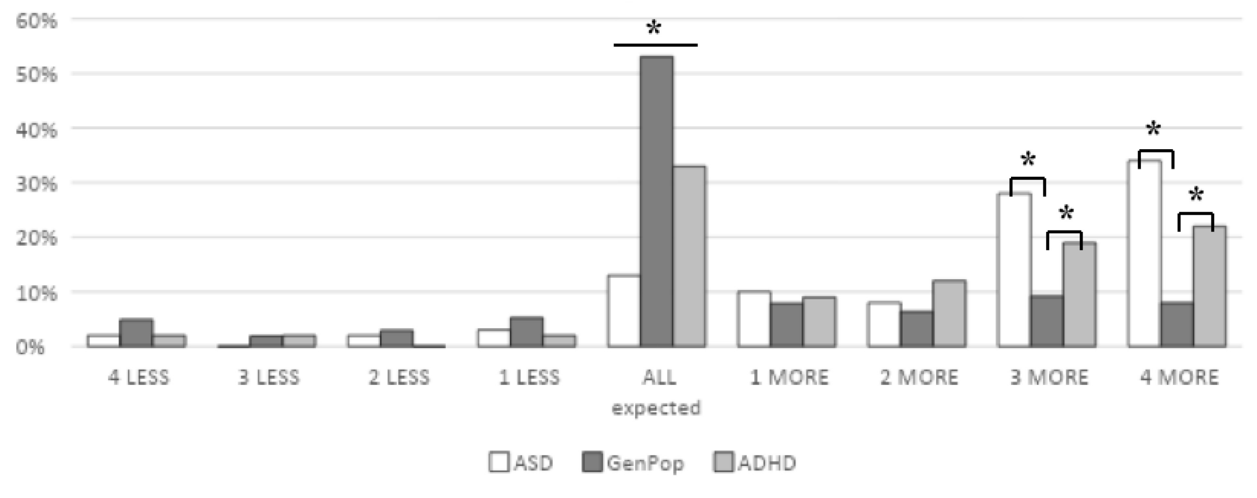

FIGURE 2 | Distribution of sensory pattern scores among three groups of children. ASD, autism; GenPop, general population; ADHD, attention deficit hyperactivity disorder. *Denotes significant differences at $p < 0.05$.

TABLE 2 | Number of children who had some pattern of "more than others" scores.

More than others scores	No. of patterns in "more than others" range (more than + 1 SD)	Groups		
		Gen. pop.	Autism	ADHD
All 4 More than others	4	24**	21*	18*
Avoid Seek Sens More	3	7	5	3
Reg Avoid Seek More	3	10	0	2
Reg Avoid Sens More	3	14	11**	8**
Reg Seek Sens More	3	9	4	3
Avoid Seek More	2	6	0	1
Avoid Sens More	2	9	4	1
Reg Avoid More	2	8	0	3
Reg Seek More	2	11	0	1
Reg Sens More	2	7	1	3
Seek Sens More	2	6	0	1
Avoid More	1	16	2	4
Reg More	1	8	2	1
Seek More	1	27*	0	1
Sens More	1	10	2	2
Total with "more than others" scores		172	53	52
% of the group totals		21%	76%	61%

**Highest number of children in group. **Second highest number of children in group. avoid, avoiding score; seek, seeking score; sens, sensitivity score; reg, registration score. Other groups were excluded from this analysis (DD, ID, DS, learning disability, and gifted).*

may be broadly supported for all children by contextual interventions (e.g., adapting places and tasks to meet the sensory preferences) and universal design that provides a way to participate for everyone (Dean et al., 2019). Further, this research adds weight to the argument that we need to normalize rather than pathologize sensory preferences outside of the expended range and focus instead on building supports for participation. There is a need for research focused on understanding the strategies that children use to successfully participate in environments that do not match their sensory preferences, which can inform practitioner strategies for supporting children who have not yet learned to participate successfully in those same environments.

Some Children in All Groups Have All "Expected" Scores

Some children in all the groups (i.e., general population, autistic, ADHD) had all 4 patterns of sensory processing scores in the expected range (i.e., between −1 and +1 standard deviation from the mean). As expected, children in the general population were the most likely to have this pattern, although only 61% of them have this profile. Since the standardization cut scores are based on standard deviations, we would expect to see about 68% in the expected score range for each of the 4 sensory processing pattern scores.

Researchers have reported that only about half of children with ADHD have sensory processing as a correlate of their learning challenges (Dove and Dunn, 2008); we see in our data that 32% (n = 27) of children with ADHD have all expected scores on the sensory profile. This finding suggests that we must differentiate the underlying features for children with ADHD to design the most effective interventions to support their learning and participation.

The literature contains many reports about the sensory processing differences of autistic children (Baranek et al., 2006; Tomchek and Dunn, 2007) and ADHD (Parham and Ecker, 2007; Reynolds and Lane, 2008). This study points out that even though group studies report significant differences, there are some children with these conditions whose sensory patterns are in the expected range. Perhaps for children with conditions such as Autism and ADHD who have sensory processing scores in the expected range, other factors are interfering with participation, such as cognitive or psychosocial factors not related to sensory processing. Alternatively, these children could face situations that provide a more intense sensory experience than they are equipped to handle even with expected patterns. Consider a situation that would overwhelm an otherwise calm person, such as a fire drill or a family reunion. It is important to remember that a person with any sensory processing pattern can reach a limit within a particular context.

We also need to examine other features (e.g., demographic variables such as age, cognition) for the children with disabilities that we would expect to have sensory processing differences, but who have all expected scores on the SP2. In our sample, we verified there was no relationship between age and having all expected scores in the autistic or ADHD groups. This finding contrasts with other data which suggests older children are more adaptable (Kern et al., 2006; Ben-Sasson et al., 2009).

Some Children in All Groups Have at Least One "More Than Others" Scores

Even though children with disabilities are more likely to have differences in their sensory patterns (76% of autistic children and

61% of children with ADHD, see **Table 2**), 21% of children in the general population group have at least 1 "more than others" score as well. These data make it hard to suggest that "more than others" scores are indicators of a problem. In fact, 3% of the general population children have all 4 sensory processing patterns in the "more than others" range. Recent research studying children in the general population have found children with Avoiding and Seeking patterns also have protective factors, such as resilience and adaptability (Dean et al., 2018). It would be useful to observe and interview children who have "more than others" scores and who are doing well in school and at home to identify the strategies they use to manage their detection and responsiveness to sensory events. Perhaps their methods for adaptation would also be helpful to children who have not figured out how to manage their daily lives as successfully.

Twice as Many Children Exhibit "More Than Others" Behaviors Than "Less Than Others" Behaviors

Another interesting observation is that in the overall sample, twice as many children have "more than others" scores ($n = 327$) than have "less than others" scores ($n = 166$). There seem to be 2 hypotheses for this finding. First, it might be that the items on the Sensory Profile 2 are worded in such a way that they foster a bias toward the "more than others" responses. Studies about sensory processing have reflected a larger theme of behaviors that are more noticeable; since the SP2 asks about frequency of behaviors, it might be that parents and professionals pay more attention to these noticeable behaviors. Secondly, it might also be true that the groups of children with disabilities that researchers study the most (e.g., Autism, ADHD) are children who exhibit more frequent sensory responding behaviors, and so the scores reflect our attention to those groups rather than all possibilities.

Some Patterns of Sensory Processing Are More Likely to Occur

It is not surprising based on the literature that children with disabilities are most likely to have a predominance of "more than others" scores (76% for autistic children, 61% for children with ADHD). Consistent with previous literature, 47% of autistic children and 30% of children with ADHD have 3 (with Registration, Avoiding and Sensitivity as primary pattern) or 4 sensory processing pattern scores in the "more than others" range (Kern et al., 2006; Reynolds and Lane, 2008; Ben-Sasson et al., 2009). Many contexts and activities contain sensory features that are likely to be overwhelming for most autistic children or children with ADHD, leading to behaviors related to attention, persistence, withdrawal and/or distractibility. There may be a relationship between sensory patterns and display of automatic responses such as eye movement patterns and attentional processing in ADHD (Capri et al., 2020; Mohammadhasani et al., 2020); specifically, if one's tendency is to detect more sensory input because of low thresholds, this tendency might result in what appears to be random eye movements and unexpected attentional shifts to "notice" all the input without filtering. Previous research has shown that while autistic children and children with ADHD show heighted responses to sensory stimuli, those with ADHD demonstrate significantly increased rates of visual processing as compared to autistic children and typical development (Little et al., 2017).

If we consider the sensory processing patterns of Registration, Avoiding, and Sensitivity all being in the "more than others" range in more depth, questions can certainly arise about how Registration (a high threshold pattern) fits in with Sensitivity and Avoiding (low threshold patterns). One might expect to see a co-occurrence of Sensitivity and Avoiding as they both reflect a high noticing/responding behavioral profile, and the literature has reported many hyper-responsive behavior patterns for autistic children and ADHD (Baranek et al., 2007; Reynolds and Lane, 2008). But how does Registration fit in?

We gained some insights from the TSP2 standardization data and from the adult literature on sensory processing. On the Registration score on the TSP2 there are 3 items that one might consider inappropriate based on our knowledge about Registration during the first edition of the Sensory Profile (Dunn, 1999). However, when examining the data from these items, they clearly loaded with Registration most strongly and did not load with other sensory patterns (Dunn, 2014). When looking at the adult literature, there is a repeating pattern of Sensitivity and Avoiding having moderate relationships with features such as anxiety, post-traumatic stress and pain catastrophizing (Engel-Yeger and Dunn, 2011a,b,c; Engel-Yeger et al., 2013). In these studies, Registration also has a low but significant correlation with anxiety, post-traumatic stress and pain catastrophizing, with Seeking being unrelated. What could this mean? One hypothesis is that people who tend to miss cues (the behavior profile for people with a "more than others" score on Registration) will eventually notice a potentially challenging stimulus, but by the time they notice, the situation requires immediate action due to the delay in noticing/responding. People with low thresholds notice quickly and take action quickly. When an individual experiences a delay in noticing sensory stimuli, their actions could look similar to noticing early and acting in a big way because of low thresholds. In a latent profile analysis, researchers called this pattern "Mellow…until" to reflect the delay in noticing (mellow part) along with the eventual big response (…until part) (Little et al., 2018).

Children in the general population group were most likely to have only the Seeking score "more than others" (3% of total group) with the other 3 scores in the expected range. Seeking behaviors provide a means for children to gather information and subsequently learn how their bodies (i.e., person factors) work within their contexts (i.e., environmental factors). It would be interesting to study this group of children to see if they are more adaptable, have more insights, are more creative or design solutions differently from their peers with all expected scores.

Limitations and Future Directions

We did not incorporate additional demographic data into our analyses that might provide a more detailed profile about children with particular sensory patterns. We also focused on the "more than others" categories since these were more prominent in the data; another analysis might investigate the characteristics of children in the "less than others" groupings in more detail. Finally, sensory processing in this study was measured using a standardized parent report measure. While this measure is widely used in research and practice, research using other experimental methods could add new insights into the sensory experiences of the groups of children who participated in this study.

The findings from this study suggest that understanding how children in the general population with differences in sensory processing determine the strategies they use to manage themselves in everyday life is a critical area for research. Insights from these children could provide a way to understand the person/environment interaction for creating universally designed contexts to support all children's participation. Additionally, these strategies might highlight the importance of considering the impact of the context on expression of sensory patterns.

CONCLUSION

Sensory processing provides a bridge between person and environmental factors. This study illustrated that individualized sensory patterns occur in all children. Our findings call into question the practice of saying that sensory processing differences (i.e., "more than others," "less than others") alone indicate a problem, deficit or disability. Children with conditions such as autism and ADHD do seem to exhibit certain patterns more frequently than their general population peers. We propose that children in the general population with differences in sensory patterns can be a source of insights about effective methods for managing everyday life successfully. Our findings suggest that adaptation (of activities and environments) based on a child's sensory patterns may be a powerful vehicle to successful participation, creating a more inclusive context for children with disabilities. When children, their families and professionals understand sensory patterns as a critical feature of person/environment interaction, these insights expand opportunities for learning, development, participation and health.

DATA AVAILABILITY STATEMENT

The data analyzed in this study is subject to the following licenses/restrictions: The dataset is owned by the publisher of the sensory profile: Pearson Publishing. Requests to access these datasets should be directed to https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Motor-Sensory/Sensory-Profile-2/p/100000822.html.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Institutional Review Board, University of Kansas Medical Center. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work, and approved it for publication.

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Conflict of Interest: WD is the author of the Sensory Profile 2; she does not own the copyright for the material but does receive a royalty for the sale of this assessment.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Caregiver Strategies to Sensory Features for Children With Autism and Developmental Disabilities

Lauren M. Little[1]*, *Karla Ausderau*[2], *Ashley Freuler*[3], *John Sideris*[4] and *Grace T. Baranek*[4]

[1] College of Health Sciences, Rush University, Chicago, IL, United States, [2] Department of Kinesiology, University of Wisconsin-Madison, Madison, WI, United States, [3] Chapel Hill-Carrboro City Schools, Carrboro, NC, United States, [4] Chan Division of Occupational Science and Occupational Therapy, University of Southern California, Los Angeles, CA, United States

Background: Caregivers of children with autism spectrum disorders (ASD) and developmental disabilities (DD) implement myriad strategies to support their children during daily activities and routines, which are laden with sensory stimuli. Children's sensory features are often characterized by three patterns of response (i.e., hyperresponsiveness, hyporesponsiveness, sensory seeking), and little is known about how caregivers' strategies differ among these patterns. Therefore, we used a mixed methods analysis to examine the complex interplay between children's sensory response patterns, child characteristics (diagnosis, chronological age, mental age), and caregiver strategies. Specifically, we examined how children's sensory response pattern scores were associated with caregiver strategies within sensory response pattern and at the item level. Lastly, we described the differential strategies implemented by caregivers of children with ASD and DD by sensory response pattern.

Materials and Methods: Participants included children with ASD (n = 77) and DD (n = 40) aged 2–10 years. Caregivers completed the Sensory Experiences Questionnaire-2.1. A convergent parallel mixed methods approach was used to analyze data.

Results: Children's sensory response pattern scores were significantly, positively associated with caregiver strategies within each sensory pattern (hyperresponsiveness, hyporesponsiveness, seeking); however, child mental age, and chronological age were not significantly related to the rate of caregiver strategies across patterns. While caregivers of children with ASD reported using more strategies, child diagnosis did not moderate the association between child sensory response pattern scores and the rate of caregiver strategies used. Item analysis demonstrated specific child behaviors in response to sensory stimuli that elicited high rates of strategies among caregivers. Qualitative analysis revealed distinct themes characterized caregiver strategies within each sensory pattern for children with ASD and DD.

Conclusion: Our findings demonstrated specificity of caregiver strategies to children's sensory response patterns in the context of families' everyday lives, which were not

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Edited by:
Batya Engel-Yeger,
University of Haifa, Israel

Reviewed by:
Michal Hochhauser,
Ariel University, Israel
Liron Lamash,
University of Haifa, Israel

****Correspondence:***
Lauren M. Little
lauren_little@rush.edu

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contingent on child diagnosis, mental age, or chronological age, thereby highlighting universal qualities of caregiving for young children who experience varying levels of sensory challenges. Targeted intervention approaches may differentially incorporate types of strategies based on sensory response patterns to more optimally facilitate children's activity participation.

Keywords: autism spectrum disorders, participation, sensory processing, caregivers, routines

INTRODUCTION

Among families of children with developmental disabilities (DD) and autism spectrum disorders (ASD), research suggests that children's sensory features, or behavioral responses to sensory stimuli, influence families' daily activities and routines (Bagby et al., 2012; Dunn et al., 2016; Pfeiffer et al., 2017). Studies show that caregivers implement myriad strategies to support child engagement in everyday activities and these strategies are often matched to specific child characteristics such as communication skills (e.g., Bernheimer and Weisner, 2007; Kirby et al., 2017; Pfeiffer et al., 2017) and self-care abilities (Kellegrew, 2000). However, the ways in which caregivers use strategies in response to children's specific sensory features has been less researched. For example, caregivers may dampen the sensory stimuli of certain activities (e.g., turning down sound, using a softer toothbrush) or amplify the sensory input of other activities (e.g., using brighter lighting, offering a trampoline for more intense movement experience). Given that sensory features are highly prevalent among both children with ASD and DD (Baranek et al., 2006; Tomchek and Dunn, 2007; Dunn, 2007; Ausderau K. K. et al., 2014; Kirby et al., 2022), the investigation of specific caregiver strategies in response to these child characteristics is needed.

Children's sensory features are commonly grouped into three patterns of response: hyperresponsiveness (HYPER), hyporesponsiveness (HYPO), and sensory seeking (SEEK) (Ausderau K. et al., 2014; Dunn et al., 2016; Baranek et al., 2019). HYPER is characterized by an exaggerated response to and/or aversion to sensory stimuli (i.e., distress during grooming) (Schoen et al., 2008; Ausderau K. et al., 2014). HYPO is described by a lack of or under response to sensory stimuli (i.e., lack of reactivity to pain) (Ben-Sasson et al., 2007; Watson et al., 2011). SEEK has been described as fascination with or craving sensory stimuli (e.g., fascination with the visual appearance of water) (Boyd et al., 2010; Kirby et al., 2016).

Evidence points to the ways that caregivers consider the ways that sensory qualities of daily activities interact with the sensory processing preferences and aversions of children with disabilities. Qualitative research has illuminated the role that sensory features play in the everyday activities of children with ASD, pointing to how caregivers implement specific strategies, such as changes to daily routines, to mitigate their children's responses to sensory stimuli (Rodger and Umaibalan, 2011; Schaaf et al., 2011; Bagby et al., 2012). Moreover, caregivers of preschool aged children with ASD reported that their children's sensory features contributed to their lack of participation, in addition to the parents' lessened provision of opportunities for participation (LaVesser and Berg, 2011). Bagby et al. (2012) found that among families of children with ASD, children's unusual sensory features impact what a family chooses to do or not do, how the family prepares for occupations, and the extent to which experiences, meaning, and feelings are shared during occupations. In another study, Schaaf et al. (2011) reported that families of children with ASD expressed the need to be flexible with daily activities, especially outside of the home, due to the children's unpredictable responses to sensory stimuli. Pfeiffer et al. (2017), in a qualitative study on how caregivers perceived the influence of sensory environments on child participation, found that caregivers of young children with ASD implemented specific strategies to promote child participation based on whether the activity was essential or not.

While studies have illuminated how caregivers consider children's sensory features when planning and engaging in everyday activities, research has not uncovered specific strategies in which caregivers differentially employ in response to children's sensory response patterns. Instead, caregiver strategies to support child engagement in activities may be contingent on child characteristics, such as chronological age or cognitive abilities. While not specific to sensory issues, one early study by Kasari et al. (1988) showed that children's mental age was related to caregivers' implementation of strategies, such as parents of children with intellectual disabilities provided increased gestures to facilitate dyadic engagement while those of children with ASD provided more physical supports. In another study, Dumas et al. (2003) reported that parents of children with acquired brain injuries (ABI) used routine, repetition, and consistency; supports and modeling; and curriculum and environmental modifications to promote child participation. Additionally, parents of children with ABI identified that they used following strategies across home, community, and school contexts: creating opportunities, teaching skills, and supporting child cognitive and behavioral regulation (Bedell et al., 2005). Caregivers of children with ASD have reported that they not only implement various strategies to promote child participation in the context of sensory challenges, but these strategies may differ in the context of home- vs. community-based activities (Kirby et al., 2017). Clearly, caregivers of children with varying developmental conditions implement strategies based on child characteristics and more research is needed to understand these differential strategies based on child sensory response patterns.

This research addresses a number of gaps in the literature on the intersection of child sensory processing and caregiver strategies. First, while research has established that caregivers of children with ASD and DD implement strategies in response to children's responses to sensory information (e.g., Weisner et al., 2005; Bagby et al., 2012; Kirby et al., 2017; Pfeiffer et al., 2017), there is little information about how the intensity of children's sensory preferences and aversions influences the amount or types of strategies used by caregivers. That is, is it unclear if children with intense behavioral responses to specific sensory stimuli result in a higher utilization of specific strategies among caregivers. For example, some caregivers may implement strategies when children demonstrate mild responses to sensory stimuli, while others may have a higher threshold for child responses such that they do not use strategies when children's sensory features are more extreme.

Second, it is unclear if child diagnosis differentially contributes to the ways that caregivers use strategies to optimize child participation in daily activities. Previous studies of caregiver strategies have used relatively diagnostic homogenous samples of children (e.g., Schiavone et al., 2018), contributing to a limited understanding of potential commonalities of caregiver strategies. It may be that there are specific child characteristics associated with ASD (e.g., differences in social interaction, communication, repetitive behavior) that influence caregiver strategies. Conversely, there may be universal qualities of caregiving for young children with developmental delays, regardless of diagnosis, that emerge when children show responses to sensory information. Therefore, we tested the influence of diagnosis on the association between rate of caregiver strategies and children's sensory response pattern scores.

Third, it is unclear if types of caregiver strategies differ by sensory response pattern. It is likely that caregivers use particular strategies in response to children's hyperresponsiveness vs. hyporesponsiveness. However, research has largely taken a qualitative approach and focused on general strategies to children's sensory features (e.g., changing the routine, limiting community outings) instead of parsing out strategies that correspond with specific child behaviors that reflect each sensory response pattern in specific contexts. Our research questions included:

1. Does the intensity of children's sensory response patterns predict the rate of caregiver strategies, as moderated by child diagnostic group (ASD, DD), chronological age, or mental age?
2. Do caregivers of children with ASD vs. DD differ in the extent to which they implement strategies in response to specific child behaviors?
3. How do caregivers describe the strategies that they implement specific to each sensory response pattern?

MATERIALS AND METHODS

Design

A convergent parallel design was used to evaluate our research questions (Creswell and Clark, 2007). Within mixed methods, decisions are made related to timing of data collection and mixing (relating the two data sets) of each approach (Creswell and Clark, 2007). For the current study, we collected all data at the same time point using one instrument (Sensory Experiences Questionnaire 2.1 [SEQ.2.1] Baranek, 1999) that has both a qualitative (descriptive text) and quantitative (frequency ratings) component. We first examined the quantitative ratings associated with item frequencies of children's behavioral responses across the three sensory response patterns as well as the amount of parent strategies endorsed. Then, we examined the qualitative data to identify *specific types* of caregiver strategies that the quantitative data did not address. To integrate findings, we compared how the quantitative and qualitative findings converged and diverged. Our purpose was to not only identify differences in the associations between sensory pattern and *overall frequency* of caregiver strategies, but also gain insight into the nature of the specific strategies in which caregivers implemented and how these strategy types were differentially characterized within each of the three sensory response patterns.

Participants

Participants were caregivers of children aged 2–10 years with a diagnosis of either ASD ($n = 77$) or DD ($n = 40$) (see **Table 1**). Data were collected as part of a larger grant-funded study, and caregivers gave written informed consent as approved by the University's Institutional Review Board. Children included in the ASD group had been diagnosed by a licensed psychologist and had met criteria on the Autism Diagnostic Observation Schedule (Lord et al., 1999). Children in the DD group had a diagnosis associated with intellectual disability (e.g., Down syndrome) or of non-specific origin (e.g., speech language disorder). Exclusionary criteria for all groups included: significant visual or hearing impairments, seizure activity, and genetic conditions that are often comorbid with ASD, such as fragile X syndrome. In the current analysis, we excluded $n = 2$ children with ASD and $n = 2$ children with DD due to incomplete data (e.g., lack of cognitive assessment).

Measures

Sensory Experiences Questionnaire Version 2.1 (SEQ-2.1)

This study used the SEQ-2.1 (Baranek, 1999) a 43-item caregiver report instrument designed to evaluate everyday sensory experiences in children. The SEQ-2.1 measures sensory features across the three sensory response patterns (HYPO, HYPER, SEEK) in both social and non-social contexts, and across all modalities. Previous research demonstrated that the SEQ shows discriminant validity between children with DD, ASD, and typical development for those aged 6 months to 6 years (Baranek et al., 2006). Additionally, the SEQ shows high internal consistency (α = 0.80), and test-retest reliability (ICC = 0.92) (Little et al., 2011).

The items on the SEQ 2.1 are each divided into three parts: (a), (b), and (c). Questions in part (a) ask the caregiver to rate the frequency of occurrence of a child's sensory experience, based on a 5-point Likert scale (1 = almost never to 5 = almost always). Thus, part (a) of the questionnaire provides a quantitative metric of the child's behavioral response to each item; scores are summed to derive total scores across each of the three sensory response patterns: HYPER, HYPO, and SEEK. Part (b) of each SEQ 2.1 item asks the caregiver to choose (yes/no) if he/she attempts to change the child's behavior (i.e., uses a

TABLE 1 | Participant demographics.

Diagnostic group	N	% male	Race/Ethnicity n (%)	CA Mean (SD) Range (months)	MA Mean (SD) Range (months)
ASD	77	78.8	African American = 9 (11.7) White = 56 (79.2) More than 1 race = 7 (9.1) Hispanic = 4 (5.2)	51.58 (16.30) 20–84	34.37 (20.80) 4–69
DD	40	55.0	African American = 3 (7.5) Asian = 1 (2.5) White = 32 (80.0) More than 1 race = 4 (10.0) Hispanic = 2 (5.0)	48.18 (23.06) 20–118	32.2 (17.25) 8–69

strategy in response to child behaviors associated with specific sensory experience). From part (b), the number of "yes" scores is summed to calculate the proportion of strategies implemented for each sensory response pattern. Part (c) requests the caregiver to qualitatively describe the specific types of strategies used in these situations. Part (c) is an open ended question that allows caregivers to convey qualitative information about the strategies that they employ in response to children's sensory features; such strategies may be those that were modeled in therapies or as part of the caregiver's personal choices based on their problem solving in context with their child. An example of parts a-c of an item on the SEQ 2.1 includes: (a) How often does your child refuse new foods? (b) Do you attempt to change this behavior; and (c) If yes, please describe. For the current mixed methods analysis, we utilized quantitative data from parts (a) and (b) of the SEQ-2.1, and qualitative, descriptive text responses from caregivers from part (c) of the questionnaire.

Child Chronological and Mental Age

Child chronological age was calculated from the child's birthdate to the completion of the SEQ 2.1. A variety of measures were used to test the child's cognitive functioning, including the Bayley II- Mental Developmental Index (Bayley, 1993), Mullen Scales of Early Learning (Mullen, 1995), and/or the Leiter-R (Roid and Miller, 1997), depending upon the child's age and ability level. Mental age (MA) was derived directly from cognitive assessments or extrapolated from standard scores. All cognitive assessments were administered within 4 weeks within completion of the SEQ-2.1.

QUANTITATIVE DATA ANALYSIS

SPSS 17.0 was used to analyze quantitative data. Children's sensory scores were obtained from the SEQ 2.1 (part a) for each item and summed within the HYPER, HYPO, and SEEK scales. Similarly, caregiver strategy scores were obtained and summed from the SEQ 2.1 (part b) for each scale. First, we used t-tests to examine potential chronological and mental age differences between children with DD and ASD in the sample. Second, we used a series of regression analyses to examine: (a) the influence of children's scores on HYPER scales on the reported frequency of parent HYPER strategies; (b) the influence of children's scores on HYPO scales on the reported frequency of parent HYPO strategies; and (c) the influence of children's scores on SEEK scales on the reported frequency of parent SEEK strategies. In each model, we also tested the moderating effects of diagnosis (ASD, DD), chronological age, and mental age.

Lastly, we used chi-square tests to examine differences between caregivers that endorsed "Yes" vs. "No" for Part (b) on each of the SEQ 2.1 items (i.e., if caregiver used strategy in an attempt to change the child's behavior). This analysis allowed us to understand if strategy use significantly differed by item and by diagnosis (ASD, DD).

QUANTITATIVE RESULTS

The two diagnostic groups (ASD, DD) did not significantly differ on MA (p = 0.555) or CA (p = 0.356). Given that these child variables may influence caregiver strategy use, however, we tested the influence of MA and CA in regression models. Regression results are shown in **Table 2**. Overall, MA and CA did not demonstrate significant main or moderating effects on the association between sensory response pattern scores and rate of strategy use within each sensory response pattern, and were therefore removed from subsequent models. In other words, child chronological and mental age were not significant predictors of caregiver reported rate of strategy use within each sensory response pattern, showing that the significant predictors of caregiver reported strategies were the child's sensory response pattern scores and diagnostic category.

Next, we analyzed if the rate caregiver strategies (i.e., endorsements for attempts to change child behavior) differed

TABLE 2 | Strategy use as predicted by sensory response pattern scores.

	t	B	p	Adjusted R Squared
HYPO strategy use				
Hyporesponsiveness score	6.825	0.159	0.000	0.399
Diagnosis	3.289	0.112	0.001	
HYPER strategy use				
Hyperresponsiveness score	7.287	0.155	0.000	0.426
Diagnosis	2.520	0.062	0.013	
SEEK strategy use				
Seeking score	2.889	0.068	0.005	0.123
Diagnosis	2.189	0.074	0.031	

at the item level on the SEQ 2.1 (see **Table 3**). Ten items on the SEQ 2.1 showed there were significant differences in caregiver endorsement of strategies by diagnostic group, with caregivers of children with ASD reporting increased attempts to change children's behavior (e.g., avoid looking at face, flap arms, or hands) with specific strategies. Four items (i.e., *Refusal of new foods*, *Ignore being called by name*, *Shows distress during grooming*, and *Putting objects in mouth*) were endorsed highly (>50%) in both groups as situations where caregivers invoked various strategies in response to child sensory behaviors. Strategies for *Refusal of new foods* was the highest endorsed (85.7% of caregivers with ASD, 62.5% of those with DD), followed by strategies for *Ignore being called by name* (84.4% of caregivers with ASD, 62.5% of those with DD). Child sensory behaviors with the lowest reported endorsement of caregiver strategies included *Dislike being tickled* (3.9% of caregivers with ASD, 0% of those with DD) and *Ignore loud noises* (1.3% of caregivers with ASD, 2% of those with DD).

Qualitative Data Analysis

Given the non-significant interactions between diagnostic group and sensory response pattern, we analyzed the qualitative data with data from caregivers of children with ASD and DD combined. The quantitative analysis suggested the number of caregiver strategies were contingent on the level of sensory response pattern scores rather than diagnostic group. Therefore, thematic analysis was conducted by combining diagnostic groups and examining themes within sensory response patterns (hyperresponsiveness, hyporesponsiveness, sensory seeking).

ATLAS.ti 6.2 (Muhr, 2004) was used for data management and to support analysis of qualitative responses (i.e., text) from the SEQ-2.1 (part c) describing the nature of the types of strategies parents implemented. Each pattern was analyzed separately using thematic analysis as outlined by Braun and Clarke (2006) to characterize caregiver strategies within each sensory pattern. This iterative process of analysis began with individual team members reviewing all of the qualitative responses within sensory pattern while generating preliminary codes and initial ideas about the data. Through team discussion, the codes were then collated and further refined within each sensory response pattern and ideas surrounding broader themes were discussed. The codes and themes were again reviewed and discussed by the team. The iterative and reflexive process continued until codes and themes were agreed upon by all team members. The broader themes that best represented the data for each sensory response pattern were then further refined, defined, and named. Within each sensory response pattern, clear themes emerged that characterized caregiver strategies as follows.

QUALITATIVE FINDINGS

Hyperresponsiveness Sensory Pattern

Step by Step

Caregivers reported strategies that reflected a graded approach to reducing their children's aversive responses to everyday activities, and these strategies were meant to facilitate increased participation in the desired activity over time. Caregivers reported attempts to try to slowly introduce or break up the activity into small components to encourage participation. One caregiver reported, regarding her child's avoidance of touching certain textures, "*I try a little bit more each day as long as he does not get upset.*" In response to a question about her child's refusal of new foods, another parent indicated a graded approach to her child's picky eating: "*Try to offer new foods, eat them and enjoy them in front of him, have peers eat the same food.*"

Remove and Avoid

In contrast, this theme described a process by which caregivers implemented strategies during everyday activities aimed at removing the child from the aversive experience, extinguishing the aversive stimuli, or planning an activity to ensure the stimuli would not be present. Children's aversions to loud sounds elicited caregiver responses such as: "*Extinguish the source of the sound or try to move her away from it*" and "*Adjust volume, remove him from environment or give him some space further from it.*" Another caregiver reported, "*Try to have him go to a quieter place in the house if the vacuum is on.*" An example of a caregiver planning an activity to ensure the child would not be exposed to an aversive stimuli would be, "*[I] do not use the vacuum when he is home.*"

Whatever We Need to Do to Get Through It, Because It Has to Be Done

Caregivers reported that certain activities, regardless of their children's aversive responses, are necessary aspects of everyday routines. Caregivers subsequently did whatever they could to get through these activities with their children, and attempted any strategy aimed at completing certain tasks. With regard to a child's distress during grooming, one parent reported, "*Teeth brushing is the worst–we have been just fighting through it.*" Another caregiver reported that during grooming activities, "*Provide a lot of support; toys to hold onto during haircutting; Try to make teeth brushing as fun as possible; Brush his sister's teeth at the same time so he can see her do it.*" Caregivers described a determination for completing the activity in the presence of the child's strong aversive responses and providing support for the child when possible during completion.

Soothe and Comfort

Caregivers' implemented strategies aimed at simply calming or comforting the child during or in anticipation of aversive reactions. In response to a question about children's distress during loud conversations or singing, a caregiver reported, "*We just comfort and reassure him.*" Similarly, a caregiver expressed how they accommodate due to the child's aversive reactions to loud voices: "*Is frightened by men with loud voices (like his uncle). [He] cries when he is near. I try to tell him it's okay.*"

Hyporesponsiveness Sensory Pattern

Engagement

When children demonstrated HYPO behaviors (i.e., a lack of/delayed response to sensory stimuli during everyday activities), the strategies that caregivers reported emerged as one overarching theme: *Engagement*. Caregivers described

TABLE 3 | Item level results.

SEQ 2.1 item	Reported strategy use ASD, DD n (%)	X^2 (df, N)	*p*-value
Do you attempt to change your child's following behaviors. . .			
Refuse new foods[a] (HY)	66 (85.7), 25 (62.5)	8.208 (1, 117)**	0.004
Ignore called by name[a] (HO)	65 (84.4), 25 (62.5)	7.123 (1, 117)**	0.008
Avoid looking at face[a] (HY)	58 (75.3), 7 (17.5)	35.649 (1, 117)**	0.001
Show distress during grooming[a] (HY)	55 (71.4), 25 (62.5)	0.971 (1, 117)	0.325
Put objects in mouth[a] (SK)	48 (62.3), 26 (65.0)	0.080 (1, 117)	0.777
Startle to loud sounds (HY)	33 (42.9), 8 (20.0)	6.042 (1, 117)*	0.014
Ignore something new entering room (HO)	37 (48.1), 3 (7.5)	19.240 (1, 117)**	0.001
Ignore being tapped (HO)	31 (40.3), 8 (20.0)	4.862 (1, 117)*	0.027
Like to jump, rock, spin (SK)	23 (29.9), 5 (12.5)	4.363 (1, 117)*	0.037
Slow to notice new objects (HO)	23 (29.9), 2 (5.0)	9.691 (1, 117)**	0.002
Stare at objects (SK)	22 (28.6), 2 (5.0)	8.970 (1, 117)**	0.003
Flap arms or hands (SK)	19 (24.7), 1 (2.5)	9.134 (1, 117)**	0.003
Avoid touching certain textures (HY)	28 (36.4), 9 (22.5)	2.340 (1, 117)	0.126
Distress at loud conversation (HY)	19 (24.7), 6 (15.0)	0.226 (1, 117)	0.226
React negatively when touched (HY)	15 (19.5), 3 (7.5)	2.903 (1, 117)	0.088
Disturbed by too much light (HY)	14 (18.2), 5 (12.5)	0.625 (1, 117)	0.429
Dislikes cuddling (HY)	14 (18.2), 3 (7.5)	2.419 (1, 117)	0.120
Dislike being in water (HY)	13 (16.9), 4 (10.0)	1.004 (1, 117)	0.316
Slow to react to pain (HO)	11 (14.3), 3 (7.5)	1.151 (1, 117)	0.283
Seek out rough-housing (SK)	12 (15.6), 4 (10.0)	0.695 (1, 117)	0.404
Interested in way people smell (SK)	6 (7.8), 1 (2.5)	1.311 (1, 117)	0.252
Uneasy on a swing (HY)	5 (6.5), 3 (7.5)	0.042 (1, 117)	0.838
Notice sounds in environment (HY)	4 (5.2), 2 (5.0)	0.964 (1, 117)	0.964
Smell objects or toys, change behavior (SK)	4 (5.2), 2 (5.0)	0.002 (1, 117)	0.964
Dislike being tickled (HY)	3 (3.9), 0	1.599 (1, 117)	0.206
Ignore loud noises (HO)	1 (1.3), 2 (5.0)	0.230 (1, 117)	0.230

*[a] >50% of participants in one diagnostic group reported strategy use; *<0.01; **<0.05; HR, hyperresponsivness; HO, hyporesponsiveness; SK, sensory seeking.*

strategies to promote their children's involvement in various everyday activities and these efforts reflected a desire to increase their children's interactions with individuals. Two subthemes described strategies within this broader theme, including: *Persistence Using Multiple Strategies to Engage* and *Explanation and Encouragement Surrounding Engagement.*

Caregivers of children with ASD and DD reported that they utilized a number of different strategies in an attempt to gain a response from their child, sometimes increasingly salient in nature, which were labeled as *Persistence Using Multiple Strategies to Engage*. In response to a question regarding the child's ignoring his name being called, one caregiver reported that she "*speaks[s] louder; claps hands; go get him; make eye contact.*" In response to the child appearing to ignore someone new entering the room, a caregiver reported, "*I always let him know who's coming; introduce him; ask him to say "Hi".*" Strategies within this theme reflected a sequence of strategies that caregivers used specifically to elicit engagement from the child.

In contrast, the second subtheme reflected caregivers' efforts to encourage engagement through explanation and support. For instance, in response to a child's ignoring name call, a caregiver reported, "*We remind him to look and listen.*" Another caregiver related, "*Explain that she needs to respond when called.*" One caregiver explained, when her child ignores or tunes out loud noises, "*I point out that which has happened and why.*" Caregivers used strategies that provide the child with knowledge and encouragement primarily through verbal input.

Sensory Seeking Pattern

Do Not Do It

This theme reflected caregivers' efforts to directly limit or constrain children's sensory seeking behaviors. The strategies reported in SEEK conveyed that such child behaviors are not tolerated, and caregivers reported efforts to stop the behaviors after the child had begun to engage in them. For example, in response to her child mouthing non-food items, a caregiver reported, "*Make him spit them out and explain it's not safe to put anything not food in his mouth.*" In response to a similar question, another caregiver related, "*[I] tell him "NO".*"

Redirect and Replace

As opposed to efforts to directly eliminate sensory seeking behaviors, this theme reflected caregivers' strategies aimed at either altering the child's behavior into something socially acceptable or substituting the behavior for another way to meet the child's sensory needs. At times, caregivers would encourage a different behavior or direct the child to a different activity. With regard to a child's hand flapping, one caregiver reported that she attempted to redirect by "*diverting [his] attention, put something* *in [his] hands.*" Another caregiver reported that in response to her child's flapping, she will "*try to redirect him.*"

It's Okay. . .Sometimes

The last theme reflected how caregivers attempted to meet their child's sensory seeking behaviors within specific limits, and how some children may be allowed to engage in sensory seeking behaviors in certain contexts or at certain times. For instance, in response to children's jumping, one caregiver reported that she stopped the behavior "*Only if it's out in public or he could get hurt–I ask him to stop–he usually does.*" Another caregiver allowed her child to jump in a specific environment, the child's room, and constructed that setting specifically for sensory seeking behaviors: "*His room has been emptied out of all furniture and replaced with crash pad, foamies, and bop toys.*"

DISCUSSION

This study used a mixed methods approach to examine caregiver strategies based on children's sensory response patterns. Novel findings from this study showed that regardless of a child's diagnosis (ASD or DD), higher levels of children's sensory behaviors were associated with significantly increased use of caregiver strategies to address the sensory experiences. Interestingly, we found that the association between sensory response pattern and caregiver strategy use was not significantly influenced by mental or chronological age in this sample of children with ASD and DD. This finding suggests that there may be universal qualities about children's responses to sensory stimuli that elicit caregiver involvement regardless of the children's overall child cognitive or developmental level among those with developmental conditions.

Quantitative results suggested that the level of children's hyperresponsiveness, hyporesponsiveness, and sensory seeking, but not necessarily their diagnostic group, were significant predictors of the amount of caregiver strategies used during everyday activities. Item level analyses revealed that caregivers of children with ASD and DD implemented similar rates of strategies in response to specific child behaviors, aligned with hyperresponsiveness (e.g., refusal of new foods) and hyporesponsiveness (e.g., ignoring name being called). Contrastingly, there may be behaviors that align with the diagnostic features of ASD that caregivers attempt to increasingly change (e.g., avoid looking at face), which contributed to the significant differences in rate of item level strategies among diagnostic groups. Clearly, some behaviors associated with sensory response patterns are more acceptable to caregivers, as they reported low use of strategies (e.g., avoiding certain textures) to intervene in these situations. Also, certain strategies may be easier to implement during daily routines (e.g., not purchasing clothing of certain textures), and caregivers may learn over time to structure children's activities and environments to match their children's sensory preferences and aversions.

Findings pointed to the ways that caregivers implemented different types of strategies based on the three sensory response patterns. While some research suggests that parents use strategies in response to children's overall sensory processing differences (Kirby et al., 2016), results from this study suggest that the *types* of strategies used within each sensory response pattern are distinct. Thus, strategies used to support children when they display hyperresponsiveness in daily activities are qualitatively different from those strategies used for hyporesponsiveness or sensory seeking behaviors.

Thematic analysis further revealed the type and range of strategies caregivers may employ to help children cope with hyperresponsiveness to sensory stimuli during daily activities. Previous research has demonstrated that specifically among children with ASD, children's aversive responses to sensory stimuli during meal times and grooming present particular challenges for caregivers (Kientz and Dunn, 1997; Tomchek and Dunn, 2007). Item analysis findings in the current study aligned with these previous findings, and showed that children's refusal of new foods and distress during grooming are areas in which caregivers highly endorse as having to implement strategies. Further, our analysis extended previous research by suggesting adaptive strategies are implemented similarly across diagnoses to help children cope with sensory-laden situations that trigger hyperresponsiveness. In some situations, caregivers may eliminate (i.e., *Remove and Avoid)* elements of activities that elicit severe discomfort. In other situations, caregivers employ strategies that systematically expose their children (i.e., *Step by Step)* and gradually desensitize them over time so they can more fully participate in these activities.

While previous research has focused on hyperresponsiveness among children with ASD and DD in the context of daily activities, fewer studies have focused on hyporesponsiveness. Harrop et al. (2018) reported that caregivers of minimally verbal children with ASD most frequently reporting prompting, followed by redirection strategies. Aligned with these findings, qualitative and quantitative results from this study revealed the value caregivers place on their child's active involvement in daily activities and social interactions in the presence of hyporesponsiveness. The child's degree of hyporesponsiveness significantly predicted the amount of strategies that were implemented by caregivers. *Engagement*, a salient theme from the qualitative data, characterized the ways in which caregivers of children with ASD and DD responded to their children's hyporesponsiveness, implementing two different intensities of strategies (verbal and/or multi) to initially facilitate the child's response, as well as explanation and encouragement to maintain their child's participation in everyday activities.

Qualitative analysis revealed that caregivers may respond to children's sensory seeking behaviors in a number of ways, including allowing or encouraging behaviors, encouraging replacement behaviors, or attempting to eliminate such child behaviors. Studies have characterized children's sensory seeking as a fascination or intense interest in the sensory elements of activities (Dunn, 2007; Boyd et al., 2010; Kirby et al., 2017), however, previous research on the ways in which sensory seeking impacts families' activities and the strategies that they use is limited. Thematic analysis suggested that caregivers may be implementing fewer strategies in response to their children's sensory seeking behaviors if they interpret the child's behaviors as pleasurable or serving a regulatory purpose. If caregivers perceive a child's sensory seeking behaviors as pleasurable or regulatory, or perhaps as having a shared meaning with the caregiver (Bagby et al., 2012), they may be less likely to implement strategies to limit such child behaviors. Previous research (Spitzer, 2003) reported that a mother perceived her child's sensory seeking behaviors as a way in which to engage with her non-verbal child, and emerging evidence from autistic self-advocates suggests that sensory seeking behaviors serve specific purposes (e.g., Ekblad and Pfuhl, 2017). Conversely, the theme *Do not Do It* suggests that select caregivers may not tolerate certain sensory seeking behaviors for various reasons, and implement strategies in an attempt to eliminate these behaviors. For example, some caregivers may perceive that a particular sensory seeking behavior poses danger to a child (e.g., mouthing non-food items) or others may find a behavior (e.g., flapping, spinning in public contexts) to be inappropriate or disruptive to their family's social situation. Although caregiver interpretations of the function of their child's sensory seeking behaviors were beyond the current investigation, future research may further illuminate how such perceptions influence caregivers' strategies.

Limitations and Future Directions

There are several limitations of this work. First, the SEQ 2.1 was the only instrument used in this study and utilized a written parent-report format; future studies could incorporate observational methods as well as in-depth interviews to corroborate or expand upon these findings. Second, we described the amounts and types of strategies used for each sensory response pattern, but could not evaluate the relative effectiveness of these strategies, which could be expanded upon in future studies. Evidence has shown that the three sensory response patterns often co-occur (Ben-Sasson et al., 2007; Ausderau et al., 2016) and that varying sensory related subgroups show differential outcomes (Ausderau et al., 2016; Tomchek et al., 2018), thus future studies could assess the degree to which caregiver strategies differ across subgroups of children with mixed patterns of response, and how these strategies may moderate outcomes. Future mixed methods research may further explore how caregivers' attitudes, beliefs, and other psychological characteristics (e.g., levels of stress) influence the types of strategies used in the context of their children's sensory response patterns, and their relative effectiveness to support children's engagement in daily activities and overall participation. Lastly, the current research does not delineate how caregivers learned the strategies that they reported to employ in response to children's sensory features. Future studies may investigate the extent to which enrollment in different types of therapies (e.g., occupational, physical, speech therapies) influence the frequency and type of strategies in which caregivers use.

DATA AVAILABILITY STATEMENT

The data supporting the results and analyses presented in this article will be made available by the authors, upon reasonable request.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of North Carolina at Chapel Hill. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

GB: data collection. All authors: study conception, design, analysis and interpretation of results, draft manuscript preparation, reviewed the results, and approved the final version of the manuscript.

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Conflict of Interest: GB is the author of the Sensory Experiences Questionnaire version 2.1 but receives no royalties since it is freely available.

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Relationship Between Childhood Sensory Processing Differences and Quality of Life as Adults

Teresa A. May-Benson[1]*, Alison Teasdale[2] and Olivia Easterbrooks-Dick[2,3]

[1] TMB Educational Enterprises, LLC, Norristown, PA, United States, [2] SPIRAL Foundation, Newton, MA, United States, [3] OTA The Koomar Center, Newton, MA, United States

Research suggests a relationship between sensory processing, motor skills and quality of life (QOL) in a variety of clinical populations of adults and children. There have been no studies which investigated the relationship of childhood sensory processing and integration and related motor performance (sensori-motor) patterns identified using an Ayres Sensory Integration® (ASI) frame of reference and later QOL of those children as adults. This longitudinal follow-up study examined this relationship. Adult QOL was also examined in relation to current adult sensori-motor patterns. Fifty-three adults who received occupational therapy services as children, were identified as having sensori-motor difficulties at that time and completed a sensory history and a quality-of-life measure as adults participated. Measures included the *OTA the Koomar Center Sensory History (SXHX)*, *Adult/Adolescent Sensory History (ASH), and the World Health Organization Quality of Life-Brief* (*WHOQOL-BREF*). MANCOVA found that Total childhood sensori-motor scores had a small relationship to Physical Health QOL as adults that approached significance. Pearson Correlations found that adults with childhood sensori-motor challenges who report sensori-motor challenges as adults had a moderate significant relationship among overall sensori-motor functioning and Physical Health ($r = -0.56$, $p = 0.018$). Visual ($r = -0.76$, $p = 0.001$), movement (vestibular; $r = -0.48$, $p = 0.042$) and tactile processing ($r = -0.63$, $p = 0.008$) had moderate to large significant relationships with Physical Health. Visual processing ($r = -0.54$, $p = 0.024$) was also significantly related to Psychological Health. Motor Coordination trended to significance for Physical Health ($r = -0.42$) and Psychological Health ($r = -0.41$). Conversely, adults who reported typical sensori-motor scores as adults, despite childhood sensori-motor challenges, had a good QOL. Furthermore, similar to previous research, there was a relationship between current visual, movement (vestibular) and tactile (touch) sensory processing and adult Physical and Psychological Health. A multivariate linear regression found Sensory Discrimination and Modulation accounted for one-quarter of the variance in QOL in adults with only Discrimination being statistically significant. Therefore, it is important to consider childhood sensori-motor function as well as adult functioning when examining QOL. Further, heretofore unexamined Sensory Discrimination was found to play a role in adult QOL.

Keywords: sensory processing, quality of life, longitudinal, motor coordination, physical health

Edited by:
Antoine Bailliard,
Duke University,
United States

Reviewed by:
Ashley Mason,
Ithaca College,
United States
Helen Lynch,
University College Cork, Ireland
Elysa Jill Marco,
Cortica, United States

***Correspondence:**
Teresa A. May-Benson
tmb@tmbeducation.com

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INTRODUCTION

Occupational therapists using an Ayres Sensory Integration® (ASI) frame of reference who work with children experiencing sensory processing and integration challenges typically treat children with a variety of diagnoses including ADHD, Autism Spectrum Disorder, trauma and attachment disorder and mental health conditions (Bundy and Lane, 2020). However, ASI intervention was originally designed to address sensory processing and integration problems with related motor performance challenges, such as postural control and praxis challenges, (Ayres sensori-motor patterns) in children with learning disabilities and those with no other diagnoses (Ayres, 1972). Application of this model of intervention rapidly spread to use with other diagnoses and in recent years the majority of research on ASI has been focused on children with ASD and the population of children with Ayres sensori-motor challenges who have no other diagnoses has been largely ignored. Particularly with this population of children without other diagnoses, clinicians report that parents question how these sensori-motor challenges may impact the long-term health, well-being and social participation success of their children (Cohn et al., 2000). Thus, an important aspect of evidence-based practice is examination of the prognosis of a given disorder or difficulty on later performance of functional skills, health and well-being. There is little to no such prognosis information available in any area of functioning regarding children with Ayres sensori-motor challenges, particularly those with no other diagnoses.

A few studies have examined the longitudinal outcomes of various sensory processing and integration patterns in children over the course of relatively short periods of time extending approximately 2–6 years (McCormick et al., 2016; Perez Repetto et al., 2017; Baranek et al., 2019). No studies, however, have followed children with known sensory processing and integration challenges (and related postural and motor challenges) into adulthood to examine potential long-term implications of these childhood sensori-motor challenges. The authors of this paper have endeavored to follow-up with children with known Ayres sensori-motor challenges who had no other known diagnoses to examine various aspects of adult functioning in these individuals over a period of five to 25 years. Sensori-motor functioning, diagnoses, education, employment, and quality of life (QOL) were areas of particular interest as they are areas of long-term concern frequently expressed by parents in clinical practice. Detailed results of this follow-up study regarding changes in sensori-motor functioning from childhood to adulthood and relation to education and employment will be presented elsewhere. This paper will examine the relationship of childhood patterns of Ayres sensori-motor challenges and adult sensori-motor characteristics as they relate to adult QOL. The authors sought to determine if early sensori-motor characteristics were related to or could predict adult QOL and to examine what adult QOL is like in adults who have known childhood Ayres sensori-motor challenges whether those sensori-motor characteristics are still present in adulthood or not. In this paper, the terms sensori-motor patterns and sensori-motor characteristics will refer specifically to sensory processing and integration (and related postural and motor skills) characteristics and patterns identified using an ASI theoretical model and will inclusively refer to individuals with patterns of sensory modulation, sensory discrimination, and postural control/motor performance/praxis function.[1] Further, although there continues to be some debate about terminology regarding motor performance patterns referred to variously as dyspraxia, praxis challenges or developmental coordination disorder (DCD), recommendations by Gibbs et al. (2007) suggest that examination of literature across these diagnostic labels can be useful.

LITERATURE REVIEW

Quality of life (QOL) is a concept that has been identified by the World Health Organization to approach health from a holistic lens, which considers the impact of disease or impairment on areas such as daily activities, behavior, and perceived health (World Health Organization, 1996). It is considered a primary indicator of overall health and wellness. The World Health Organization (WHO) defines QOL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 2022). Aspects of QOL include current physical and psychological health, social relationships, and environmental components (World Health Organization, 1996). Further, QOL has been defined in different ways and may be influenced by numerous factors across the lifespan including medical diagnoses, cardiorespiratory and muscular fitness status, social support and participation (Tal-Saban et al., 2014; Engel-Yeger et al., 2016; Wallander and Koot, 2016; Lin and Huang, 2019; Jovellar-Isiegas et al., 2020; Bermejo-Cantarero et al., 2021; Costa-López et al., 2021; Lestari et al., 2021).

Studies examining sensory processing and integration differences (including related praxis and motor challenges) as defined by a number of theoretical frameworks (e.g., Ayres Sensory Integration®, Dunn's Model of Sensory Processing, developmental coordination disorder) have identified sensory and motor factors that may impact QOL in both children and adults (Kinnealey et al., 2011; Lin and Huang, 2019; Costa-López et al., 2021). Costa-López et al. (2021) conducted a systematic review of 14 studies examining sensory processing and QOL. All but one study examined adults and the remaining

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[1] Dr. A. Jean Ayres, occupational therapist, developed the theory, assessment, and intervention for the field of occupational therapy practice known as Ayres Sensory Integration®. Ayres described two primary constructs of sensory integration: praxis (which depends on sensory discrimination) and sensory modulation (Bundy and Lane, 2020). Praxis, in sensory integration theory, is referred to as the ability to generate ideas for, plan and execute novel movements, and involves postural control, somatosensory processing, and bilateral integration and sequencing (Bundy and Lane, 2020). Sensory modulation involves sensory defensiveness, gravitational insecurity, aversive responses to movement, and under responsiveness to sensation (Bundy and Lane, 2020). Collectively, these sensori-motor functions are commonly referred to as sensory processing and integration and are thought to form the foundation for adaptive behavior, functional performance of daily occupations and ultimately are believed to be related to overall quality of life (QOL) in children and adults.

article examined adolescents. While studies which examined QOL in children and adolescents have been conducted, these have exclusively examined children and adolescents with various physical disabilities or medical conditions such as cerebral palsy (Makris et al., 2021), asthma (Kouzegaran et al., 2018), traumatic brain injury (Di Battista et al., 2012), disease conditions (Wolf et al., 2018; Wardoku et al., 2019; Marschner et al., 2020) and trauma and mental health challenges (Bastiaansen et al., 2020; Lawson et al., 2020; Pinto et al., 2021). A number of studies have examined QOL in children with autism with or without specifically identified sensory processing challenges (Benen Demchick et al., 2014; Chuang et al., 2014; Xu et al., 2019; Leader et al., 2021; Oakley et al., 2021). However, to date no studies have been located which examine QOL in children with only Ayres sensori-motor challenges and none have examined the relationship between these early sensori-motor challenges and later adult QOL.

Research on sensory processing and QOL has been conducted primarily on those groups with sensory modulation or sensory-over-responsivity patterns largely using Dunn's (1999) or Miller et al. (2007) models of sensory processing. No studies were found that examined sensory discrimination patterns in relation to QOL in either children or adults. Studies have been conducted on the relationship of various patterns of sensory processing to QOL in groups with and without additional medical diagnoses, including mental health diagnoses such as bipolar disorder (Engel-Yeger et al., 2016); autism (Lin and Huang, 2019); and cerebral palsy (Jovellar-Isiegas et al., 2020). Results found some similarities and differences in the sensory processing patterns of these different groups and their patterns of QOL. Lin and Huang (2019) found that autistic adults with sensory processing challenges scored significantly lower on QOL measures than their neurotypical counterparts. These autistic adults scored higher (more dysfunctional) on the four sensory processing quadrants defined by Dunn than the neurotypical group and had higher levels of anxiety (Lin and Huang, 2019). High sensory sensitivity was also related to decreased performance in both the Physical and Psychological Health domains of QOL for this group of autistic adults (Lin and Huang, 2019). Further, Kinnealey et al. (2011) investigated the relationship of sensory modulation and health-related quality of life (HRQOL) in adults without clinically diagnosed mental health conditions or confounding medical diagnoses and found that three out of four sensory processing patterns (sensory sensitivity, sensory avoiding, and low registration) were correlated with role emotional and mental health factors of HRQOL. In this study, a sensory over-responsive group had similar HRQOL as a non-sensory-overresponsive group in the areas of "physical functioning, role physical, role emotional, and mental health," however, there were significant differences in the areas of "bodily pain, general health, vitality, and social functioning" (Kinnealey et al., 2011, p. 325). In a group of college students, Hwang et al. (2021) found that individuals with low registration and sensory sensitivity were negatively correlated with QOL and resilience, except for the social domain. More recently, Costa-López et al. (2021) conducted a systematic review to better understand the relationship between sensory processing and QOL. This review found that high sensitivity to sensory stimuli may have a negative impact on QOL. Overall, these findings support a relationship between aspects of current sensory processing and QOL in adults.

Some studies examined the relationship of motor performance challenges and QOL (Caçola and Killian, 2018; Engel-Yeger, 2020). No studies were found which specifically examined praxis or motor performance challenges as identified by ASI; however, studies were located which examined DCD and QOL. These studies can inform this topic as praxis, as conceptualized within ASI theory, is viewed by many as a subtype of DCD (Vaivre-Douret et al., 2016) and Gibbs et al. (2007) suggest that labels of DCD and dyspraxia essentially identify the same children. This view was further supported by Cermak and May-Benson (2020). In addition, Allen and Casey (2017), Chung (2018), Delgado-Lobete et al. (2020), and Mikami et al. (2021) found relationships between sensory processing difficulties and individuals with DCD, supporting the presence of sensory processing and integration difficulties in individuals with motor coordination challenges. The relationship of motor performance challenges and aspects of QOL was noted as children with DCD were found to have lower HRQOL (Redondo-Tébar et al., 2021) and leisure activity levels (Raz-Silbiger et al., 2015) than their typically developing counterparts. Young adults with DCD also scored lower than a control group on QOL, overall participation, and life satisfaction, with the Psychological Health domain of the *WHOQOL-BREF* being a significant predictor of life satisfaction (Tal-Saban et al., 2014). Another study of adults with DCD revealed that although current levels of motor coordination did not predict QOL in this population, three behaviors potentially related to praxis challenges (avoidance, work/school impairment, social impairment) demonstrated by this group did predict QOL scores (Forde and Smyth, 2021). Further, Engel-Yeger (2020) suggested that early motor skills performance impacted later QOL. Thus, these findings suggest that sensori-motor challenges may impact aspects of QOL in both children and adults.

Much of the available research investigating relationships between various sensori-motor patterns and QOL in individuals without additional clinical diagnoses examined QOL at the group's current age, either in childhood or adulthood. To our knowledge, there are no studies that investigate the QOL of adults who were identified as having documented childhood sensori-motor challenges. In addition, much of the research available examined only the construct of sensory modulation, which was found to impact QOL. Little evidence exists examining sensory processing in general, praxis with its related features, and QOL in individuals without additional clinical diagnoses. Since we know that adults with DCD have decreased QOL related to their motor coordination challenges, it is important to investigate the relationship between all sensori-motor constructs as defined by Ayres (Bundy and Lane, 2020) and QOL in individuals with sensori-motor challenges without other diagnoses.

The purpose of this study was to examine the relationship between early childhood sensori-motor patterns and QOL in adulthood. In addition, current QOL in adulthood as related to current sensori-motor patterns was examined in this group of individuals with known sensori-motor challenges as children.

Research hypotheses were:

1. There will be a significant relationship between childhood sensori-motor characteristics and QOL in adulthood in individuals with childhood sensori-motor challenges (i.e., poorer sensori-motor functioning will be associated with poorer QOL).
2. There will be a significant relationship between adult sensori-motor characteristics and current adult QOL in individuals with childhood sensori-motor challenges (i.e., poorer sensori-motor functioning will be associated with poorer QOL).

MATERIALS AND METHODS

This study was approved by the Spiral Foundation Institutional Review Board, protocol #1039. Informed consent, including permission to access clinical records, was obtained from all adults who participated. All information was collected in accordance with the Office of Human Rights Protection and all HIPAA protections for privacy of protected personal information were observed.

Procedures

Information for this study was obtained from a larger longitudinal follow-up study conducted by the authors on adults with known sensori-motor challenges with no other known diagnoses who received ASI-based occupational therapy services from a private occupational therapy clinic as children. For the current study, individuals' childhood sensori-motor data (obtained at clinical intake) were matched to their current data as an adult using name and date of birth. Childhood information was provided by the individuals' parent/guardian and was retrieved retrospectively from the children's clinical records. Adult information was provided by the individuals themselves by completing an online survey as part of the larger longitudinal follow-up study. Sensori-motor characteristics are known at childhood clinical intake and 5–25 years later as an adult. A QOL measure is only available as an adult.

Recruitment for Follow-Up Study

Former clients, identified from clinical records, eligible to participate in the larger follow-up study were individuals identified with sensori-motor differences as children but whom had no other diagnoses at the time of clinical intake. All client materials were accessed and handled in accordance with HIPAA regulations. Inclusion criteria for the follow-up study were: the child was <18 years of age at time of initial services, parent and/or the adolescent completed the practice's sensory history (which included motor and social skills) at intake, had no diagnoses except sensori-motor challenges as reported on the sensory history, was currently aged 18–50 years at time of the follow-up study, was discharged from occupational therapy services prior to 2014, and contact information could be located.

The 1,305 eligible participants were identified via a clinic database of 4,556 records of former clients. Information on the client's name, date of birth and discharge year was accessed. Individuals were divided into 5 groups based on discharge year to ensure that recruitment efforts across time would be roughly equal. Each group consisted of a 5-year time frame. The first group included individuals who initiated services 5–10 years prior to the start of the study and proceeded to the last group which included individuals whose initial services were > 25 years prior to the study. Within each group, names were placed in a randomized order (to ensure randomized selection of potential participants) and records screened for eligibility. Records that did not meet inclusion criteria were removed. Names, addresses and phone numbers of the client's parents were extracted from the clinical records. Only 89 individuals in the 2009–2013 group were eligible, all were invited to participate. It was not possible to locate contact information for 33 individuals.

Once parent contact information was obtained, publicly available information from the internet was used to update the child's contact information (e.g., parent's name and address were searched in the publicly available white pages which lists other individuals living or associated with that address). Invitations were sent to the now-adult child at the obtained address. The invitation letters came from the clinical practice who invited their previous clients to participate in a research study conducted by the SPIRAL Foundation. By the end of the recruitment phase 1,272 individuals had been invited to participate in the research. The post office returned 117 invitations with no forwarding address. $N = 102$ (response rate of 8.8% of non-returned invitations) individuals completed one or more sections of the *Adult/Adolescent Sensory History* (ASH) and therefore were eligible for inclusion in the larger follow-up study. The online survey was completed on Qualtrics, which is secure and HIPAA compliant. Participants were asked to complete an informed consent document which included permission to access their childhood clinical records, a demographics form (which included self-report of current diagnoses), the *ASH* and the *WHOQOL-BREF*.

Participants

Participants in the current study were individuals who participated in the follow-up study of former clients of a private occupational therapy clinic specializing in Ayres Sensory Integration® services. All participants received sensory integration-based occupational therapy services (e.g., evaluation and/or intervention) at the clinic between 1983 and 2013; and fully or partially completed a follow-up survey. Inclusion criteria for this study was that the adult completed the demographics, *ASH* and *WHOQOL-BREF* portions of the follow-up survey ($N = 62$). Exclusion criteria was that the adult self-reported a current diagnosis of ASD ($n = 9$) leaving a sample size of $N = 53$.

At time of initial childhood services, the current study sample was $M = 7.1$ years, $SD = 3.4$ years of age. At follow-up the group was $M = 26.9$, $SD = 5.5$ years of age. At clinical intake individuals had no reported diagnoses other than sensori-motor difficulties. As adults, 26 individuals reported no diagnoses and 27 reported one or more conditions of ADHD, anxiety, and/or depression. For analysis purposes, this Total Group was further divided into adults who currently reported typical sensori-motor functioning (Typical Group: $n = 26$), those who currently reported mild sensori-motor challenges (Mild Difficulties Group: $n = 13$) and those who currently reported definite sensori-motor challenges (Definite Difficulties Group: $n = 14$) based on performance on the *Adult/Adolescent Sensory History* (May-Benson, 2015). See **Table 1** for participant demographics. In addition, the Total Group was divided into those with self-reported diagnoses as adults and those with no reported diagnoses for some analyses.

Measures

As noted above, one childhood measure of sensori-motor functioning and two adult measures, one of sensori-motor functioning and one of quality of life, were completed.

Childhood Measure

OTA the Koomar Center Sensory History (*SXHX*). The *OTA the Koomar Center Sensory History* consists of several comparable versions of a parent-report clinical sensori-motor history measure used in a sensory integration clinic to provide detailed information on the sensory processing and integration, motor (praxis) and social–emotional functioning of children and adolescents who experience sensori-motor difficulties. Various versions of the measure are appropriate for individuals from infancy to 18-years of age. Most versions included check boxes for reporting the presence of common diagnoses found to be comorbid with sensori-motor challenges (e.g., ADHD/ADD, Anxiety, Depression, Autism/Pervasive Developmental Disorder, and Learning Disabilities/Non-Verbal Learning Disorder) with an early version which only included a write-in response for reporting of diagnoses. Each version of the measure included comparable sensori-motor questions divided into the sensory areas of visual spatial, auditory, movement (vestibular), taste and smell, tactile processing, motor coordination, and a social emotional section. A 3-point Likert scale (1 = Never/Rarely, 2 = Sometimes and 3 = Often/Always) was used for all ratings except a few versions of the school-aged *SXHX*. All ratings were converted to a 3-point scale for analysis as needed. Comparability of the 3-point and 5-point scales has been examined by the authors in previous analyses. The *SXHX* is a clinical tool which has not been standardized (OTA The Koomar Center, 1981, 1993, 2004, Unpublished Measure). The school-aged *SXHX* with a 5-point response scale has strong concurrent validity with the *Sensory Profile* (Dunn, 1999) for this population with Total Score on the *SXHX* and the *Sensory Profile* having a Pearson correlation coefficient of −0.80, $p < 0.001$, individual sensory, motor, and social emotional sections have Pearson *r*'s of −0.41 to −0.81, *p*'s < 0.001 with equivalent sections on the *Sensory Profile* (May-Benson, et al., Unpublished Data). For comparison with *ASH* scores, scores on the *SXHX* were calculated for Total Score and the following section scores: Visual/Spatial Processing, Auditory/Language Processing, Movement (Vestibular), Taste/Smell, Touch, Motor Coordination, and Social/Emotional Functioning. On this measure, low scores indicate more typical sensori-motor functioning.

TABLE 1 | Demographics of Total adult group and *ASH* subgroups.

	Total group	Typical functioning	Mild difficulties	Definite difficulties
Gender				
Male	*n* = 32 (60%)	*n* = 9 (35%)	*n* = 5 (39%)	*n* = 7 (50%)
Female	*n* = 21 (40%)	*n* = 17 (65%)	*n* = 8 (62%)	*n* = 7 (50%)
Intake age	*m* = 7.1 years *sd* = 3.4 years Range 1.3–16.0 years	*m* = 6.5 years *sd* = 3.5 years Range 1.3–15.8 years	*m* = 6.8 years *sd* = 2.8 years Range 3.2–12.9 years	*m* = 8.4 years *sd* = 3.2 years Range 4.3–16.0 years
Current age	*m* = 26.9 years *sd* = 5.5 years Range = 18–39 years	*m* = 26.4 years *sd* = 4.7 years Range = 18–34 years	*m* = 27.1 years *sd* = 6.8 years Range = 18–39 years	*m* = 27.7 years *sd* = 5.7 years Range = 18–35 years
Education				
High school	*n* = 8 (15%) (*n* = 7[1])	*n* = 4	*n* = 2	*n* = 2
Some college/ associates	*n* = 10 (19%) (*n* = 5[1])	*n* = 4	*n* = 5	*n* = 1
Bachelors	*n* = 20 (38%) (*n* = 4[1])	*n* = 11	*n* = 4	*n* = 5
Post graduate	*n* = 12 (23%) (*n* = 3[1])	*n* = 5	*n* = 2	*n* = 5
Doctoral/ post-doctoral	*n* = 3 (6%)	*n* = 2		*n* = 1
ASH total score	*m* = 355, *sd* = 93.0	*m* = 282, *sd* = 55.0	*m* = 377, *sd* = 20.1	*m* = 471, *sd* = 53.4
SXHX total score[2]	*m* = 1.7 *sd* = 0.34	*m* = 1.7 *sd* = 0.29	*m* = 1.8 *sd* = 0.23	*m* = 1.8 *sd* = 0.29

[1] *Denotes number of the group pursuing next level of education full time.*

[2] *No statistically significant difference between groups F(2,50) = 1.26, p = 0.293.*

Adult Measures

World Health Organization Quality of Life-Brief (WHOQOL-BREF). The *WHOQOL-BREF* is a 26-question measure for adults responded to on a 5-point Likert scale based on the participants' experiences during the previous 2 weeks. There is no total score, but scores are obtained for four domains: Physical Health, Psychological Health, Social Relationships, and Environment. There are three to seven items per domain, which are summed then scaled to be directly comparable to the *WHOQOL-100*. On this measure, high scores indicate better QOL. The *WHOQOL-BREF* has good discriminant and content validity, internal consistency and discriminant reliability (Skevington et al., 2004).

Adult/Adolescent Sensory History. The *ASH* (May-Benson, 2015) is a standardized 163-item self-report questionnaire for ages 13–95 years. The *ASH* is based on Ayres Sensory Integration® model of sensori-motor functioning that assesses behaviors thought to reflect sensory processing in various sensory systems, sensory modulation, sensory discrimination, praxis/postural challenges and social/emotional functioning. Items are rated on a 5-point Likert scale (1 = Never, 5 = Always). *ASH* items assess functioning in the following areas: Visual/Spatial Processing, Auditory/Language Processing, Movement (Vestibular), Taste/Smell, Touch, Proprioception, Postural Control, Motor Coordination Skills (praxis), and Social/Emotional Functioning. Results include a Total Score, individual subscores for each sensory processing and integration/motor/social area as well subscores for sensory modulation and sensory discrimination functions. Only Total Score, Modulation, Discrimination and individual sensory processing and integration/motor/social subscores are reported here. All scores are categorized based on Typical (score range up to +1.0 SD), Mild Difficulty (score range of +1.0 to +2.0 SD), and Definite Difficulty (greater than +2.0 SD) performance. On this measure high scores indicate more dysfunction. All subscores were validated through factor and Rasch analysis of items (May-Benson, 2015). Internal consistency of the Total Score and sensory sections using Cronbach's Coefficient Alpha was 0.80–0.97. The *ASH* has good inter-rater ($r = 0.68$ for Total score and 0.39–0.77 for subscores) and test-re-test reliability ($r = 0.85$ for Total Score and 0.74–0.87 for subscores; May-Benson, 2015).

Data Analysis

Demographic data and level of sensori-motor functioning were summarized using means, standard deviations, frequency counts and percentages. Due to varying childhood sensory history versions and differences in numbers of items in sections, mean item scores on a 1–3 scale were used to describe participants' childhood sensori-motor patterns. The number of scored items on the *SXHX* ranged from 26–149 ($m = 117$, $sd = 14.4$). *ASH* scores were used to describe current level of sensori-motor functioning. Independent two sample t-tests were used to compare the QOL domain scores from the study sample to the US sample from the *WHOQOL-BREF* field trial (Skevington et al., 2004). Multivariate analysis of covariance (MANCOVA) was completed to examine potential relationships between the four domains of QOL, demographic variables and participants' childhood and current level of sensori-motor functioning. Results of this MANCOVA led to subsequent analyses being completed on the Total adult Group and on three sub-groups consisting of adults who currently report Typical sensori-motor functioning and those who currently report characteristics of Mild and Definite sensori-motor challenges. One-tailed Pearson Correlation analysis was used to further examine all relationships. As study hypotheses stated that sensori-motor characteristics indicating dysfunction would be associated with poorer QOL, correlations were expected to be negative given the scoring of the two measures. In addition, two multivariate linear regressions were also completed on the adult ASH and WHOQOL-BREF data. Analysis was conducted using SPSS v22 (IBM Corp, 2013).

RESULTS

Demographics

Mean age at intake of the Total Group was 7.1 years as expected based on the demographics of the larger follow-up study, and current age was 27 years. Females were more likely to respond to the follow-up study invitation and be eligible for the current study than males. Thus, participants were slightly more likely to be female than expected (e.g., 40% female in the study sample compared to approximately 20% of individuals sent invitations to participate). While all participants had no known diagnoses as children, as adults, 51% of participants reported a diagnosis of ADD/ADHD, Anxiety and/or Depression. The Total Group reported an overall upper-middle to high SES-equivalent level as they were either still in full time education and/or well-educated (e.g., 66% received at least a bachelor's degree and a further 22% were still in full time education). This finding was consistent with the participants' parents' education levels and the population seen at the private clinic when they were children. While all participants had known sensori-motor challenges as children, approximately half of the study sample reported Typical overall discrimination and modulation and motor skills as adults, while approximately a quarter each reported Mild and Definite Difficulties in adult sensori-motor patterns based on responses to the *ASH*.

As information was available for all respondents at two time periods, clinical intake as children and study participation in adulthood, direct comparisons over time are at the individual level. Participants were divided into three groups based on Total Score on the *ASH*. The *n*'s among the three groups were unequal with twice as many participants with Typical sensori-motor characteristics as those that reported Mild and Definite sensori-motor difficulties. Childhood sensori-motor scores were similar across these groups, as were all other demographics. See **Table 1** for details.

Before examination of sensori-motor patterns to QOL relationships, overall performance on domains of the *WHOQOL-BREF* of the Total Group were compared to known values of the WHOQOL-BREF to examine how the current study sample compared to a known population sample. The current sample scored the same as published US data from WHO (Skevington et al., 2004) for the Physical Health and Psychological Health domains. The current Total Group scored significantly better on QOL than the WHO data for the Social Relationships [$t(210) = 2.5$, $p = 0.014$] and Environment domains [$t(210) = 13.0$, $p < 0.001$]. See **Table 2** for details.

A number of demographic variables, (i.e., age, gender, diagnoses or no diagnosis, education level), known to be related to QOL, were then included as independent variables in a MANCOVA with Total Score on the *SXHX* and Total Score on the *ASH* to determine the possible influence of these variables on the four domains of current QOL. Education level was included in the analysis as an SES proxy. Results of the MANCOVA found that, for this sample, there were no relationships between the four domains of QOL on the *WHOQOL-BREF* and the demographic variables of diagnosis, education, gender, age at completion of childhood *SXHX* or current age. Additional results will be reported below.

Childhood Sensory Processing and Adult Quality of Life

Contrary to our hypothesis, the initial MANCOVA reported above found no significant relationship between overall childhood

TABLE 2 | Comparison of *WHOQOL-BREF* domains of adults with known childhood sensory processing challenges and published data.

WHOQOL-BREF domains	Total group	*ASH* group			WHO 2004 USA*
		Typical	Mild difficulties	Definite difficulties	
Physical health	$M=16.4$	$m=17.5$	$m=16.4$	$m=14.6$	$M=15.5$
	$SD=2.6$	$sd=2.4$	$sd=1.8$	$sd=2.8$	$SD=3.2$
Psychological health	$M=14.2$	$m=15.3$	$m=13.4$	$m=12.8$	$M=13.8$
	$SD=2.9$	$sd=2.7$	$sd=2.6$	$sd=2.8$	$SD=3.2$
Social relationships	$M=14.6$	$m=15.9$	$m=13.3$	$m=13.2$	$M=13.2$
	$SD=3.4$	$sd=3.1$	$sd=3.3$	$sd=3.5$	$SD=3.6$
Environment	$M=17.0$	$m=17.8$	$m=16.8$	$m=15.8$	$M=11.7$
	$SD=2.1$	$sd=1.8$	$sd=1.9$	$sd=2.1$	$SD=2.7$

Age and gender adjusted.

sensori-motor functioning and adult QOL in the Total Group when included with other demographic and adult sensori-motor variables. However, we wished to examine this relationship further, so a one-tailed Pearson Correlation (given our initial directional hypotheses) was conducted on childhood Total Score on the *SXHX* with adult *WHOQOL-BREF* domains. Overall (Total Score) sensori-motor patterns were only found to have a small relationship with Physical Health ($r=-0.23$, $p=0.051$) that approached significance.

We then further examined the relationship in the Total Group between specific sensory systems in childhood with adult QOL with a one-tailed Pearson correlation. Of the specific sensory areas, only childhood visual processing and motor coordination (praxis) were related to aspects of adult QOL. Small significant correlations among visual processing in childhood were related to Physical Health ($r=-0.29$, $p=0.017$) and Psychological Health ($r=-0.27$, $p=0.027$) in adulthood. Most notably there was a small significant relationship among the motor coordination (praxis) subsection and all QOL domains of Physical Health ($r=-0.24$, $p=0.045$), Psychological Health ($r=-0.25$, $p=0.034$), Social Relationships ($r=-0.26$, $p=0.030$) and Environment ($r=-0.23$, $p=0.046$).

We then further examined whether there were different relationships within the adult *ASH* subgroups. One-tailed Pearson correlations were conducted between Total *SXHX* Score and sensory system subscores and adult QOL for each *ASH* subgroup (e.g., Typical, Mild Difficulties, Definite Difficulties). No significant relationships were found between childhood sensori-motor patterns and later QOL in any *WHOQOL-BREF* category in the Typical or Mild Difficulties Groups. Notably the correlations among these two groups were predominantly very small (in the $r=0.00$ to -0.20 range) and were highly non-significant. Only the Definite Difficulties Group had significant relationships among sensori-motor pattern subscores on the childhood *SXHX* and adult *WHOQOL-BREF* domains.

The Definite Difficulty Group had a moderate significant relationship among overall (Total Score) sensori-motor functioning and Physical Health ($r=-0.56$, $p=0.018$). This was consistent with the finding of the Total Group. Visual processing ($r=-0.76$, $p=0.001$), movement (vestibular) processing ($r=-0.48$, $p=0.042$) and tactile processing ($r=-0.63$, $p=0.008$) also all had moderate to large significant relationships with Physical Health. Visual processing (*$r=-0.54$, $p=0.024$*) was also significantly related to Psychological Health. Motor Coordination was not significant for this Group but trended to significance ($p=0.067$ and 0.077, respectively) for Physical Health ($r=-0.42$) and Psychological Health ($r=-0.41$).

Current Quality of Life and Sensori-Motor Characteristics in Adults With Known Childhood Sensori-Motor Challenges

Total Group

As hypothesized, the initial MANCOVA on the Total Group reported above found a strong relationship among current adult sensori-motor functioning on the Total Score of the *ASH* and current QOL domains on the *WHOQOL-BREF*, $F(4,41)=6.4$, $p<0.001$; *Wilk's* $\Lambda=0.62$, *partial* $\eta^2=0.38$. Each of the four QOL domains was significantly related to the Total Score of the *ASH* with $F(1,44)$ ranging from 9.4–17.7, all $p\leq 0.004$.

To further examine which aspects of adult sensori-motor functioning were related to specific QOL domains for the Total Group, Pearson correlations were completed on the individual sensory systems, Modulation, Discrimination and the four *WHOQOL-BREF* domains. Results found all *ASH* sensory/motor/social subsections had moderate significant correlations with all four domains of QOL in the Total Group as hypothesized which was consistent with the initial MANCOVA on Total Score. See **Table 3** for details.

To examine which aspects of adult sensori-motor functioning were most important to QOL two multivariate linear regressions were conducted. First, analysis, including only adult Modulation and Discrimination subscores on the *ASH* and *WHOQOL-BREF*, was completed. All demographic variables were excluded as they were non-significant in the first model. In this analysis, the model (intercept, Modulation and Discrimination) accounted for approximately one quarter of the variation in each QOL domain (adj R^2s 0.22–0.31). Modulation was highly non-significant ($p=0.967$) while Discrimination was statistically significant with $F(4,47)=3.5$, $p=0.015$; *Wilk's* $\Lambda=0.77$, *partial* $\eta^2=0.23$. Discrimination was related to all four QOL domains with $p\leq 0.01$. The second analysis included the independent variables of individual sensori-motor functions. Again, approximately one quarter of the variability in the QOL domains was accounted for by the model (Adj R^2s 0.22–0.36). This analyses found only Motor Coordination (praxis) was significantly related to QOL $F(4,41)=4.0$, $p=0.007$; *Wilk's* $\Lambda=0.72$, *partial* $\eta^2=0.28$. Specifically, Motor Coordination (praxis) was found to be related to the QOL domains of Psychological Health ($p=0.011$) and Environment ($p=0.001$).

ASH Subgroups

As current level of sensori-motor function, as identified by the *ASH* subgroups, had varying patterns of relationships among childhood sensori-motor patterns and QOL, we further examined

TABLE 3 | Results of follow-up MANOVA with Bonferroni adjustment of *WHOQOL-BREF* domains by *ASH* categories.

WHOQOL-BREF subsections	*ASH* categories	Mean difference	Std. error	Sig. level[1]	95% Confidence interval
Physical Health	Typical – Mild	1.1	0.80	0.531	–0.9–3.1
	Typical – Definite	2.8	0.78	0.002	0.9–4.8
	Mild – Definite	1.7	0.91	0.185	–0.5–4.0
Psychological Health	Typical – Mild	1.9	0.92	0.116	–0.3–4.2
	Typical – Definite	2.5	0.90	0.021	0.3–4.7
	Mild – Definite	0.6	1.0	1.00	–2.0 - 3.2
Social Relationships	Typical – Mild	2.6	1.1	0.070	–0.2–5.3
	Typical – Definite	2.7	1.1	0.049	0–5.3
	Mild - Definite	0.10	1.2	1.00	–3.0–3.2
Environment	Typical – Mild	1.0	0.65	0.382	–0.6–2.6
	Typical – Definite	2.0	0.63	0.007	0.5–3.6
	Mild – Definite	1.0	0.73	0.509	–0.8–2.8

[1] *Bonferroni correction.*

current level of sensori-motor function in relation to the four domains of QOL in adults. A follow-up MANOVA with *post hoc* testing was conducted with the *ASH* subgroup (e.g., Typical, Mild Difficulties, Definite Difficulties) as the only independent variable. Statistically significant differences between *ASH* subgroups were detected $F(8,94) = 2.4$, $p < 0.019$; *Wilk's* $\Lambda = 0.69$, *partial* $\eta^2 = 0.17$. *Post hoc* comparisons with Bonferroni corrections confirmed a statistically significant difference in all four domains of the *WHOQOL-BREF* for the Typical and Definite Difficulties *ASH* subgroups. The Mild Difficulties subgroup was not statistically different from either of the other subgroups. Adults with Definite Difficulties in current sensori-motor patterns had the poorest QOL. Adults with Typical current sensori-motor patterns had the best QOL outcomes.

As overall sensori-motor functioning had varying relationships with *WHOQOL-BREF* by *ASH* subgroups we further examined whether specific subsections of sensory/motor/social functioning on the *ASH* (e.g., modulation, discrimination, sensory systems, motor/postural or social sections) had different relationships to the four *WHOQOL-BREF* domains by *ASH* subgroups. The assumption being that the sensory processing subsections (as expected with the Total Score) would also be inversely related to the QOL domains. One-tailed Pearson correlations were therefore conducted on the sensory/motor/social functioning subscores for the three *ASH* subgroups (Typical, Mild Difficulties, Definite Difficulties) for each of the four QOL domains. For these adult sensori-motor characteristics varying relationships among QOL domains and aspects of sensori-motor functioning emerged as they did with childhood sensori-motor characteristics and QOL.

Typical Group

The Typical Group demonstrated moderate significant relationships between Modulation and Discrimination and Physical Health ($r = -0.32$, $p = 0.032$ and $r = -0.35$, $p = 0.040$) and Social Relationships ($r = -0.44$, $p = 0.012$ and $r = -0.43$, $p = 0.015$) that were very similar. Discrimination was also significantly related to Psychological Health ($r = -0.36$, $p = 0.037$) where Modulation was not. Significant moderate to large relationships ($r = -0.44$ to - 0.77, $p = 0.012$ to <0.001) were found among the Motor Coordination (Praxis) and Social Emotional *ASH* subsections and all *WHOQOL-BREF* domains. Taste and Smell had moderate significant relationships with the Physical Health ($r = -0.54$, $p = 0.002$), Psychological Health ($r = -0.43$, $p = 0.014$) and Social Relationships ($r = -0.55$, $p = 0.002$) domains. Tactile processing had similar significant relationships with Physical Health ($r = -0.34$, $p = 0.044$) and Proprioception was also similar with relationships with Physical Health ($r = -0.41$, $p = 0.020$) and Psychological Health ($r = -0.34$, $p = 0.043$). Auditory processing had significant relationships with Psychological Health ($r = -0.39$, $p = 0.025$) and Social Relationships ($r = -0.65$, $p < 0.001$). Visual processing had a significant relationship with Social Relationships ($r = -0.39$, $p = 0.026$).

Definite Difficulty Group

The Definite Difficulty Group demonstrated a different pattern of significant relationships. Discrimination was significantly related to the *WHOQOL-BREF* domains of Physical Health ($r = -0.55$, $p = 0.021$) and Social Relationships ($r = -0.51$, $p = 0.030$); however, no statistically significant relationships with Modulation were found. Moderate significant relationships were found among the Social Emotional Functioning *ASH* subsection and the *WHOQOL-BREF* domains of Physical Health ($r = -0.57$. $p = 0.016$), Psychological Health ($r = -0.48$, $p = 0.042$), and Environment ($r = -0.52$, $p = 0.028$). Tactile functioning had significant relationships with Physical Health ($r = -0.50$, $p = 0.034$), Psychological Health ($r = -0.55$, $p = 0.020$) and Social Relationship ($r = -0.63$, $p = 0.008$) QOL domains. Taste and Smell had similar significant relationships with QOL domains of Physical Health ($r = -0.46$, $p = 0.049$), Psychological Health ($r = -0.52$, $p = 0.030$) and Environment ($r = -0.50$, $p = 0.034$). Movement (Vestibular) had significant relationships with Social Relationships ($r = -0.48$, $p = 0.042$) and Environment ($r = -0.56$, $p = 0.019$). Auditory processing only had a significant relationship with Physical Health ($r = -0.52$, $p = 0.027$); Postural Control only had a significant relationship with Psychological Health ($r = -0.54$, $p = 0.023$); and Motor Coordination (Praxis) only had a significant relationship with Environment ($r = -0.\ 65$, $p = 0.006$).

Mild Difficulties Group

In the Mild Difficulties Group Discrimination was only significantly related to Social Relationships ($r = -0.53$, $p = 0.031$). A moderate significant relationship was also found between Taste and Smell and the Social Relationships ($r = -0.50$, $p = 0.039$) and Environment ($r = 0.57$, $p = 0.021$) QOL domains. All other relationships were non-significant. Thus, as adults, some sensori-motor patterns may have a stronger relationship with certain areas of QOL depending on the severity of current sensori-motor characteristics. See **Table 4** for details.

TABLE 4 | 1-tailed Pearson correlations of adult QOL on *WHOQOL-BREF* and sensori-motor functions on *ASH* ($N=53$).

ASH subscores	Physical health				Psychological health				Social relationships				Environment			
	Total	**Typical**	**Mild**	**Definite**	**Total**	**Typical**	**Mild**	**Definite**	**Total**	**Typical**	**Mild**	**Definite**	**Total**	**Typical**	**Mild**	**Definite**
Total	−0.60	−0.50	0.00	−0.55	−0.55	−0.49	−0.24	−0.55	−0.52	−0.53	−0.25	−0.49	−0.52	−0.25	−0.27	−0.56
ASH	$p<0.001$	$p=0.004$	ns	$p=0.020$	$p<0.001$	$p=0.005$	ns	$p=0.022$	$p<0.001$	$p=0.003$	ns	$p=0.038$	$p<0.001$	ns	ns	$p=0.019$
Visual	−0.46	−0.20	0.27	−0.36	−0.37	−0.13	0.14	−0.	−0.42	−0.39	0.17	−0.29	−0.45	−0.09	−0.33	−0.32
	$p<0.001$	ns	ns	ns	$p=0.003$	ns	ns	ns	$p=0.001$	$p=0.026$	ns	ns	$p<0.001$	ns	ns	ns
Auditory	−0.49	−0.22	0.07	−0.52	−0.41	−0.39	0.37	−0.22	−0.53	−0.65	−0.03	−0.35	−0.40	−0.21	−0.23	0.09
	$p<0.001$	ns	ns	$p=0.027$	$p=0.001$	$p=0.025$	ns	ns	$p<0.001$	$p<0.001$	ns	ns	$p=0.002$	ns	ns	ns
Movement	−0.44	−0.13	−0.11	−0.27	−0.39	−0.09	−0.06	−0.34	−0.47	−0.20	−0.36	−0.48	−0.47	−0.07	−0.25	−0.56
	$p<0.001$	ns	ns	ns	$p=0.002$	ns	ns	ns	$p<0.001$	ns	ns	$p=0.042$	$p<0.001$	ns	ns	$p=0.019$
Taste and Smell	−0.60	−0.54	−0.18	−0.46	−0.54	−0.43	−0.21	−0.52	−0.44	−0.55	−0.50	−0.36	−0.40	−0.25	0.57	−0.50
	$p<0.001$	$p=0.002$	ns	$p=0.049$	$p<0.001$	$p=0.014$	ns	$p=0.030$	$p<0.001$	$p=0.002$	$p=0.039$	ns	$p=0.002$	ns	ns	$p=0.034$
Tactile	−0.53	−0.34	0.11	−0.50	−0.48	−0.26	−0.20	−0.55	−0.47	−0.31	−0.05	−0.63	−0.41	−0.04	0.03	−0.44
	$p<0.001$	$p=0.044$	ns	$p=0.034$	$p<0.001$	ns	ns	$p=0.020$	$p<0.001$	ns	ns	$p=0.008$	$p=0.001$	ns	ns	ns
Proprioception	−0.51	−0.41	−0.35	−0.19	−0.42	−0.34	−0.24	−0.17	−0.32	−0.24	−0.15	−0.03	−0.27	−0.12	0.09	0.09
	$p<0.001$	$p=0.020$	ns	ns	$p=0.001$	$p=0.043$	ns	ns	$p=0.010$	ns	ns	ns	$p=0.026$	ns	ns	ns
Postural Control	−0.44	−0.30	0.05	−0.20	−0.47	−0.27	−0.19	−0.54	−0.31	−0.06	−0.10	−0.28	−0.30	0.03	0.15	−0.34
	$p<0.001$	ns	ns	ns	$p<0.001$	ns	ns	$p=0.023$	$p=0.013$	ns	ns	ns	$p=0.014$	ns	ns	ns
Motor	−0.53	−0.57	0.12	−0.20	−0.55	−0.61	−0.06	−0.33	−0.43	−0.44	−0.08	−0.14	−0.61	−0.46	−0.34	−0.65
Coordination	$P<0.001$	$p=0.001$	ns	ns	$p<0.001$	$p<0.001$	ns	ns	$p=0.001$	$p=0.012$	ns	ns	$p<0.001$	$p=0.009$	ns	$p=0.006$
Social Emotional	−0.66	−0.66	−0.03	−0.57	−0.67	−0.77	−0.36	−0.48	−0.53	−0.54	−0.46	−0.21	−0.55	−0.44	−0.04	−0.52
	$p<0.001$	$p<0.001$	ns	$p=0.016$	$p<0.001$	$p<0.001$	ns	$p=0.042$	$p<0.001$	$p=0.002$	ns	ns	$p<0.001$	$p=0.012$	ns	$p=0.028$
Modulation	−0.49	−0.32	0.15	−0.26	−0.40	−0.24	0.41	−0.33	−0.42	−0.44	0.56	−0.28	−0.38	−0.04	0.26	−0.33
	$p<0.001$	$p=0.032$	ns	ns	$p<=001$	ns	ns	ns	$p<=001$	$p=0.012$	ns	ns	$p\leq 003$	ns	ns	ns
Discrimination	−0.58	−0.35	−0.15	−0.55	−0.52	−0.36	−0.44	−0.41	−0.54	−0.43	−0.53	−0.51	−0.50	−0.23	−0.39	−0.38
	$p<0.001$	$p=0.040$	ns	$p=0.021$	$p<0.001$	$p=0.037$	ns	ns	$p<0.001$	$p=0.015$	$p=0.031$	$p=0.030$	$p<0.001$	ns	ns	ns

DISCUSSION

The findings of this study provide new and unique insight into the importance of childhood sensori-motor functioning to adult QOL. It examined the relationship between childhood sensori-motor characteristics and later adult quality of life and the relationship between adult sensory processing and adult quality of life in adults with known childhood sensori-motor challenges.

Key Findings

In the Total Group, visual processing in childhood had a small relationship to Physical and Psychological Health in adulthood. Motor coordination (praxis) had a small relationship to all QOL domains including Physical Health, Psychological Health, Social Relationships and Environment. Approximately, 50% of the study adults with childhood sensori-motor difficulties reported Typical adult sensori-motor functioning. Twenty-five percent each reported characteristics which reflected Mild and Definite Difficulties with sensori-motor functioning. In those adults that reported Typical functioning or Mild Difficulties in sensori-motor functioning there were no significant relationships among childhood sensori-motor challenges and adult quality of life. However, in those adults that reported Definite sensori-motor difficulties as adults, childhood characteristics in areas of visual processing, tactile processing and movement (vestibular) processing were related to the Physical Health domain of QOL. Visual processing was also significantly related to Psychological Health. Motor coordination (praxis) approached a significant relationship with Physical Health. Therefore, results suggest that childhood sensori-motor challenges in areas of visual, tactile and movement (vestibular) sensory processing and motor coordination (praxis) are related to later Physical and Psychological Health aspects of quality of life, particularly in those individuals whose childhood sensory processing challenges persist into adulthood. Most importantly, when early sensori-motor challenges are not resolved in adulthood, these adult sensori-motor challenges are further related to current QOL across all domains. Conversely, if childhood sensori-motor challenges are remediated by adulthood childhood sensori-motor patterns do not appear to relate to adult QOL.

In the Total Group of adults, current sensori-motor functioning was related to all QOL domains. Of note, Sensory Modulation and Sensory Discrimination were related to both Physical Health and Social Functioning domains of QOL while Sensory Discrimination was also related to Psychological Health. Results also found that when adults report current sensori-motor characteristics of Definite Difficulty with sensori-motor functions only Sensory Discrimination was significantly related to the Physical Health and Social QOL domains. Further examination found that in the Total Group adult Motor Coordination (praxis) and Social Emotional functioning was also significantly related to all QOL domains. Specific sensori-motor functions were significantly related to varying aspects of QOL. Tactile processing was significantly related to Physical Health. Proprioceptive processing was related to Physical and Psychological Health. Auditory processing was related to Psychological Health and Social. Taste and Smell were related to Physical Health, Psychological Health and Social. Lastly, visual processing was related to the Social QOL domain. Therefore, in adults with known sensori-motor challenges as children, adult sensori-motor characteristics are significantly related to adult QOL, particularly Physical and Psychological Health.

Relation of Findings to the Literature

These are the first findings to examine adults with known sensori-motor challenges in childhood and the first to compare childhood sensori-motor characteristics with later QOL. Findings related to childhood sensori-motor functioning and adult QOL have not previously been addressed in the literature. This study provided new insight into this relationship. This study has also contributed to understanding of the relation of adult sensori-motor characteristics with adult QOL. Many factors can impact adult QOL, and sensori-motor skills, both in childhood and as adults, are only two factors. QOL is an important aspect of life. Sensory processing and integration challenges, specifically sensory modulation, and motor coordination difficulties have been found to be related to decreased QOL. Previous studies examined aspects of sensory processing using the sensory processing model proposed by Dunn (1999). This study examined sensori-motor functions using Ayres Sensory Integration® model. Varying sensori-motor skills were found to be related to the four QOL domains. The finding that Motor Coordination functioning in adults was significantly related to all QOL domains was consistent with studies on DCD and QOL in adults (Tal-Saban et al., 2014). Social Emotional functioning (which included questions on anxiety, depression, making friends, etc.) was also related to all QOL domains. This finding was similar to previous findings by Kinnealey et al. (2011). The relationship of specific sensory systems to current QOL was also illuminated. Along with Motor Coordination skills, Auditory processing, Taste and Smell processing and Tactile processing were found to be related to Physical and Psychological Health and Social relationships.

Some previous studies examined adults with current sensory processing challenges (Kinnealey et al., 2011) or developmental coordination disorder (Tal-Saban et al., 2014; Smits-Engelsman et al., 2018; Cleaton et al., 2021), but most have not identified specific sensory or motor characteristics in their populations. Some studies suggested that sensory hypersensitivities in some of these areas of sensory processing are related to QOL, but this study is the first to examine overall sensori-motor patterns to QOL, as well as specifically the relation of Sensory Modulation and Discrimination skills to QOL. This study found that Sensory Modulation and Discrimination accounted for approximately one quarter of the variance in each QOL domain. When each was examined, Modulation was highly non-significant while Discrimination was statistically significant and significantly related to all four QOL domains. These findings provide new information on the important role of Sensory Discrimination skills on current QOL and the relation of specific sensori-motor characteristics on QOL in adults with known childhood sensori-motor difficulties. Further, this study suggests that individuals who report typical or only mild difficulties with sensori-motor functioning as adults following childhood sensori-motor dysfunctions, are likely to experience a higher QOL than adults whose childhood sensori-motor challenges persist into adulthood.

Limitations

While many factors may impact current QOL, an individual's life history may also have an influence. This study found that the current study sample of adults with known childhood sensori-motor challenges based on ASI is representative of a US national sample in relation to two of four areas of QOL. The current sample had significantly higher Social Relationships and Environmental QOL than the national sample. The current sample is known to consist of individuals with a higher-than-average educational status, reflecting a higher socio-economic status, which is likely related to this finding. There were no significant relationships among QOL and other demographic variables including gender, diagnoses, age at childhood intake or adult age of questionnaire completion. Although the higher educational status of this study group may influence overall QOL, there is no evidence that this population characteristic affected the relationships among sensori-motor patterns and QOL in this sample.

These results are clearly initial findings. This sample was largely homogenous, the sample size was small and subgroup sample sizes were smaller. Multiple correlations could possibly result in some significant relationships, but the robustness of the significant relationships and the extreme non-significance of the other findings suggest that findings are worth further examination. This group consists of a larger than expected number of adult female participants compared to the known predominately male child population. It is possible that this may lead to some bias in the results or the population under examination. Lastly, due to differences in the rating scales of the childhood sensory history versions, it was necessary to convert some scores from a 5 point to a 3-point scale which could also have contributed to some statistical drift in results.

Conclusion

In summary, this study found that when individuals with childhood sensory processing and integration with motor coordination challenges report that their sensori-motor issues are largely resolved in adulthood, those adults have a good QOL. However, adults who continue to have sensori-motor challenges from childhood have poorer QOL as adults. In these individuals, childhood visual, movement (vestibular) and tactile sensory processing, in particular, were related to later physical and psychological health. While sensory modulation functions have traditionally been evaluated in studies about adult QOL, sensory discrimination functions have not, and this study suggests that sensory discrimination and motor coordination (praxis) skills also play an important role in QOL. These findings make sense as the Physical Health domain of the *WHOQOL-BREF* asks questions about participation in work and activities, pain, energy, sleep and mobility. Individuals with sensory modulation problems, especially those with sensory hyper-responsivity, are likely to exhibit pain and sleep challenges. Also, the three areas of sensory processing identified, and specifically sensory discrimination functions are known to be related to motor coordination and praxis functions and therefore may contribute to challenges in mobility, as well as, participation in work and activities (Bundy and Lane, 2020).

The Psychological domain of the *WHOQOL-BREF* asks about areas such as positive feelings, thinking, self-esteem, negative feelings and body image. Children with patterns of sensori-motor dysfunction as identified by Ayres are known to have challenges in many of these areas. Motor coordination (praxis) challenges are known to be related to self-esteem and poor body awareness. Difficulties in tactile and vestibular sensory discrimination are known to be related to decreased motor skills and decreased self-esteem and body image as well (Bundy and Lane, 2020). Thus, the relation of our findings to these areas of QOL is reasonable. Challenges in any of these areas is likely to contribute to difficulties in participation in daily life activities from self-care activities to participation in work and leisure activities.

Much additional information is needed to fully understand the results of this study and to understand the potential relationships among sensori-motor functions and QOL. Clearly, the change in sensori-motor functioning from childhood to adulthood plays an important role as those individuals who persist in having difficulties with sensori-motor functioning as adults reported poorer QOL than those who reported their childhood sensori-motor challenges were remediated. Factors that might contribute to this change may also contribute to QOL. The amount and type of therapy received from childhood to adulthood would be important to examine including mental health and occupational therapy services. This sample was very homogenous across SES/education, diagnoses, and other demographic variables but examination of a more diverse group may yield different findings. Lastly, this study is the first known longitudinal follow-up study that has included participants that have been followed up over 15+ years later. Additional studies which follow-up children with known sensori-motor challenges as adults are needed, both retrospectively and prospectively. Understanding factors which may contribute to adult functioning for these children is needed for clinicians to provide accurate prognosis information to families and to guide intervention.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Spiral Foundation Institutional Review Board, protocol #1039. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

TM-B, OE-D, and AT contributed equally to the conceptualization of the study and writing and editing of the manuscript. AT contributed with statistical analysis. TM-B and AT contributed with data analysis and interpretation of the study data. All authors contributed to the article and approved the submitted version.

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EDITED BY
Batya Engel-Yeger,
University of Haifa, Israel

REVIEWED BY
Sarah A. Schoen,
STAR Institute for Sensory Processing Disorder, United States
Liat Gafni-Lachter,
Boston University, United States

*CORRESPONDENCE
Helen Lynch
h.lynch@ucc.ie
Gina Daly
107567626@umail.ucc.ie

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Family life and autistic children with sensory processing differences: A qualitative evidence synthesis of occupational participation

Gina Daly*, Jeanne Jackson and Helen Lynch*

Department of Occupational Science and Occupational Therapy, University College Cork, Cork, Ireland

Autistic children with sensory processing differences successfully navigate and engage in meaningful family daily occupations within home and community environments through the support of their family. To date however, much of the research on autistic children with sensory processing differences, has primarily been deficit focused, while much of the caregiver research has focused on issues of distress, burden, effort, and emotional trauma in coping with their child's diagnosis. This study aimed to conduct a qualitative evidence synthesis, using a meta-ethnographic approach to explore the gap identified in understanding successful occupational experiences of family participation and daily family routines when supporting an autistic child with sensory processing differences and to offer an alternative strengths-based perspective. Inclusion criteria were studies which were peer-reviewed qualitative design, published from 2000 to 2021, and that concerned parents/caregivers' perspectives of family occupations of children diagnosed with autism spectrum disorder. Studies were electronically searched in eight databases from October to December 2021 and 23 studies were identified which met the inclusion criteria. Noblit and Hare's seven step approach for conducting analysis in meta-ethnography was used, and three themes identified: (1) sensory processing differences in daily life, (2) what is hard about hard, and (3) orchestrating family life. Results identified the centrality of sensory experiences in understanding family life. Living with unpredictability while orchestrating certainty through routines was core to successful participation. This review provides insights into how parents negotiate the complexities of constructing family life when living with an autistic child. The results can inform the design of future interventions that specifically address the relationship between meaningful participation in family occupations and daily routines and sensory processing in autistic children.

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KEYWORDS

meta-ethnography, meaningful participation, occupation, family-centered practice, autistic children, sensory processing, routines

Introduction

The World Health Organization (2022) states that the global incidence of Autism Spectrum Disorder (ASD) is 1% and therefore it is the most prevalent neurodevelopmental disorder in childhood. As a neurodevelopmental disorder, ASD is still largely understood *via* the medical or deficit model. For example, ASD is diagnosed when there is evidence of particular behaviors or communication skills that differ from typically developing children (American Psychiatric Association, 2013). Core features in such a diagnosis include (a) persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, (b) restricted, repetitive patterns of behavior, interests, or activities (c) symptoms must be present in early childhood and (d) symptoms together limit and impair everyday functioning (American Psychiatric Association, 2013). In addition, in 2013, the APA included atypical sensory reactivity (over or under responsive) as a further ASD criterion (Robertson and Simmons, 2013; Tavassoli et al., 2014), which, until then, had long gone unrecognized. Indeed, studies have found that 80–90% of autistic children[1] experience significant difficulties in sensory processing which influences their participation in daily activities (Lane et al., 2010; Lloyd et al., 2013; Williams et al., 2018). Yet, it is the impact of these symptoms on social participation, and on education, employment and wellbeing that is a most significant concern for families of autistic children, and the potential risk of poverty of experience, and ultimately occupational deprivation (Durocher et al., 2014; Wilcock and Hocking, 2015).

The challenge in enabling social participation is complex for autistic children and their families, and for the services who work with them. It requires an integrated understanding of how the core symptoms of ASD combine to influence and steer the child to develop and experience meaningful daily occupations, in the context of their social and physical environments. When exploring meaningful occupations for autistic children and their families this translates to understanding how a child's sensory differences are embodied within their daily occupational experiences. A child's intolerance for dressing may be due to the feel of certain clothing, reactivity to the taste and smell of certain foods could result in the restriction of many foods based on their sensory properties, the need for increased vestibular input for sensory regulation may require regular visits to the playground and attending the local shopping center during peak opening times could escalate a child's auditory hyperreactivity. Within this context, there has been an increased exploration within the field of behavioral science to understand how sensory experiences influence brain-behavior relationships within the autistic population (Wolff et al., 2012), Studies of autistic children who have sensory processing differences show that they integrate sensory information differently to typical children, and present with sensory differences across different senses (Kern et al., 2008; Schoen et al., 2009; Lane et al., 2010; Marco et al., 2011). For example, studies have demonstrated a marked difference between autistic children and typically developing children regarding their tactile defensiveness and lower tolerance to tactile stimuli (Baranek et al., 2006; Tomcheck and Dunn, 2007). These difficulties have been found to include atypical responses to textures, an abnormal detection of tactile stimuli (Blakemore et al., 2006) preoccupations with sensory features of objects, and problems habituating to prior sensory experiences (Tannan et al., 2008). So, evidence exists that sensory differences are significantly associated with the core features of ASD (Lane et al., 2014; Zachor and Ben-Itzchak, 2014) and within this evidence, sensory reactivity is the most discussed and acknowledged sensory processing difference and as such is the primary focus of this research (Botha et al., 2021).

As noted earlier, such sensory differences among autistic children impacts on the nature of their participation in daily life. Autistic children may have different needs in being able to participate in activities of daily living at home (White et al., 2007; Schaaf et al., 2011), particularly where a child has sensory over-responsivity or reactivity (Reynolds and Lane, 2008). Sensory reactivity can significantly influence everyday functioning in occupations (Bagby et al., 2012; Reynolds et al., 2012; Bodison, 2015). Indeed, studies have found a significant relationship between sensory reactivity and occupational performance in activities of daily living for autistic children, including sleep, dressing, eating, engaging in play and participation in leisure and school related activities (Miller Kuhaneck and Britner, 2013; Mazurek and Petroski, 2015). However, sensory processing differences influence not only the lives of autistic children but also the context within which they live. Consequently, families of autistic children have also been the focus of significant study across cultures, to understand how families experience living with ASD, including experiences of the diagnostic process (Khara et al., 2021), of marginalization (Chiaraluce, 2018), pathologicalization of ASD (Mackay and Parry, 2015), adjusting and coping with life with an autistic child (Kapp and Brown, 2011; Harrop et al., 2018), parental identity and stress (Rocque, 2010) and how it impacts parental quality of life (Fong et al., 2021; Beheshti et al., 2022). Overall, these studies all address the significant impact of living with an autistic child and tend to prioritize the subsequent limitations that result on family participation in work, family, and leisure activities. While these studies provide insight into family life, they primarily examine parental experiences of difficulties, and of living an arduous life, from a deficit perspective, which has been highlighted in other studies (Boyd et al., 2014).

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[1] Note: For this paper, the use of identity-first language (autistic child) will be applied. The preference of many autistic-led and autism-focused organizations, when talking about themselves and their condition, is to use autistic as their identity (Botha et al., 2021).

In order to understand successful, meaningful participation in family life, one place to start is to explore how parents structure family life which for autistic children typically involves the use of routines (Boyd et al., 2014). The adoption of routines in family life is typically associated with transmission of family and cultural values, as well as providing structure to family occupations (Boyce et al., 1983; Spagnola and Fiese, 2007). For families of autistic children, predictability within their daily life is an important feature (Boyd et al., 2014). However, this means that families are required to structure their family routines around the autistic child, to remove spontaneity, and avoid unplanned family events (Boyd et al., 2014). In this way, routines can be considered a double-edged sword, whereby there is a cost to family values in order to benefit the child, which Larson describes as a paradox (Larson, 1998). Yet for these families, routines crucially provide stability to what can be a frightening world (Boyd et al., 2014), and have been found to promote healthier coping mechanisms among families of autistic children (Kapp and Brown, 2011). Further exploration of the role of routines in family life with older autistic children is less well known however, and warrants further study (Boyd et al., 2014).

From this preliminary review of evidence, it is clear that living with an autistic child presents challenges, yet there is an inadequate understanding beyond the deficits and difficulties, of what works well in daily life and what shared participation within the home environment might look like for families with autistic children. While evidence has been previously synthesized relating to routines specifically (e.g., Boyd et al., 2014), to our knowledge no study has been conducted to date that synthesizes evidence for composing meaningful family life more generally. Thus, the purpose of this study was to analyze multiple studies of parental perspectives, views and experiences in parenting an autistic child with sensory processing differences and synthesize the means by which they have successfully negotiated challenges and effectively supported autistic children within their families. The aims of the study were to strengthen our understanding of meaningful family occupation by exploring: (1) What is known about parental perspectives of autistic children and sensory processing differences within the context of family life and routines (2) How do families overcome the challenges that their child experiences to co-construct daily routines and occupations within their home environment, and (3) How do parents and their children optimize meaningful engagement in family occupations. This evidence has the potential to inform intervention and service delivery through generating new understandings of the experiences of parents, and their autistic children within the family context and the wider family unit, in order to more effectively meet parents needs relating to successful family participation (Anaby et al., 2014).

TABLE 1 Search strategy terms.

- autism OR autism spectrum disorder* OR autistic spectrum disorder* OR ASD OR asperger* OR HFA
- "parent* perspective*" OR "caregiv* perspective*" OR famil*
- "sensory processing*" OR "sensory processing dysfunction" "sensory integration*" OR SPD* OR "sensory integration difficulties"
- Qualitative OR mixed methods
- "family routines" OR "occupational participation" OR "activities of daily living" OR "family life" OR "occupational engagement"

Methods

Design

This qualitative synthesis used a meta-ethnographic approach as detailed by Noblit and Hare (1988) and follows the eMERGe guidelines in reporting the synthesis, which is recommended when reporting meta-ethnographies in particular (France et al., 2019). Meta-ethnography is one of the most consistently used approaches to qualitative evidence synthesis in healthcare (Cahill et al., 2018) because of its effective and robust methods of strengthening the evidence through synthesis. Meta-ethnography offers a well-delineated approach to the synthesis of qualitative research which produces novel interpretations and conceptual innovation of the area of interest. This approach was chosen by the authors as it provided a method to examine and reinterpret the current evidence base in a new and novel way, producing innovative findings to inform the field of practice. Subsequently, a preliminary search of the literature indicated that there were enough studies to merit a meta-ethnography. A study protocol for this meta-ethnography was registered and published on Prospero | (Registration number: CRD42022298938) (Daly et al., 2022).

Search strategy

Initially the search was a pre-planned comprehensive search to seek all available studies. The search strategy then became iterative to prioritize theoretical sampling (Booth, 2016; Cahill et al., 2018). The search strategy was developed initially from reviewing qualitative literature on parental perspectives of children with autism spectrum disorder and sensory processing. Support was then received from an academic librarian in University College Cork, Ireland. A combination of keywords, thesaurus and MeSH terms were utilized. Keywords used in the search were drawn from recently conducted systematic reviews for autistic children and from a review on strategy searching for qualitative research. The search strategy combined three concepts which were central to the research objective (see Table 1).

The SPIDER search strategy tool (sample, phenomenon of interest, design, evaluation, research type) was used to structure the process for screening and the selection of studies as it is identified as a more effective tool compared to the more traditional PICO approach (Methley et al., 2014; Booth, 2016). A systematic search of peer-reviewed studies was conducted in September 2021 using eight databases from health, science, education, and humanities to ensure the inclusion of diverse perspectives: Academic Search Complete, CINAHL, ERIC, MEDLINE, PsycINFO, Scopus, Web of Science and PubMed. Searches were limited to English language publications between the dates 2000–2021, so as to capture the most recent research in the field. The PRISMA-checklist for systematic reviews was used to illustrate the search strategy procedures.

Inclusion/exclusion criteria

Primary research studies using only qualitative methods of data collection and analysis to explore parental perspectives of the occupational participation of autistic children and young persons (3–18 years) with sensory processing differences in daily life were included. All cultural and geographic contexts were considered and settings such as home and the community where the parent is present with the child were included. Studies were excluded if (a) they employed mixed methods or where only a quantitative design was employed, (b) had a co-occurring physical disability and/or whose child did not have a diagnosis of autism spectrum disorder. In addition, if the studies primary focus data was not on the child's daily routines and participation in family occupations (for example, studies in airports, school, or dentist), they were excluded.

Screening

Once duplicates were removed, the first author (GD) and a second reviewer (e.g., HL or JJ) screened all titles and abstracts against the defined eligibility criteria. Each paper was screened by two reviewers to check for consistency and rigor. Subsequently, full-text review for all eligible papers was conducted by two reviewers. Each reviewer independently considered the paper's relevance to this qualitative synthesis. Ambiguities were addressed *via* a third reviewer to resolve differences of opinion. The entire screening process is presented *via* a PRISMA flowchart.

Data extraction and data synthesis

The synthesis was conducted using the seven phases of meta-ethnography originally described by Noblit and Hare (1988). The seven phases are as follows: (1) Getting started, (2) Deciding what is relevant to the initial interest, (3) Reading the studies, (4) Determining how the studies are related, (5) Translating the studies into one another, (6) Synthesizing translations, and (7) Expressing the synthesis. In contrast to other forms of systematic reviews, in meta-ethnography, theoretical sampling is used to identify studies that provide rich data rather than including every study identified (Atkins et al., 2008; Cahill et al., 2018). The analysis aims to create third-order constructs or themes from first order constructs (respondents' quotations) and second-order constructs (authors' interpretation). Each of the included full-text studies were imported into NVivo qualitative data analysis software to facilitate extraction of second-order concepts, coding and comparison. As suggested, by Noblit and Hare (1988), all studies were read several times in full. Key quotations, metaphors, and concepts related to parental perspectives of daily routines and family occupations in autistic children were extracted using the words and explanations provided by the authors (second-order constructs). Throughout the process of meta-ethnographic analysis and synthesis, two reviewers completed initial coding and data extraction independently and collaborated and compared findings regarding emerging themes. Studies were translated into each other, and a reciprocal translation was conducted for this synthesis, as the studies concerned similar concepts (Noblit and Hare, 1988; Toye et al., 2014).

Quality appraisal

Two reviewers independently appraised each of the 23 papers included in the review. The quality of the included studies was assessed using the Critical Appraisal Skills Programme (CASP) checklist (Critical Appraisal Skills Programme, 2022). The CASP is a checklist specifically designed for the formal appraisal of qualitative research and was chosen as it provides a systematic process to identify the strengths and weaknesses of a research study. Each item was recorded as "Yes", "No", "Unclear" or" Not applicable". Once complete, the appraisal findings were contrasted, variations in decisions were examined and consensus was reached *via* discussion between both reviewers (HL and GD) and when required with the third reviewer (JJ). We made a decision in advance not to exclude studies with low quality scores, as the focus of the review was around conceptually rich data on autistic children and families and their occupational participation. Quality appraisal meetings between the team were conducted fortnightly whereby

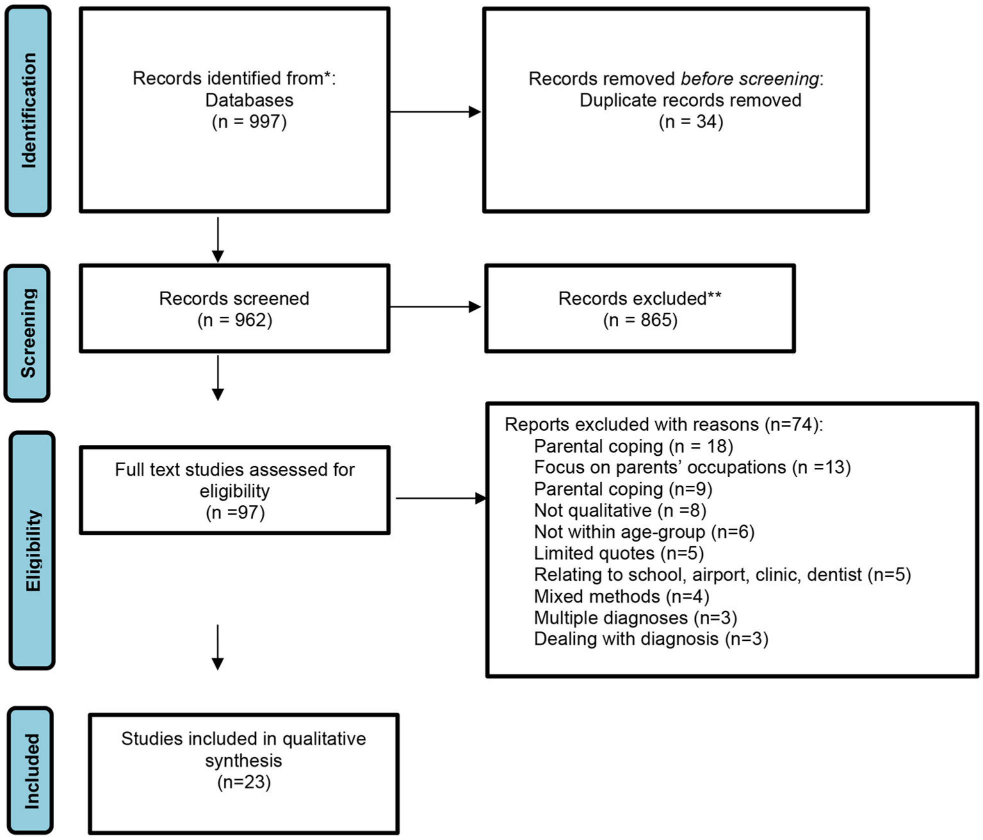

FIGURE 1
Adapted PRISMA flow diagram of study selection process (Moher et al., 2009).

each of the studies was scrutinized using the well-defined inclusion/exclusion criteria.

Results

Study selection

Initial searches yielded 997 results, 963 after removing duplicates prior to screening. Screening by title and abstract excluded 865 studies, leaving 97 studies for full text review. Seventy-four studies were excluded and 23 met eligibility and were included in the review (November 2021). Figure 1 presents a PRISMA Flowchart diagram, detailing the entire process, which led to the inclusion of 23 studies. The 23 studies are represented by numbers to support the flow and readability of the synthesis section.[2]

Study characteristics

Twenty-three papers were identified for synthesis from this search and are listed here alphabetically (DeGrace, 2004; Larson, 2006, 2010; Burrows et al., 2008; Dickie et al., 2009; Marquenie et al., 2011; Schaaf et al., 2011; DeGrace et al., 2014; Keller et al., 2014; Suarez et al., 2014; Potter, 2017; Kim et al., 2018; Epstein et al., 2019; Harwood et al., 2019; Kirkpatrick et al., 2019; Naik and Vajaratkar, 2019; Columna et al., 2020; Galbraith and Lancaster, 2020; Redquest et al., 2020; Rios and Scharoun Benson, 2020; Burkett et al., 2021; Shannon et al., 2021; Tokatly Latzer et al., 2021) (see text footnote 2).

A detailed summary of all aspects of the 23 included articles from the study is provided in Table 2. The majority of identified

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[2] Note the following numbers are used to represent the 23 articles included as eligible for this meta-ethnographic synthesis: 1, DeGrace, 2004; 2, Larson, 2006; 3, Burrows et al., 2008; 4, Dickie et al., 2009; 5, Larson, 2010; 6, Marquenie et al., 2011; 7, Schaaf et al., 2011; 8, DeGrace et al., 2014; 9, Keller et al., 2014; 10, Suarez et al., 2014; 11, Potter, 2017; 12, Kim et al., 2018; 13, Harwood et al., 2019; 14, Epstein et al., 2019; 15, Kirkpatrick et al., 2019; 16, Naik and Vajaratkar, 2019; 17, Columna et al., 2020; 18, Galbraith and Lancaster, 2020; 19, Rios and Scharoun Benson, 2020; 20, Redquest et al., 2020; 21, Burkett et al., 2021; 22, Tokatly Latzer et al., 2021; 23, Shannon et al., 2021.

TABLE 2 Article characteristics.

Article number	References Country	Title	Methods as described in the study	Participants	Country and ethnicity	Focus of study relating to participation in family occupations
1	Burkett et al. (2021) USA	Restricted eating in pre-schoolers with Autism: Mother stressors and solutions	Focus group and ethno-nursing design	11 mothers of pre-school children (3–6 years)	9 = non-Hispanic/Caucasian from a large Midwestern city 1= African American 1= Asian American.	Mealtimes routines and preferences
2	Burrows et al. (2008) Canada	Sentinels of safety: Service dogs ensure safety and enhance freedom and well-being for families with autistic children	Participant observation and video; semi-structured interviews	10 families (children 4.5–14 years)	Southwestern Ontario (Canada)	Family activities in the home and public outings
3	Columna et al. (2020) USA	The experiences of Hispanic families of children with autism spectrum disorder regarding physical activity	Semi-structured telephone interviews	9 parents (Hispanic families) (children 6–14 years)	Hispanic Parents - Participants resided in five different states in the U.S. (Georgia, Florida, New York, Massachusetts, and Texas) and one participant did not report their state of residence.	Recreational activities, exercise and hobbies
4	DeGrace (2004) USA	The everyday occupation of families with children with autism	In-depth interviewing	5 families (5 children 9–10 years)	USA	Everyday occupations of families
5	DeGrace et al. (2014) USA	Families' experiences and occupations following the diagnosis of autism	Semi-structured interviews	7 families (7 children 3–18 years)	USA	Family occupations
6	Dickie et al. (2009) USA	Parent reports of sensory experiences of preschool children with and without autism: a qualitative study	Telephone or face-to-face interviews	Parents of 66 pre-schoolers (37 parents of autistic children 6–17 years))	USA (White, Black and Hispanic included)	Responses to sensory experiences (food-related, self-care)
7	Epstein et al. (2019) Australia	Parent-observed thematic data on quality of life in children with autism spectrum disorder	Semi-structured interviews	21 parents (19 mothers, 2 fathers) (children 6–17 years)	Parents living in Australia. Country of Birth for Parents: Australia (10) and other (11) which included Argentina, England, Scotland, Germany, Poland, Ireland, New Zealand, Singapore	Relaxation, natural environment, routines and social connection
8	Galbraith and Lancaster (2020) Australia	Children with autism in wild nature: Exploring Australian parent perceptions using photovoice	Photovoice	3 Participants (children 5–10)	Australia	Nature and the outdoors, and balancing needs of sibling
9	Harwood et al. (2019) Australia	Parental perceptions of the nature of the relationship children with Autism Spectrum Disorders share with their canine companion	Case design - interviews	11 mothers (children aged 5–12)	Western Australia	Companionship and influence of assistant dog on sensory experiences relating to sleep and social connection

(Continued)

TABLE 2 (Continued)

Article number	References Country	Title	Methods as described in the study	Participants	Country and ethnicity	Focus of study relating to participation in family occupations
10	Keller et al. (2014) USA	Relationships of children with Autism Spectrum Disorders and their fathers	Semi-structured interviews	7 fathers (children 4–6 years)	USA	Shared family activities, fathering
11	Kim et al. (2018) USA	Listening to the screaming whisper: a voice of mother caregivers of children with autistic spectrum disorder (ASD)	Semi-structured interviews	12 mothers (average age of child was 9)	Indiana, USA	Leisure and recreation: negotiation and constraint
12	Kirkpatrick et al. (2019) Ireland	Qualitative study on parents' perspectives of the familial impact of living with a child with autism spectrum disorder who experiences insomnia	Focus groups	15 parents (15 children 4–12 years)	Ireland	Bedtime routine, eating, sleep, social connections
13	Larson (2006) USA	Caregiving and autism: how does children's propensity for routinization influence participation in family activities?	Semi-structured interviews	9 participants (children 3–14 years)	USA based (6 Caucasians of European descent, 1 Puerto Rican/African-American, 1 Chinese, and 1 Mexican)	Routines in family life including restaurant, leisure activities, morning routines
14	Larson (2010) USA	Ever vigilant: Maternal support of participation in daily life for boys with autism	Semi-structured interviews	9 mothers (children 3–8 years)	USA based varied in self-identified ethnicity (6 Caucasians of European descent, 1 Puerto Rican/African-American, 1 Chinese, and 1 Mexican),	Routines in self-care, leisure and social activities
15	Marquenie et al. (2011) Australia	Dinnertime and bedtime routines and rituals in families with a young child with an autism spectrum disorder	Semi-structured interviews	14 mothers (children 2–5 years)	Australia	Routines: bedtime and dinnertime
16	Naik and Vajaratkar (2019) India	Understanding parent's difficulties in executing activities of daily living of children with Autism Spectrum Disorder	Semi-structured interviews	20 participants (fathers = 9 and mothers = 11) (children 5–9 years)	India	Self-care activities including eating, toileting, dressing, brushing, grooming, sleep
17	Potter (2017) UK	Fathers experiences of sleeping problems in children with autism	Semi-structured interviews	25 fathers (20 children: 15 were under 10 years)	Fathers living in the UK (24 white and 1 Black)	Sleep challenges, and fathers management of night-time waking
18	Redquest et al. (2020) Canada	Social and motor skills of children and youth with autism from the perspectives of caregivers	Semi-structured interviews	8 participants (children 6-16 years)	Canada	Physical hobbies, social skills concerning physical activity
19	Rios and Scharoun Benson (2020) Canada	Exploring caregiver perspectives of social and motor skills in children with Autism Spectrum Disorder and the impact on participation	Semi-structured interviews	17 participants (mothers, fathers and 1 grandmother) (children 5–9 years)	Canada	Participation in social activities and influence of motor skills and social skills

(Continued)

TABLE 2 (Continued)

Article number	References Country	Title	Methods as described in the study	Participants	Country and ethnicity	Focus of study relating to participation in family occupations
20	Schaaf et al. (2011) USA	The everyday routines of families of children with autism Examining the impact of sensory processing difficulties on the family	Semi-structured interviews	4 Families (children 7–12 years)	USA white, non-Hispanic	Participation in family activities inside and outside the home
21	Shannon et al. (2021) Canada	"There's nothing here": Perspectives from rural parents promoting safe active recreation for children living with autism spectrum disorders	Open ended & semi-structured interviews	12 parents (10 mothers, 2 fathers) of children (3–12 years)	Canada	Participation in safe active recreation in rural areas
22	Suarez et al. (2014) USA	Phenomenological examination of the mealtime experience for mothers of children with autism and food selectivity	Semi-structured interviews	4 mothers (children 6–9 years)	USA - 3 white non-Hispanic and 1 white Hispanic	Mealtime routines and preferences
23	Tokatly Latzer et al. (2021) Israel	Core experiences of parents of children with autism during the COVID-19 pandemic lockdown	Semi-structured interviews	Parents of 25 children (children 4–6 years)	Israel - low ($n = 7$), middle ($n = 8$), and high ($n = 10$) socioeconomic backgrounds recruited	Adjusting to home routines during COVID-19 lockdown

articles were from USA ($N = 11$), with other represented countries including Canada ($N = 4$) Australia ($N = 4$), UK ($N = 1$), India ($N = 1$), Israel ($N = 1$) and Ireland ($N = 1$). Most studies used interviews to collect data (DeGrace, 2004; Larson, 2006, 2010; Dickie et al., 2009; Marquenie et al., 2011; Schaaf et al., 2011; DeGrace et al., 2014; Keller et al., 2014; Suarez et al., 2014; Potter, 2017; Kim et al., 2018; Epstein et al., 2019; Harwood et al., 2019; Naik and Vajaratkar, 2019; Columna et al., 2020; Redquest et al., 2020; Rios and Scharoun Benson, 2020; Shannon et al., 2021; Tokatly Latzer et al., 2021). The remaining studies used focus groups (Kirkpatrick et al., 2019; Burkett et al., 2021); Qualitative ethology (Burrows et al., 2008); and photovoice (Galbraith and Lancaster, 2020). A combined total of 301 parents/caregivers/families of autistic children aged between (3–18 years) were included across the studies, with study sample sizes ranging from three to 37 parents/caregivers. Of these, the majority (95%) of the studies included parents of primary school aged children within their sample, with 26% of studies including parents of secondary school aged children. Parents of children aged between 16 and 18 years were represented in 13% of studies.

Quality appraisal

All 23 studies were of high quality based on criteria used in meta-ethnographies as they all received "yes" answers for at least 7–10 of 10 CASP checklist questions (see Table 3).

Synthesis

This meta-ethnographic synthesis of qualitative data synthesized first order and second order constructs from the 23 studies which resulted in the identification of three core themes (third order constructs): (1) Sensory differences and routines in daily occupations, (2) What is hard about hard, and (3) Orchestrating family life. Table 4 presents the 23 studies and how they contributed to the themes and subthemes.

Theme 1: Sensory differences and routines in daily occupations

The first theme relates to how parents experience living with a child with sensory differences. Three subthemes were identified: occupational experiences in sensory worlds, forensic sense making of sensory experiences, which allowed parents to understand these processes further and routines in daily occupations of families.

TABLE 3 CASP qualitative research scoring tool (rated as yes [green], no [red], unclear [purple]).

References	Question 1: Was there a clear statement of the aims of the research?	Question 2: Is a qualitative Methodology appropriate?	Question 3: Was the research design appropriate to address the aims of the research?	Question 4: Was the recruitment strategy appropriate to the aims of the research?	Question 5: Was the data collected in a way that addressed the research issue?	Question 6: Has the relationship between researcher and participants been adequately considered?	Question 7: Have ethical issues been taken into consideration?	Question 8: Was the data analysis sufficiently rigorous?	Question 9: Is there a clear statement of findings?	Question 10: How valuable is the research?
Burkett et al. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Burrows et al. (2008)	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	Yes	
Columna et al. (2020)	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
DeGrace (2004)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
DeGrace et al. (2014)	Yes	Yes	Unclear	Yes	Yes	No	Yes	Yes	Yes	
Dickie et al. (2009)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	
Epstein et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	
Galbraith and Lancaster (2020)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	
Harwood et al. (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	
Keller et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Kim et al. (2018)	Yes	Yes	Unclear	Yes	Yes	No	Yes	Yes	Yes	
Kirkpatrick et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Larson (2006)	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	Yes	
Larson (2010)	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	Yes	
Marquenie et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	
Naik and Vajaratkar (2019)	Yes	Yes	Unclear	Unclear	Yes	No	Yes	Yes	Yes	
Potter (2017)	Yes	Yes	Yes	Yes	Yes	NO	Unclear	Unclear	Yes	
Redquest et al. (2020)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	
Rios and Scharoun Benson (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	
Schaaf et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	
Shannon et al. (2021)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	
Suarez et al. (2014)	Yes	Yes	Yes	Unclear	Yes	No	Unclear	Yes	Yes	
Tokatly Latzer et al. (2021)	Yes	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	

TABLE 4 Contribution of included studies toward themes.

References	Theme 1: sensory differences and routines in daily occupations			Theme 2: what is hard about hard?		Theme 3: orchestrating family life	
	Occupational experiences in sensory worlds	Forensic sense making of sensory experiences	Routines in daily occupations of families	The hard work in establishing routines	The relentless need for vigilance	Positive sensory experiences for the child	Doing family differently
1. Burkett et al. (2021)		X		X			
2. Burrows et al. (2008)			X	X	X		X
3. Columna et al. (2020)				X	X		X
4. DeGrace (2004)			X		X		X
5. DeGrace et al. (2014)			X		X	X	
6. Dickie et al. (2009)	X	X	X	X		X	X
7. Epstein et al. (2019)	X	X		X		X	X
8. Galbraith and Lancaster (2020)	X	X				X	X
9. Harwood et al. (2019)	X					X	
10. Keller et al. (2014)			X	X			
11. Kim et al. (2018)						X	X
12. Kirkpatrick et al. (2019)		X	X	X			X
13. Larson (2006)			X	X	X		X
14. Larson (2010)	X		X	X	X		X
15. Marquenie et al. (2011)			X	X			
16. Naik and Vajaratkar (2019)	X		X	X		X	
17. Potter (2017)			X	X			
18. Redquest et al. (2020)	X					X	
19. Rios and Scharoun Benson (2020)				X			
20. Schaaf et al. (2011)	X	X	X	X			
21. Shannon et al. (2021)				X			X
22. Suarez et al. (2014)		X	X	X			
23. Tokatly Latzer et al. (2021)		X	X	X			X

Occupational experiences in sensory worlds

Parents described a multitude of occupational experiences that can be understood from a sensory perspective, primarily relating to auditory and tactile sensitivity. Auditory sensitivity was a common theme spoken about from the parents' perspective, and parents reported on the severe impact these sensory experiences were having on their children and how they impacted their daily occupations and family routines: *"It's not just the loudness. It's the intensity. He perceives it so clearly that he goes into the moment. He can't separate himself from it"* (14). Children frequently responded by "*having a meltdown*" due to unexpected unpredictable sudden sounds, or from too many competing sounds such as fire alarms, toilet flushes in public restrooms, dogs barking, other children crying, loud coughing (6, 8). Auditory sensitivities were particularly evident in family outings to museums, movies, amusement parks, or religious events which were often accompanied by sensory qualities, such as unexpected loud noises (14). However, even ordinary occupational routines such as vacuuming was discussed by many as upsetting and distressing their child (6, 7, 9, 18, 20). *"She's slightly sensitive toward noise . . . . if there is a lot of chaos going on she does become really quite agitated, and they don't help"* (14).

Parents reported on the tactile experiences of their children and how this altered the bathing occupations of their child. *"I get him out of the bathtub and wrap him really tight in the towel. I do it quick.... If you start wiping him instead of wrapping him in a towel to try and get the water off... that is something that is aversive to him"* (20). Children often experienced distress from self-care occupations requiring tactile input, relating to their face and head (6), such as having their ears cleaned, having their face touched, and having haircuts. One mother reflected on her child's experiences: *"I'm not sure if it is exactly painful or not. But it's definite he feels it differently than we do, that's for sure"* (6). Occupational experiences of dressing were also documented and associated with tactile sensitivity: "*He does not like tight fitting clothes and clothes with tags*" (16). Consequently, these children avoided wearing certain types of cloth materials, printed clothes, and clothes with tags and collars (16). Overall, parents expressed the realization that their child experienced senses differently, that this experience was real, and even perhaps painful, and certainly caused distress (6, 8). This is indicative of how parents have a unique and invaluable insight into their child's lived experience within their daily occupations.

Forensic sense making of sensory experiences

Forensic sense-making of sensory experiences was a recurring concept across these papers and conveys the need to conduct constant scientific analysis and interpretation of physical evidence, in order to understand what the child's sensory experiences were. This second sub theme relates to how parents engaged in an ongoing process of detective-work, and that this could be confusing, and required a forensic approach: "*What's the issue? How can we help them? because I don't get it. You know, I have been with this kid for 8 years. And, uh, I still don't get it*" (22). Many parents reflected on the erratic and unpredictable pattern to their child's sensory processing needs. One mother was particularly mystified by her child's sensory needs: "*My mind is constantly on... What can I do now? How can I handle this? [he's telling me] the car seat... It's not firm enough... it's like a sensory integration thing... I'm tired of thinking*" (12). Parents tried to make sense of their children's responses to sound *"Maybe his reactions are just a little brisker than most people..."* (6). Being able to understand what sounds bother a child, under what circumstances, makes it possible for parents to avoid situations, prepare the child, or use other strategies to diminish the impact on the child. *"I have no idea why he likes things. I don't know if he's experiencing it in the same way I would"* (6). Yet, parents showed an intense understanding of sensory influences because of this forensic work: for example, where the child avoided the vacuum cleaner only when it was turned on but was seen to play with it when it was turned off proved to this family that the child was sensitive to the loud sound and not the object (6).

Parents often hypothesized why their child liked various sensations *"she loves being under water. Maybe the pressure of the water, the blocking out maybe of certain sounds?"* (7). Unusual sensory experiences presented puzzles that parents tried to understand *"why you would need to jump up and down, you know, and make yourself feel good, or, you know, why you constantly need to chew on stuff"* (6). One parent reported that after her child engaged in swimming activities, he would have to have a P-chewy device: "*We have got to have a P-chewy right there and he needs like a minute or two [of chewing]. I don't know if it is because of all the input of the water and swimming that he just needs to kind of download...*" (20).

Forensic sense-making existed concurrently with confusion. For example, in relation to food sensitivities one parent said: *"Could it be the flavor, could it be the color, could it be the sensory aspect, could it be this, could it be constipation? It's over analyzing things. . . to the point of exhaustion. It's like you have to cover so many bases for one simple problem"* (1). Parents put themselves in the child's shoes and reflected "*I don't know how I'd go eating something that was different to what I expected*" (8). There appeared to be confusion over mealtimes in that one strategy may work 1 day but not on another: "*He KNOWS the difference. He refuses; he will just spit it out unless it's exactly right. Like, even macaroni and cheese. If I cook the noodles for 2 min too long and they get soggy, he won't touch it. Even though it's the same exact ingredients*" (22). Parents detailed understanding of their child's interoceptive cues was also discussed across the papers and was evident in relation to the child's variable hunger responses: "*He is always saying, I'm hungry, I'm hungry, especially at bedtime. I sometimes think he is hungry . . . and then . . . is he getting enough to eat but you just don't know*" (12). *"All day long he opens the refrigerator. He just wants to eat all day. He can't get full. He* *just stuffs more and more things in his mouth and he cries and shouts that he wants more food. He's getting fat and it's unhealthy"* (23). Parents knowledge, attitudes and practices of their child's individual physical health needs was a prominent feature and demonstrated the essential resource they have in managing their child's success in daily occupations.

Routines in daily occupations of families

Routines as a way of living life were a significant theme in these studies and highly valued as a means to mitigate the sensory-emotional world experienced by the child. Functioning routines were proposed as the main way to order and structure life and integrate the child into family occupations across childhood (4, 13). Indeed, the purpose of routines went beyond this and served to provide reassurance to the autistic child, that once a routine was in place the child "*knows that all is well with the world*" (13), and without routines, the child could not cope: "*it would be awful without some kind of routine at night, he would have a meltdown, he just couldn't cope without a routine*" (12). Overall, routines helped the child in a number of ways, by providing predictability and clarity therefore of expectation, to manage transitions more easily and to reduce anxiety and thus develop confidence in themselves (6, 13). They consequently provided parents with comfort in knowing the child was secure and able to participate and enjoy family life (2, 4, 14).

Routines involved a predetermined set of steps *within a task* like bathing (e.g., undressing, playtime in the bath, washing, drying), or *within the event* like preparing for bed (e.g., teeth cleaning, toileting, dressing for bed, story reading) (15, 23). Routines were also embedded in temporal contexts with set times for getting up or going to bed each day (16). While all studies explored daily occupations in general, some papers focused intensively on mealtime and bedtime routines that are consistently documented as most challenging for families of autistic children (12, 15, 16, 17). For mealtimes, for example, one study documented the diverse influences on how a child might react at mealtimes when "*issues related to food were not limited to one sensory aspect but rather included texture, taste, smell, visual aspects of the food itself, and having the food on hands or tongue."*(6). This awareness of sensory influences warranted a lot of thought and planning to ensure that the sensory experiences related to mealtimes accounted for the child's needs, and therefore were predictable and avoidant of novelty. This frequently involved multiple meals being cooked for all family members (22). For many families, mealtimes were rarely a time for togetherness emotionally or physically.

For the daily routine of bedtime, there was a core ritual of performance required: families described it in this order: "*the sequence of routines tended to involve: bathing, teeth cleaning, toileting, dressing in pajamas; then play/television or story reading; good night hugs/kiss, having a drink, getting a comfort toy, followed by lights out and lying down in bed with the child to assist transition to sleep"* (15). For bedtime routines, parents used their knowledge of the sensory sensitivities to devise sensory calming techniques to assist with settling the child to sleep, which included extra blankets, soothers or pacifiers, and low lighting (15). For some families the assistant dog provided the extra comfort for the child, enabling more successful sleep not just for the child but the parents also (2).

Common across the studies was the experience of anxiety in these children around bedtime. *"He would be fairly hyper in the evening time before getting to bed, so that it would impact on everybody. No-one gets any peace to do things"* (12). Although many families worked hard to establish bedtime routines that were predictable and calming for the child, nonetheless, children continued for many years to experience anxiety at bedtime and had extreme difficulties with sleep resulting in sleep deprived families (12, 17). This was often related to anxieties about the next day: *"If there's something happening at school that he wasn't happy about like going on a trip or something, you know out of the ordinary, he wouldn't like that. So, he would be worrying about it and he wouldn't sleep"* (12). Some families resorted to co-sleeping as a result (12, 17) but this family routine also became disruptive for the marital relationship: "*The fact that he is almost nine and still sleeping with me and you know my husband is working so he sleeps in another room. I struggle with that because it's making our relationship strained*" (12). Parents reflected on how the autistic child's sleep routine had to match the whole families *"My child will not go to sleep unless everybody in the house goes to sleep"* (16). In this instance, families were shown to be actively problem solving methods of interconnecting the child and families sleep needs, to allow for overall improved sleep for the family.

Routines were a way of enfolding family occupations into daily life and as such allowed the family to function. For example, one study (14) talked of how family members were able to find personal time for their preferred occupations once the autistic child was engaging independently in their own routines, demonstrating the positive effect of routines in family life. Yet for many, family occupations needed to be done in such a way that allowed for rapid adjustment, depending on the responses of the autistic child and determined by their sensory needs (20). This demonstrates how fluid and adaptable these families are in their ability to weave their child's needs into their daily life. A shared sense of joy was evident when everyday routines went well such as having a kiss and a hug before bed (10), parent–child hugging or snuggling routine (6), sitting in a restaurant when the child is content during the meal (5), touching or lying beside their assistant dog (2), when the child performed a new skill for the first time (jumped) (10). Overall, the outcome of orchestrating predicable and functioning routines was to achieve a "*reasonable life for family members*" (13).

Theme 2: What is hard about hard?

The second theme of "what is hard about hard" consisted of two subthemes: The hard work in establishing routines and the relentless need for vigilance, which reflects the backdrop to constructing family life. Parents documented what exactly was 'hard about hard' and how new ways of parenting were therefore required within this theme.

The hard work in establishing routines

Considerable skill, resilience and efficiency were required to develop routines (13, 14, 23). For example, families noted that although a child might engage in a routine, it often took a lot longer than expected to complete it which added much frustration in family life (13, 23). Some families talked of routines being impossible to implement or maintain however (12, 16, 17). This was often associated with the ever changing sensory and emotional needs of the child that were often difficult to identify as noted earlier (6) which one author described as the "wild card in daily routines" (13). One study (13) described it as "*a dance between creating a structure and then improvising depending on the child's responses, while minimizing the child's need to change in instances of anxiety*." A key feature across these studies therefore was the need to '*pick your battles*' as a way of constructing family life (15).

Building on the forensic sense making of sensory experiences from theme one, was the consensus that the design of routines required consistent "detective work" (14) and consistently involved consideration for the physical and sensory environment which determined the choice of tools for daily occupations, such as cups, plates, toothbrushes (1, 13), and for some was enhanced by the presence of an assistant dog (2). Designing routines also involved an understanding of how the child learns best and might include the use of verbal instruction (23) or visual schedules (16). Common to many studies was that functioning routines take significant time to develop in getting the child to try new activities and form new habits (1, 3, 19, 22). However, the outcome when a child achieved some new skill or routine was identified as extra special as a result (10).

Daily occupations were imbued with a high level of vigilance, due to the child's occupational behavior for example, roaming the house at night (5) or elopement and getting lost outdoors (21). Consequently, for daily occupations parents talked of needing to constantly build and orchestrate routines by drawing from a range of strategies: ordering, sequencing, predicting, restructuring, accommodating, performing. Sensory sensitivities commonly governed daily routines, and parents strove to understand the complex intersensory experiences of their children, for example, knowing the child's oral sensitivities for eating (6) or knowing to avoid tight clothes or clothes tags (16). Doing the small sequences of an occupation in the same order every day was a significant goal for some families (20).

Routines had a specific role and for some, family life did not require routines to be in place 100% of the time. Routines worked best when they provided an overall structure, with predictable patterns of activity (12). They also required flexibility, (7) with some families talking of needing a lack of structure at home to provide space for the child to unwind after school and place no demands on him: "*My son is calmer and quieter now, because no one is demanding anything from him. At school there are many demands, and there is discipline. At home it's much gentler and much more flexible*" (23). This difference between expectations at home and school diminished during COVID pandemic when lockdown resulted in many families dealing with home-schooling and dealing with the reality of the pandemic: "*My son had several events of anger outbursts during the night. He was wild and crazy. He wouldn't go back to sleep and screamed. I turned to a sleep clinic but due to the situation they are not working*" (23).

The relentless need for vigilance

While families within these studies explained processes for establishing functional routines, the child's inability to tolerate change in routine, the sensory environment and daily life was fundamental to how family life was hard. The natural consequence was an extreme commitment to developing routines to counter this inability to cope with change, and the "*all-encompassing extreme vigilance*" that was therefore required to support the child to take part in family life (14). As with all caregiving duties of young children, vigilance, safety and managing risks is to be expected. But the level of vigilance described in the studies reviewed, captured a more intense hardship, from the parents' perspective.

Relentless vigilance can be described as the moment to moment on guard approach taken by parents to ensure their children were in a manageable state to engage in occupations, this too included managing their child's sensory regulation in any given situation. Perhaps most consuming for parents was the anticipatory vigilance as expressed in one study "*There is this underlying current of "it's about to happen, he's going to start spiting*" (4). This persistent experience of "*somethings going to happen*" was repeatedly stated by caregivers as exhausting. "*We're all emotionally tired. We're all physically tired. We don't know if he's going to flip out if we go to somebody's house or... if somebody comes to our house... Even if he doesn't it's like a lot of work to... keep him even*" (14). Another study also reported that parents find vigilance permeates everything and as a result *"nothing we do is ever easy relaxing is difficult"* (14). Heightened sensory sensitivities of the child which were commonly associated with heightened emotional responses, led many parents to engage in hypervigilance. This often included living a life of high anxiety (6, 7, 12).

Constantly being on duty was a core feature to what was hard about hard and the impact on the family was immense:

"*Your whole family's life is always revolving around this situation, making compromises, because of doing extra work... he makes all the basic things a lot more harder, whether you're having a meal, whether you're taking care of your everyday activities, it's a lot of work*" (4). These compromises often revolved around the child's sensory preferences and needs (6, 9, 19, 20). This control of events was because the child was unable to cope with changes to routines (2, 3, 5, 13), many of which related to the sensory environment (7, 8, 12) and if adjustments were made, anxieties in the child often increased. For autistic children, this was identified as much more serious than for other children: *"the consequences are much more dire...and they leave a longer mark of anxiety...even if regular kids get anxiety ridden about the changes [when] they're tired and they're hungry...but with him it's like it build[s] up in his nervous system into this big mean anxiety blob*" (13). Yet families were also aware that long-term their child needed to build a capacity for flexibility in daily life, and the dangers of being too reliant on structured routines was a concern (3, 4). In many cases, parents had worked out contingency sensory strategies which assisted the child to adopt such flexibility to cope (9) and emphasizes the power of parents in steering their child's path.

Theme 3: Orchestrating family life

The third theme of orchestrating family life captured positive sensory experiences for the child and doing family differently as subthemes. Due to the forensic sense making of sensory experiences, and forensic vigilance, many families had worked out which sensory sensitivities and preferences their child experienced most and could anticipate which family occupations were consequently most enjoyable. This theme relates to the orchestration of family life within the context of positive regulatory sensory experiences for the autistic child and doing family differently.

Positive sensory experiences for the child

Within this theme, parents described sensory occupations that their child appeared to enjoy and in general were perceived as positive experiences. For example, children were documented as enjoying the sensory experiences of a companion canine, which seemed to provide a calming influence on them: "*he's got a very calming effect on Eve… when she is feeling a bit down or anxious and then you know he's a bit of a comfort to her*" (9). Positive experiences within daily routines and sensory encounters were reported. For example, parents reported their child enjoyed bathing compared to other self-care routines which was attributed to the calming effect of warm water on the body (16): "*He likes to dance. He likes to dance around in circles, and then any time he is in the bathtub he is happy*" (6). Deep pressure tactile experiences were described for some of the children within the studies, with examples of children seeking out opportunities for close physical contact from parents (e.g., hugs, massage): "*We have special time watching [television] at home, we have family time. He likes sitting on the couch between me and his dad, the deep pressure cuddles*" (7). Parents were quick to point out this was different to other children: "*You can definitely tell that whenever you hug him it's not, um, it's not normal. He's definitely getting more out of it than just a hug*" (6).

Visual experiences were also evident in the studies, such as "*seeing everything*," loving to see "*bubbles and balloons and things that fly around*," and enjoying turning the light on and off (6). There were also other preferred experiences relating to the vestibular and proprioceptive senses which children sought out. "*He likes swinging, he loves being on a swing. Like when it was 25°F out and snowing, we were in the swing*" (6). "*We've got a swing that she can go and take herself on whenever she's feeling stressed out, the vestibular stimulation on the swing helps a lot to calm her down*" (7). "*He likes to jump. So, he jumps a lot, and he appears to get pleasure out of that*" (6).

Outdoor access to nature was identified as an important context as it provided opportunities for diverse sensory experiences that appealed to the autistic child, for example of natural objects including sticks or leaves (6, 8) or simply watching wildlife: "*our son is an avid bird watcher. He can sit for hours filming, photographing, and documenting them*" (8). Parents in another study also shared this view *"Going out on the boat and seeing the dolphins with the family makes her incredibly relaxed and happy. Anything with the wind in her face makes her very happy"* (7). Children in this study (7) enjoyed time spent with pets, walking, or biking around their neighborhood, and visiting the beach or the zoo. Parents and their children engaged in shared participation (7) more readily in high intensity sensory experiences such as swinging (6), hiking (6), fishing (5, 11), bike-riding (18).

Doing family differently

This theme relates to how families of autistic children function differently in the way in which families go about their daily occupations, rituals and routines when living with an autistic child. Doing family differently encompassed a range of experiences such as knowing every day is a different challenge in family routines, needing flexibility for the child, following their child's agenda, shared participation and going out together as a family. In a similar approach used by Goodman et al. (2007) in their study of "doing dress", by naming this sub theme as "doing family", the concept of family is expanded beyond simply considering what a family is (e.g., family members and where they live), to include ideas of meaning, agency and context within family relationships and occupations.

Within the studies, parents described how "*every day is a different challenge*" (3). Being within the home environment appeared to provide a sense of safety, control and predictability within family routines (7, 8, 20). However, families described their days at home as being very busy and hectic (3, 4) with a significant part of the family's day revolving around the needs of the autistic child (4). Families described the differences in time pressures to get various routines fitted into the day such as eating, bathing and bedtime (3, 14). The morning routine for children and families was a key point raised (12), with getting the child up and ready in time for school being identified as a stressor in families: "*Getting him up for school in the morning is hard and you're encouraging, encouraging, encouraging him to get up, and he just gets angry … you know it's not going to be a good day in school*" (12).

Time spent in shared participation between parent and child typically pivoted around the child's occupational choices more than the parents' recreational preferences (11). Shared participation in activities as a family was usually dependent on whether the autistic child enjoyed those activities (3, 6, 11). Parents tried to be part of their children's activities and interests (2) and they would rather spend more of this time together (4). Parents found that the presence of a service dog in their family increased potential shared participation, on tasks such as grooming or petting the dog (2). Parents also reported that going places when their child had the support of their service dog such as ferry boat rides, airplane flights, weekends away were made possible (2).

Engaging in common family rituals such as going out together was discussed in some of the studies, yet due to the challenges of living with a child with sensory differences, families participated less often than they desired in activities such as shopping, going out to eat, family day trips, or vacationing (13). Going on a shopping trip could be a traumatic experience (13) and deciding to go someplace such as a restaurant or the cinema last minute was rarely an option as the child may not want to go inside once there. Given this context, there was a shared joy when families experienced success on these outings, for example being able to go to the supermarket and not have their child grabbing at things (4, 7)

Parents also noted other extra considerations that they put in place for example in outdoor nature: "*The unpredictability of wildlife! … We have deer in the yard, we have coyotes, there's bears*" (21). For these parents in Canada, their outdoor routines always required contingency plans for supervision of their child in these rural settings, to the extent that they had devised specific family safety plans to maximize success (21). Parents consequently sought safer, more enclosed outdoor places for leisure and play to avoid the constant need for supervision and to enhance the child's exposure to more independent movement outdoors.

Time together as a family was valued and prioritized (23): "*Stopping the rapid pace of life and having time together is appreciated. The more he spends time with his close family (like in family vacations), the bigger leap he makes.*" Some parents emphasized how family togetherness brought about positive shifts to the family dynamics. Their child's happiness was a core feature which parents reflected on. "*Like any other parent, it's happiness of course…you want your kids to reach milestones, reach independence*" (3).

Discussion

This qualitative synthesis explored insights into parental perspectives of autistic children with sensory processing differences within the context of family life. Three core themes were identified and categorized as; (1) Sensory differences and routines in daily occupations, (2) What is hard about hard, and (3) Orchestrating family life. The studies within this review, all shared the lived experience from the perspective of parents on meaningful participation in daily occupations, and routines when living with an autistic child. To be successful in family occupations requires a complex integration of multiple elements including knowing what is hard about the hard, in order to navigate through daily life and orchestrate success. Success does not ignore what is hard- being vigilant and forensic in making sense of the child's experiences is fundamental to being able to enable occupational participation. Therefore, the challenges cannot be ignored but instead integrated and acknowledged so that challenges are inherent in understanding successful occupations. They co-exist.

This study explored sensory differences and routines in daily occupations in family life, because less is known about living a life of sensory differences and its relationship with constructing meaningful and successful shared family occupations. The synthesis of findings suggests that living a sensory life as an autistic child is made up of multi-sensory experiences that cannot be singularly siloed or individually categorized in many circumstances of daily life. Sensory processing differences were not reported in isolation (e.g., tactile hyperreactivity) or in sensory subtypes by the parents in the studies of this review, but were discussed as a part of daily occupations and family routines. Similar to Dickie et al. (2009), findings highlighted that a child's sensory differences are multifaceted, complex, fluid and embodied in occupations rather than being experienced in silos, as individual sensory processing issues. Nature, service dogs, participation in sports, engaging with playground equipment outside the home and physical touch from their parents such as hugging were reflected as being successful multisensory experiences for some autistic children. Aversive sensory experiences added another layer to the autistic child's participation challenges and consequently family participation. For example, mealtime participation highlighted the multisensory nature of a daily occupation which autistic children must contend with, whereby issues related to food were not limited to just one sensory aspect but included texture, taste, smell, visual aspects of the food itself, having food on their hands or tongue, alongside associated aspects such as predictability, routine, and novelty. This review exposes how sensory processing differences in autistic children impacts daily routines within the context of family life, which has been well reported within the literature (Kern et al., 2008; Schoen et al., 2009; Hochhauser and Engel-Yeger, 2010; Lane et al., 2010; Marco et al., 2011; Ismael et al., 2018). Findings from this review identified how family life must be adapted and changed to flow and function in accordance with the child's own sensory needs and preferences in the moment, but with the future child in mind. The adaption and change required for successful engagement in occupation, depended on parents' intense engagement with vigilance and forensic sense making to understand the child's sensory life.

What's hard about hard was significantly associated with the sensory emotional world. The sensory-emotional world experienced by the autistic child was very clearly depicted by parents throughout this review. Many of the associated emotions reported such as pain, distress, anxiety were linked back to the child's experience of sensory stimuli, and hence parents engaged in processes of forensic sensemaking to mitigate the negative influences of living a sensory life. Parents talked of the vigilance required to understand the child's lived experience, and through detective work understood that their child experienced sensation differently. This perception of the child's lived sensory experience has been illuminated in reviews of biographies for example in Conn's work, whereby autistic adults described the intense ecstasy and vivid memories of sensory experiences as children (Conn, 2015). Understanding the connection between emotional associations with sensory experiences enhanced a parent's ability to support their child in daily life and routines, yet not all parents in these studies had made the connection between the sensory-emotional world of their children. Further promotion of sensory awareness among families is warranted to maximize understanding to support meaningful participation.

Routines are often considered to be the epitome of stability, safety and security (Fiese and Parke, 2002). Routines make up the rhythm and fabric of family life and reflect how humans can form habits to enable participation in the environment (Clark et al., 2007). For example, family routines were often used by parents as a gateway to enhance the child's participation, e.g., going out together as a family, playing in the outdoors, sharing experiences in nature or in leisure activities their child preferred. However, in this review, it was evident that routines were often enacted as a necessity and for the most part, families often had no choice in what routines were completed because as noted above, they needed a strategy to mitigate and minimize the impact of the child's sensory and emotional experiences. In addition, it was evident that some family routines occurred that did not reflect the family values, for example, taking care of a child's personal hygiene and grooming through the use of restraint, or orchestrating different mealtimes for family members. This is one of the answers to the question what is "hard about hard". Family routines may be adopted that reflect a mismatch between the values of the parents and the actions that they resort to using, which may be a result of lack of support, resources, education and/or societal pressures. Therefore, as health care professionals it is important that prejudice and judgment does not occur. An important consideration is that many think they know routines but unless you live a life with an autistic child, then the experience of routines can be very different. Hence, doing family differently needs to be accepted and embraced when addressing successful occupational participation in autistic children and their families.

Family-centered practice has been identified as a best practice framework when working with children with disabilities in health care internationally (Espe-Sherwint, 2008). The evidence base supporting this approach is strong (Dunst and Dempsey, 2007; Trivette et al., 2010) with effective outcomes for children and their families being reported in the literature (Dempsey and Keen, 2008). However, the use of this approach in practice should be continually reviewed and examined, to acknowledge the context and culture of the family narrative. One of the roles of occupational therapists within this area of practice is helping parents and families identify and understand how their child's sensory processing differences influence their daily occupations and participation in routines. Based on the findings of this review, more is needed to help parents to understand the links between sensory processing challenges and meaningful participation with the culture of family life specifically, and how supporting these functions, can champion family centered practice, in reality. Augmenting parents' understanding of how their children's sensory processing differences are linked to the specific daily routines and application of forensic sense making in their child's sensory processing is required in practice. This review builds on Boyd, Harkins-McCarthy and Sethi (2014) study, which prioritized the need for further research in this field to investigate how families successfully engage in shared daily occupations and routines within the context of family life across childhood and adolescence.

Strengths and limitations

This paper is the first meta-ethnography to our knowledge that focuses on parental perspectives of autistic children and sensory processing differences in relation to meaningful participation in daily life, family routines and co-occupations and provides new interpretations of the subject matter. This paper was conducted in a robust manner ensuring high quality standards; with the authors adhering to the eMERGe and PRISMA guidelines. Greater diversity amongst the types of families included in the studies in this review, as well as having greater representation of families from more countries globally would allow for increased generalizability of findings. The context of many of the studies included in this review captured a minority world population. Interestingly when screening the studies, a high number from Asia and the Middle East focused on the stress associated with a autistic child's diagnosis, the parental burden of caregiving for an autistic child and the cultural stigmatism associated with such a disability. While efforts were made during the screening process to include studies across diverse cultures, it was notable that stigma in many studies was the more significant factor, rather than how to live family life successfully. No studies were found that addressed this topic of autistic children and their families using a strengths based perspective from majority world countries. Additionally, variance in the quality of articles reviewed may impact results reviewed in this study and this should be taken into consideration. For the majority of studies, the relationship between the researcher and participants had not been adequately considered and it was unclear in 6/23 studies whether the recruitment strategy was appropriate to the aims of the research. In 7 of the 23 studies, it was unclear whether ethical issues had been taken into consideration. A further limitation of this review is that strategies to support routines utilized by autistic children and families were not specifically focused on, as it was beyond the scope of this paper. Furthermore, one of the authors is a clinician working with families of autistic children and this personal bias may have influenced the results. This review was a collaboration between three white authors based residing within the same country. We acknowledge that while we represent some diversity of lived experience, including culture and education, our work is influenced by our relatively privileged backgrounds. We have all been raised in developed countries, and have all completed post-graduate university education.

Future research

More research study of family routines and how this relates to a child's specific sensory differences is required, so a greater understanding exists of how to support a child's sensory needs in conjunction with their own and their families' daily occupations and routines. Future research needs to encompass a strengths-based approach to how autistic children with sensory processing differences engage in shared participation with their families. Further research within sensory processing and autism specifically, needs to focus on how family life gets addressed and how family values can be integrated into this intervention approach.

Conclusion

This study reports on a meta-ethnographic synthesis that was conducted to illuminate the parental perspectives of autistic children within the family context. The findings of this study illuminated the sensory differences and routines in daily occupations, understanding on a deeper level what is hard about hard and the outcomes of orchestrating family life. As the prevalence of autism continues to rise and the demand for effective rehabilitation services increases for this population, a greater understanding is required on how families and their autistic children with sensory processing differences engage successfully in meaningful occupations, particularly within their own home environments and community settings.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding authors.

Author contributions

GD, HL, and JJ contributed to conception and design of the study, performed the qualitative analysis and synthesis, and wrote sections of the manuscript. GD and HL organized the database and wrote the first draft of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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Conflict of interest

The authors declare that the research was c17g17gonducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.940478/full#supplementary-material

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