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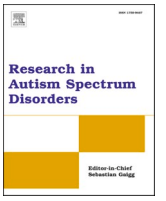

Parental descriptions of sensory processing in Autism

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ABSTRACT

Background: The processing of sensory information in autistic people has a major impact on their daily lives. Current research faces challenges in fully capturing the heterogeneity of sensory profiles in autism, but caregiver perspectives could offer valuable insights, deepening our understanding of these differences in sensory experiences. The present study aimed to explore this sensory processing characterization based on the testimonies from caregivers of children and adults with autism to contribute to the knowledge obtained from answers to questionnaires.
Methods: Caregivers of 15 participants with autism, aged between 4 and 34 years, participated in focus group sessions. Each session was conducted using open-ended questions on sensory processing, and their responses were analyzed by means of semantic analysis using NVivo software.
Results: A thematic analysis of the data corpus highlighted three themes of behavioral responsivity to sensory input as reported by parents: (1) sensory input, (2) sensory modulation, and (3) impact on daily life. Sensory input encompassed seven sub-themes related to sensory channels. Sensory modulation allowed for the identification of sub-themes such as sensory overload, emotional regulation, and regulation strategies. Finally, the theme of the impact on daily life highlighted sub-themes of reactions to change, feeding problems, and risk-taking behaviors.
Conclusions: These findings suggest that some identified aspects, such as stimming and sensory-seeking, sensory overload and regulation strategies could potentially be added to sensory evaluations.

1. Introduction

Sensory processing (SP) is commonly described as atypical in autism by the scientific and clinical community. In 2013, the DSM-5 formally recognized these sensory specificities as a diagnostic criterion for Autism Spectrum Disorder (ASD): "Criterion B4. Hyper or hypo-reactivity to sensory stimuli or unusual interest in sensory aspects of the environment" (American Psychiatric Association, 2013). Moreover, both families and autistic people report that atypical SP profoundly impacts daily life, potentially complicating routine activities and social interactions (Bagby et al., 2012; Dickie et al., 2009; Kirby, Little et al., 2015).

Conceptualizing SP within autism is challenging, primarily due to the wide variety of models and methods used for its characterization (Brouche et al., 2024; Cascio et al., 2016; Schauder & Bennetto, 2016). A review of neurophysiological SP in autism highlighted difficulties in synthesizing neuroscientific data on this topic attributable to the disorder's heterogeneity (Marco et al., 2011). A recent review of the taxonomy has highlighted the challenge posed by the inconsistent use of terms to refer to SP differences in autism (He et al., 2023). The authors have proposed a hierarchical taxonomy comprising five levels: sensory-related neural

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excitability, perceptual sensitivity, physiological reactivity to sensory input, affective reactivity to sensory input, and behavioral responsivity to sensory input.

Different frameworks have been proposed to understand the specific processing of sensory stimuli in autism at the behavioral level. Ayres (1972), pioneered studies on sensory integration disorders in children with autism and related conditions, defining sensory integration as the ability to process and organize sensory information. Building on her neuro-behavioral theory, Ayres developed a therapeutic sensory-motor approach (later known as Ayres Sensory Integration®) targeting five distinct syndromes (Ayres, 1965, 1969). This work provided the first systematic classification of sensory manifestations in children with neurodevelopmental disorders.

Currently, Dunn's theory is the most widely accepted in the scientific community regarding SP in autism (Dunn, 1997, 2007). Dunn developed a theory of *neurological thresholds and behavioral responses*, which has since predominated in the clinical practice of SP in autism. This theory suggests that a modulation anomaly in autism leads to abnormal integration of sensory stimuli in the central nervous system, resulting in either hyper- or hypo-reactive processing to environmental stimuli. These two categories (hyper/-hypo-reactivity) are used to characterize the SP of children or adolescents with autism in both clinical and research settings. Dunn's SP model is represented by a quadrant composed of two axes: neurological response thresholds (high or low) and behavioral responses (active or passive) (Dunn, 2007).

Although they have significantly advanced our understanding, current models may have certain limitations in capturing the variability of sensory experiences manifested in autistic people. Sensory responses are classified in a linear manner, which does not always reflect contextual and individual variations.

For evaluating behavioral responses to sensory input, questionnaires are the most commonly used method according to systematic reviews on the subject (Brouche et al., 2024; DuBois et al., 2017; McConachie et al., 2015). The *Sensory Profile* and its associated versions (i.e. *Short Sensory Profile , Infant/Toddler Sensory Profile, Adult/Adolescent Sensory profile*) are the most frequently cited questionnaires, used for both children and adults (Burns et al., 2017; DuBois et al., 2017; Yeung & Thomacos, 2020). Another evaluation method is semi-structured observations. The *Sensory Processing Assessment* (Baranek, 1999) and the *Sensory Processing Scale* (Schoen et al., 2014) are two clinician-administered observations that target behaviors of hyper- and hyporeactivity in response to stimuli. The *Sensory Assessment for Neurodevelopmental Disorders* (Siper et al., 2017; Tavassoli et al., 2016) also offers a comprehensive observation combined with an interview with parents. The criteria are based on those of the DSM-5, focusing on hyperreactivity, hyporeactivity, and sensory seeking behaviors.

Nevertheless, questionnaires and semi-structured observations may have limitations in capturing the complexity of an individual's sensory responses. These methods rely on standardized grids or closed-ended questions, which risk losing valuable information. For example, items related to auditory evaluation in the *Sensory Profile 2* do not include certain sensory aspects such as response latency to sounds, auditory discrimination abilities, and the capacity to localize sound origin, despite their demonstrated specificity in autism (Bouvet et al., 2016; Michel et al., 2023; Otto-Meyer et al., 2018). Identifying these aspects would provide a more precise clinical profile of the individual and facilitate more targeted intervention strategies.

A number of studies have already employed qualitative approaches to examine the sensory experiences of autistic people, contributing to a growing body of knowledge in this area (Dickie et al., 2009; Little et al., 2022; MacLennan et al., 2022, 2023; Pfeiffer et al., 2017; Schaaf et al., 2011; Strömberg et al., 2022). These sensory experiences have been explored from the perspectives of both autistic adults and children, encompassing a range of cognitive profiles (Kirby & Dickie, 2015; Robertson & Simmons, 2015). Notably, a metasynthesis of 32 articles highlighted the importance of a holistic approach to understanding these sensory experiences, integrating physical, emotional, relational, and social dimensions, while challenging the traditional cause-effect model (Sibeoni et al., 2022). However, this body of research has primarily focused on first-person accounts from autistic people.

Exploring the perceptions of parents of autistic people, who have been less explored, through focus groups can allow for the identification of new insights regarding SP in autism. This approach could potentially complement and enhance existing conceptualization and assessment tools by offering a holistic perspective that considers the complexity of sensory experiences beyond the traditional cause-effect model. By providing a unique viewpoint, parents can deepen our understanding of the diverse needs arising from these perceptual differences in daily life. Parents, as keen observers, are best placed to describe sensory experiences of their child. The objective of our study was to identify patterns of SP-related behaviors in everyday life, as described by parents, to compare the participants' descriptions with current scientific knowledge and tools. Descriptions of behavioral responsivity to sensory input in autistic people were extracted and organized from focus groups using thematic analysis.

2. Methods

2.1. Ethics

The study protocol was approved by the Ethic Committee of the UFR SPSE (Psychological Science and Education Science Formation and Research Unit) at Paris Nanterre University in accordance with the Declaration of Helsinki (Project ID 2021–03-03).

2.2. Participants

Participants were recruited from the French Autism Resource Center (CRAIF). The CRAIF relayed the study through its caregiver training mailing list and social network channels (Facebook page). Interested participants were invited to contact the investigator via email and were subsequently called to arrange a phone meeting to discuss the terms of participation. Parents who expressed interest in participating were sent a consent form and an information sheet detailing the focus group process.

Caregivers had to meet the following criteria to be included: (1) caregiver of a child or adult with autism; (2) diagnosis confirmed by a qualified practitioner; (3) absence of epilepsy and genetic diseases in the child. A total of 14 caregivers of 15 children and young adults (five women and ten men) were recruited for the focus groups (Table 1). Four focus groups were organized based on the children's age: 3–5 years ($n = 3$, m_{age}=4.33 ± 0.58); 6–12 years ($n = 5$, m_{age}=8.40 ± 1.52); 13–17 years ($n = 4$, m_{age}=15.25 ± 1.71); > 18 years ($n = 3$, m_{age}=25.33 ± 7.77). Caregivers reported that six children had comorbidities, including attention deficit hyperactivity disorder (ADHD) and attention deficit disorder (ADD). Most children ($n = 12$) were verbal, with only three non-verbal individuals. Additionally, one child had a diagnosis of dyspraxia and another had a visual impairment.

2.3. Protocol and materials

The focus groups were conducted by videoconference due to the COVID-19 pandemic, with a duration of 87 to 92 min. Each group was led by two investigators: one researcher and one clinician specialized in autism. The participants' comments during the focus group were audio recorded. The focus groups were structured into three parts: presentation of the group's objectives, open-ended questions on SP and exchanges on sensory-related situations from a question box. The open section comprised five questions. These questions were not based on any existing theoretical framework to avoid influencing the data collected. They were carefully crafted to foster discussion about sensory experiences observed by parents, ranging from general to detailed:

(1) When you hear the word "sense", what does it spontaneously make you think of?

(2) Do you think that your child's senses function differently from those of other children? If so, when or how did you become aware of this?

(3) How do you see them working differently?

(4) Which of your child's senses strikes you the most? What behaviors does it manifest?

(5) What are the consequences for you and them in your and their daily lives?

The question box was prepared before the group. Each participant was asked to write down sensory-related situations involving their relative with autism and send these to an email address created for the study. The participants' testimonies were anonymized and discussed by the investigators during the focus group.

2.4. Data analyses

For this study, thematic analysis was chosen, which is a method for generating patterns of meaning across a dataset that addresses a research question (Braun & Clarke, 2006, 2019). An inductive approach was employed, meaning that the themes were generated directly from the collected data without the influence of any pre-existing theoretical frameworks. This analysis was conducted at a semantic level, focusing on the explicit meanings within the data rather than on latent interpretations. Furthermore, an essentialist/realistic analysis was adopted, aiming to capture the parents' experiences as they were described and perceived in their everyday reality. The six phases recommended by Braun and Clarke (2006) for conducting thematic analysis were applied in this study:

2.4.1. Phase 1

An initial familiarization with the data was carried out during the transcription of the focus group audio recordings. As a

Table 1
Participant's characteristics.

Participants by age group	Child's age (in years)	Gender of the child (Female/Male)	Diagnosis age (in years)	Psychiatric or neurological comorbidity	Language (Verbal/ Non-verbal)
3−5 yrs					
1	5	F	3		Non-verbal
2	4	M	3		Verbal
3	4	M	1		Non-verbal
6−12 yrs					
4	11	M	9		Non-verbal
5	8	M	5	Dyspraxia	Verbal
6	7	M	6	ADHD*	Verbal
7	8	M	7		Verbal
8	8	M	5	ADD**	Verbal
13−17 yrs					
9	13	M	5	ADHD	Verbal
10	15	F	13	ADHD	Verbal
10#***	17	F	15		Verbal
11	16	M	16		Verbal
≥18 yrs					
12	19	M	18		Verbal
13	23	F	22		Verbal
14	34	F	32	Visually impaired	Verbal

*__ADHD__: Attention deficit hyperactivity disorder; **__ADD__: Attention deficit disorder; ***10#: Same caregiver but with two children diagnosed with autism

preliminary step, we repeatedly reviewed the *data corpus*, which comprised the complete transcriptions of the focus groups, to develop a deeper understanding of the overall data. Two reviewers took free-form notes to extract an initial list of ideas contained in the focus groups. The *data corpus* had a total duration of 469 min and included 25,056 words.

2.4.2. Phase 2

After the audio recordings of the focus groups were transcribed and imported into Nvivo 1.5 (Lumivero, 2021), initial coding was performed. Extracts from the *data corpus* (referred to as *data extracts*) that contained information on sensory manifestations were highlighted and organized into codes (see supplementary material). *Data extracts* refer to specific portions or segments of raw data that are selected from a larger dataset (Braun & Clarke, 2006). Double coding was conducted by two independent investigators and cross-checked to avoid any processing bias. A consensus coding approach was applied, in which we compared codes one by one. When discrepancies arose, the coders engaged in discussion to explore the differing interpretations and collaboratively determined the most appropriate code. Eighty-eight codes were identified, representing a total of 204 *data extracts*, amounting to 11,324 words.

2.4.3. Phase 3

Following the development of a code list derived from all focus group data, the codes were sorted into coherent sets to form themes and sub-themes. Several configurations of theme sets were tested by the authors to organize the codes until a consensus was reached on three themes and fourteen sub-themes. The data collected, comprising 14 participants right after the fifth focus group, were sufficient to reach saturation.

2.4.4. Phase 4

The coherence of the themes was verified by inspecting the data contained within each theme. The *data extracts* in each theme were reviewed to ensure they formed a coherent theme. If a theme did not correspond appropriately, it was either reworked, or the *data extracts* were removed and reassigned elsewhere. A thematic map was then created to represent all themes and sub-themes, and this map was compared against the entire data set (Fig. 1). All authors participated in and approved the final map.

2.4.5. Phases 5 and 6

During phase 5, the themes and sub-themes were refined and an exhaustive definition was applied to each. Finally, all authors participated in and approved the final categorization of the subthemes. The final step involved producing a report and detailing the analytical approach. The aim was to explain how the themes derived from our data addressed our initial research question. The results of phases 5 and 6 are presented in the results section.

2.5. Data reliability and validity

Data saturation was achieved by continuing data collection until no new ideas emerged from the focus group. Redundancies in participants' responses confirmed that the breadth of observations had been fully captured.

To ensure the trustworthiness of the data analysis, researcher reflexivity was employed by maintaining a reflexive stance to minimize the influence of personal biases on the interpretation of the results. Before and after each interview, the respective perceptions of the participants' discourse were discussed, reflecting on how expectations or hypotheses might have influenced the conduct of the interview. These discussions allowed for adjustments in follow-up questions and positioning as needed. Additionally, during the analysis, views were regularly exchanged on the rationale behind coding choices and the organization of themes and sub-themes. These critical discussions helped clarify interpretations and ensured that the conclusions were firmly grounded in the data rather than in personal expectations.

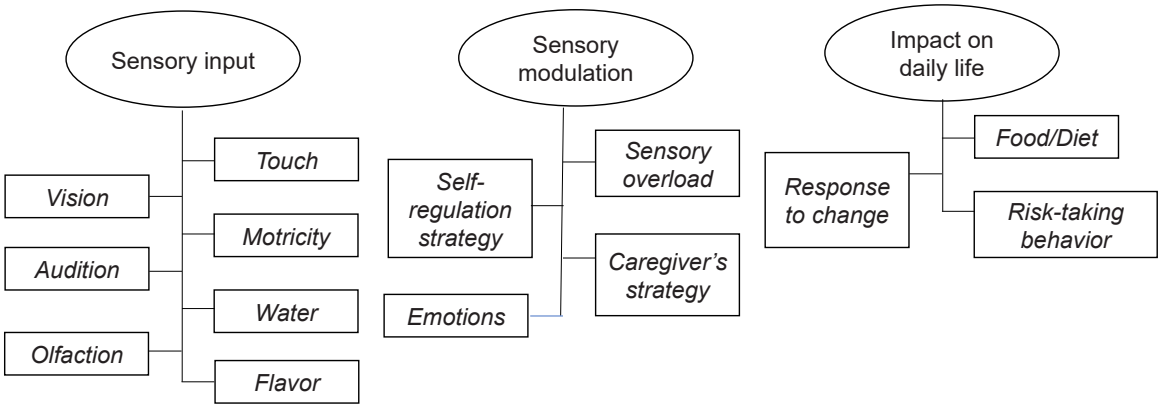

Fig. 1. Thematic map of themes and sub-themes in parental descriptions of sensory processing in autism.

3. Results

Three main themes were identified (Table 2): (1) sensory input, (2) sensory modulation, and (3) impact on daily life.

3.1. Theme 1: sensory input

The major theme identified during the focus groups ($n = 101$ *data extracts*; 49.51 % on the total sample) concerned the description of atypical behavioral responses to sensory input. Six senses were detailed as sub-themes (touch, vision, audition, proprioception/vestibular, olfaction and flavor) and a special case of sensation with water was as a multisensory stimulation source. The results of the themes and sub-themes are presented below in order of frequency. Relevant *data extracts* for each sub-theme are illustrated in Table 3.

3.1.1. Touch

Behavioral response to touch were the most often described among the theme of sensory input in the focus groups ($n = 33$; 16.18 %). Touch sensations referred to behaviors related to pressure on the skin. Several *data extracts* pertained to the relationship with textures, featuring behaviors of aversion, attraction, or sensitivity. Regarding behaviors related to body sensitivity, they appeared to be related to four types of stimulation: hair, sole of the foot, light touch and clothing. Other *data extracts* from the sub-theme of touch were linked to a search for deep pressure for the participants. Physical contact was also reported by caregivers as a significant aspect of behavioral responses related to touch. Several sensation-seeking behaviors related to touch were also described.

Temperature sensations referred to the ability to detect temperature. Some behavioral responses to temperature were described by caregivers, such as a preference for heat or cold or high sensitivity. Regarding pain sensations, the reported *data extracts* indicated that autistic people showed either hyposensitive or hypersensitive behavioral responses to the sensation of pain. This description was the least represented in terms of sense of touch. It did not appear to be present in all autistic people.

Behavioral responses related to touch sensations were widely described among participants. On the other hand, it varied greatly in intensity and manifestation between people.

3.1.2. Vision

Behavioral responses to visual stimuli ($n = 19$; 9.31 %) were the second most commonly described sensory input in this theme. Visual stimming behaviors were identified from *data extracts*. These stimming could be performed through various visual sources such as brightness, movement, alignment, or rotation. Fascinations with light were described in a few children (sunlight, LEDs and colored light). Several *data extracts* describe visual stimulations through movement. The alignment of toys/objects and rotation was described by caregivers as a source of positive stimulation. On the other hand, crises could be triggered in children if they were stopped in their exploration. Behaviors of searching for small objects in connection with an interest in details, like dust or hair, were reported by some caregivers. Changes in brightness could also be described as a source of discomfort, for example, when transitioning from a very well-lit environment to a darker one. According to the caregivers, atypical responses to visual input were one of the first signs they noticed about their child's functioning. The participants' behaviors in response to visual stimuli could be described as either overstimulating or a means of sensation-seeking.

3.1.3. Audition

Atypical behavioral responses to auditory input were reported less frequently by caregivers compared to touch and visual inputs

Table 2
Summary of data extracts frequencies by themes and sub-themes according to age groups.

Themes	Categories	Total data extract for all groups (*N*=204)	3-5 years-old (*n*=42)	6-12 years-old (*n*=73)	13-17 years-old (*n*=49)	> 18 years-old (*n*=40)
Sensory input		101	21	31	30	19
	Touch	33	2	14	11	6
	Vision	19	10	5	1	3
	Motricity	15	4	2	4	5
	Audition	16	2	5	6	3
	Water	8	1	3	4	0
	Olfaction	7	0	1	4	2
	Flavor	3	2	1	0	0
Sensory regulation		67	5	28	15	19
	Sensory overload	28	2	17	4	5
	Self-regulation strategy	19	1	7	4	7
	Caregiver's strategy	14	2	4	7	1
	Emotions	6	0	0	0	6
Impact on daily life		36	16	14	4	2
	Response to change	12	5	7	0	0
	Food/Diet	19	8	5	4	2
	Risk-taking behavior	5	3	2	0	0

Table 3
Illustrative data extracts for the 'Sensory input' theme.

Theme 1: Sensory input	
Touch	
Aversion	'[…] so, all the playdough, things like that, all the sensory activities no longer worked' (3–5 yrs) (1A)
Attraction	'We can see that he loves to touch, so anything with very special textures […]. He will play with straw, with sand.' (6–12 yrs) (6B)
Sensitivity	'She also explained to me that sometimes she touches certain surfaces and it stresses her out. So she also knows which surfaces to turn to for comfort.' (>18 yrs) (12D)
Hair	'My daughter said she had a headache, and we couldn't touch her. Whenever we brushed her hair, she would say it hurt.' (>18 yrs) (13D)
Sole of the foot	'[…] He would scream when he stepped on soft sand. However, when we tried to put him on very hard sand, it was better. […]' (6–12 yrs) (4B)
Light touch	'But, what was problematic was the face. Because, like, when it was a light touch, the contact with the skin it was complicated.' (13–17 yrs) (10C)
Clothing	'Same thing at 18 months, there was this whole thing about textures and touch. Meaning, he started to not stand certain clothes anymore. Anything that was tight became unbearable.' (3–5 yrs) (1A)
Seeking deep pressure	'[…] the first thing we noticed that seemed a bit strange was why our child would go under the mattress instead of under the sheets. If the mattress was heavy, like a regular bed instead of a baby bed, it was even better because it was a lot of weight on him.' (13–17 years) (10C)
Physical contact	'There was this sensory issue with touch contact because she was crying all the time, and when we picked her up, she was all stiff.' (13–17 yrs) (9C)
Sensation-seeking touch	'[…] she will tend to want very soft things, she will constantly touch her ear, actually touch the very soft parts there. She seeks them out. Even the very small soft parts or soft fabrics, she will constantly touch them.' (13–17 yrs) (9C)
Temperature sensations	'It's difficult, me I know once we took him to the ENT [Ear, Nose, and Throat specialist]. He put a thing in his ear that for us is cold. Actually, it's this battery thing, I don't know what it is. But he screamed. To him, "it's burning".' (6–12 yrs) (4B)
Pain sensations	'And the other day he was taking his shower, and he had these big blisters that were bleeding, that opened up, and when I noticed, I asked him, 'Doesn't that hurt?' And turns out, he doesn't feel pain. Ever since he was little, often he'd fall and not even react. And I'd think, 'He's tough.' (13–17 yrs) (11C)
Vision	
Brightness	'It always needs light in the evening. It needs bright lights as well. It needs an LED cord. Red, yellow, green, etc. […] Now we've replaced it with a disco ball and it makes projections, oracles.' (6–12 yrs) (7B)
Movement	'It's like with wind turbines. He loves watching them. Could stare at wind turbines for hours.' (6–12 yrs) (4B)
Alignment	'The first thing that caught our attention was how much he loves cars […]. And they had to be lined up perfectly, either straight or in a circle around something.' (3–5 yrs) (1A)
Rotation	'So, spinning, all the time, everything. He would grab all sorts of objects just to check if they could spin, actually.' (3–5 yrs) (2A)
Detail perception	'He didn't like big objects, he'd go after the tiny hairs, in the floorboards. Spent my time taking all the lint off his hands. And he'd roll them around in his hands for ages, the dust.' (6–12 yrs) (7B)
Light sensitivity	On the other hand, he's really sensitive to light, but in a way where he seeks it out. He loves brightness. He's mesmerized by light.' (3–5 yrs) (2A)
Audition	
Intonation	'I think it depends on the tone of voice, he's very sensitive to that. […]' (13–17 yrs) (10C)
Rhythm preferences	'[…] for me, it was pretty early on at nursery, I noticed with music, he loved anything with a rhythm. […]' (6–12 yrs) (7B)
Noise sensitivity	'However, the hand dryer is terrifying for him. […] And the thing with noises is, he always needs to find where they're coming from. He has to check out the source, where it's coming from.' (3–5 yrs) (2A)
Unpredictability	'When he goes out, it's the noises that surprise him. The ones he doesn't expect, the ones he doesn't see.' (6–12 yrs) (4B)
Noise filtering	'He is not at all capable of, I don't know, entering a room where a television is on.' (13–17 yrs) (10C)
Sleep consequence	'I immediately saw that she needed complete silence to fall asleep.' (>18 yrs) (12D)
Aggressivity	'He can be very sensitive, if his sister talks too loudly, he hits her.' (6–12 yrs) (5B)
Motricity	
Proprioceptive and vestibular stimming	'Mine, he walked like this, he walked while turning. He learned with his dad. He bent down, he learned to walk while turning. And then he spent his time turning, so I found it cute.' (13–17 yrs) (11C)
Proprioceptive and vestibular sensitivity	'[…] Her, she can't actually stand too much acceleration, too many sensations; she gets scared, even with rides and so on, she can't. […]' (13–17 yrs) (9 C)
Sensation of acceleration	'[…] She will love acceleration, enjoy thrill rides, she will actively seek that out.' (13–17 yrs) (9C)
Regulation	'And for my son, rocking his head back and forth is something that really comforts him.' (>18 yrs) (12D)
Olfaction	
Olfactory sensitivity	'Yeah, there were certain smells he couldn't stand. Things, smells that were pleasant he wanted, or even if it didn't smell bad, he wanted to smell it, he felt like smelling them.' (13–17 yrs) (11C)
Odor-seeking	'But he has a very good sense of smell, but he always needs to be stimulated by smelling, so they need to search for things, I don't know.' (13–17 yrs) (11C)
Flavor	
Flavor sensitivity	'One day I changed the toothpaste, and he screamed because it didn't taste the same. So, I had to wait until the next day to quickly run to the pharmacy.' (–12 yrs) (4B)
Sensation with water	
Aversion to water	'[…] she would always wear her raincoat and boots, even if it was hot and everything. Because actually, if there was water, she wanted to be able to play without getting wet. She would even cry to put on her boots and her raincoat.' (13–17 yrs) (9C)
Attraction to water	'As soon as we tell him we're going to wash hands, he's on it. He watches the drops falling from the faucet.' (3–5 yrs) (2A)

($n = 16$; 7.84 %). Regarding sensitivity to intonation and rhythm preferences, caregivers seemed to have noticed it early in the child's development. Noise sensitivity and unpredictability of noise were also described, but with an impact on daily life and often requiring intervention from the caregiver to facilitate adaptation. Similar consequences were reported regarding the noise filtering capabilities. Behaviors described in connection with auditory input were more commonly associated with discomfort in individuals, potentially leading to functional disruptions (e.g., sleep and aggressivity).

3.1.4. Motricity

Behaviors related to proprioception and vestibular systems were grouped in this category ($n = 15$; 7.35 %). Proprioception corresponds to the sensory system responsible for balance and spatial orientation, while the vestibular system allows us to perceive the location, movement, and actions of different parts of the body. Two main aspects have been described in this sub-theme, including proprioceptive and vestibular stimming and sensitivity. The sensation of acceleration was also reported in *data extracts*. Body swaying was identified a few times in *data extracts* as a regulatory strategy. Descriptions associated with motricity sub-themes were frequently related to the child's self-stimulation, which, according to some caregivers, might aim at regulating his/her anxiety.

3.1.5. Olfaction

Sensitivity to olfactory inputs was described as atypical by caregivers, with odor-seeking behaviors in children with autism, whether the smell was pleasant or unpleasant ($n = 7$; 3.43 %). The smell was generally reported in connection with foods, which was described in more detail in the theme 'impact on daily life'. According to caregivers, the atypicalities in olfactory responses appeared to

Table 4.
Illustrative data extracts for the 'Sensory modulation' theme.

Theme 2: Sensory modulation	
Sensory overolad	
Noises	'[…] When there is too much noise, you can see that his eyes are lost and he can't focus on a fixed point. […]' (3–5 yrs) (1A)
Crowds	'[…] The fact of being crowded, that he could actually anticipate that at a station [names the station] he would be drowned in a mass of people.' (6–12 yrs) (7B)
Attention modulation	'[…] And actually, I realize that there are noises that can be ignored. If he is really absorbed by his object or what he is doing, he hears nothing. The moment he looks up or his gaze shifts, the noises become so unbearable that he starts screaming.' (6–12 yrs) (4B)
Distress	'But when we come back from the city, when we come back [silence] it has to explode […]. It's horrible. He would hurt himself, he would make himself vomit. But now it's better. Though sometimes he still needs to hit something to release the pressure.' (3–5 yrs) (1A)
Fatigue	'He gets tired from the noise without being aware of it. So when he's tired, he's irritable. […] Almost every day we have intense tantrums.' (6–12 yrs) (5B)
Difficulty managing emotions	'She didn't actually understand her feelings, her emotions, her sensations, and it was always too much.' (13–17 yrs) (9C)
Learning difficulty	'[…] all the noises in the classroom caused him cognitive overload. So he made sounds with his mouth, he rocked back and forth. He also refused to work, he would lie on his side. […]' (6–12 yrs) (4B)
Dissociation	'Then there are moments of overload where there's disconnection. That is, he stops like, suddenly he's not there anymore. When we talk, he doesn't react. It can last a minute, two minutes. It depends, sometimes longer.' (6–12 yrs) (5B)
Sleep	During the day, if it has been extremely challenging in terms of sensory aspects, sleep becomes very difficult.' (6–12 yrs) (7B)
Modulation between the senses	'Because the senses have difficulty working together and there can be pain felt or a lack of sensation. It's beyond an adaptation of the remaining senses, because it's beyond the fineness that a blind person might have with touch. It's also about managing the different senses together and the intensity of the sensation.' (>18 yrs) (12D)
Self-regulatory strategies	
Stimming through a preferred sensory channel	'Before, he used to roll his eyes. His eyes did strange things. It lasted for a while; it's rare to see it now, but until the age of eight, we had those eyes that… I don't know, that rolled.' (6–12 yrs) (4B)
Action	'He developed a strategy for dealing with noise when he has nothing. When noise appears, he sings. So, his voice lowers the outside noise. He copes better.' (6–12 yrs) (5B)
Shut down	'[…]He would lean against the big bay window. He would look outside a lot and stay still. Or after a big meltdown, he would lie on the floor and stay there for a little while.' (6–12 yrs) (4B)
Reproduction	'But the problem is, when he comes home, he reproduces everything he heard, and it makes really intense noises. In fact, he reproduces them in the same way he perceived them.' (6–12 yrs) (8B)
Repetition	'For example, listening to music for my son, so repetitive things, is comforting.' (>18 yrs) (12D)
Caregiver's strategies	
Anticipation	'There's fear, the fact that he didn't see the situation coming. However, for the same noise, if I tell him there's going to be the sound of a door slamming, he doesn't care.' (6–12 yrs) (7B)
Adaptation to the child	'[…] I noticed it was when he was a bit anxious that he needed it. So, I made him a little weighted blanket […].' (13–17 yrs) (11C)
Tools	'[…] When I understood that, it allowed us to buy the headphones and adapt much more to situations.' (>18 yrs) (12D)
Deep pressure	'[…]in fact, I had established a ritual because she really didn't like contact, and I would give her containment massages.' (13–17 yrs) (9C)
Verbalize	'I verbalize all these emotions to help him understand what's happening. Then I let him calm down.' (6–12 yrs) (5B)
Emotion regulation	
Dysregulation	'My husband scolded my son while he was eating pasta. Since then, he vomits when he eats pasta. It's intense stress. […] It has actually become an anxiety.' (>18 yrs) (12D)
Modulator	'For example, situations of fatigue and anxiety will exacerbate certain sensitivities.' (>18 yrs) (12D)

be less invasive in daily life. However, the challenge of externally apprehending the individual's olfactory experience from an external viewpoint might explain the low occurrence of *data extracts* on this theme.

3.1.6. Flavor

Flavor is the perception of food in the mouth, encompassing both the basic tastes and the aromas experienced during eating. Behavioral responses to flavor were weakly observed directly by caregivers ($n = 3$; 1.47 %). Most often, they were identified by the child's food selectivity (see theme 3 'impact on daily life' – eating problems). However, another indicator was put forward by a caregiver in relation to hygiene. The lower frequency of descriptions of this sense could be explained by its proximity to the eating category, which caregivers described more often as consequences related to food rather than atypicalities in flavor responses.

3.1.7. The sensations with water – a special case

Water, as a chemical compound, can stimulate diverse senses (visual, touch, auditory, and temperature). Caregivers frequently described it in their observations, noting that water often elicited significant sensory reactions in their children ($n = 8$; 3.92 %). Descriptions related to feelings with water represented a variety of behaviors among caregivers. Their children might have shown fascination with or rejection of water. Nevertheless, its occurrence as a spontaneous description in the caregivers' discourse implied that it could have been an important indicator in the identification of sensory behavioral specificities.

3.2. Theme 2: sensory modulation

The highlighted behaviors from the second theme by the caregivers were related to the sensory modulation of their child ($n = 67$; 32,84 %) (Table 4). Sensory modulation was organized into four aspects: sensory overload, self-regulatory strategies, caregiver strategies, and emotions.

3.2.1. Sensory overload

Sensory overload is the process of saturation of sensory information in an individual. When the individual's processing capacity threshold is exceeded, it precipitates a state of dysregulation (Scheydt et al., 2017). In the focus groups, caregivers spontaneously reported this type of manifestation in their children ($n = 28$; 13.72 %). These represented a significant part of the focus group's data extracts on the sensory modulation theme.

Triggers leading to a state of sensory overload in autistic people were identified in the *data extracts*, such as noises, crowds, and difficulties in attention modulation. Regarding the consequences, distress, fatigue, difficulties in emotion regulation, learning difficulties, dissociation, and sleep problems were identified in the *data extracts*. Finally, one last aspect concerning the difficulty of sensory modulation, potentially causing a state of overload, was hypothesized by a caregiver. This phenomenon appeared to be complex, likely influenced by the interaction of both internal and external factors.

3.2.2. Self-regulatory strategies

This category included 19 *data extracts* (9.31 %). Among the strategies, self-stimulation through a preferred sensory channel was frequently identified in the *data extracts*. Another strategy was the child's active behavior in modulating environmental stimuli. In some cases, caregivers described a state of disconnection or a self-induced altered state of consciousness. Finally, the reproduction of the stimulation that the child had been confronted with appeared to be a calming strategy. It was often associated with so-called 'repetitive behavior' but it seemed to allow better integration of perceived sensory information. Similarly, exposure to repeated pleasant stimuli also appeared to be a regulation strategy. These descriptions highlighted the use of internal and external control resources. According to the caregivers, these strategies were sometimes sufficient to stabilize the child but might have required the help of a partner.

3.2.3. Caregiver strategies

Caregivers developed strategies to help regulate the child's responses to sensory inputs ($n = 14$; 6,86 %). Notably, the anticipation of sensory stimulation was also used to predict the child's environment, either through verbal or visual support if the child did not have access to language (pictograms, visual planning). Adaptations were described by parents as being made to accommodate the individual characteristics of the child. The use of visual and sensory tools was also described by caregivers multiple times as an effective strategy. The use of deep pressure appeared frequently in the *data extracts*. When the child was in crisis and if they had mastered the language, caregivers described using verbal support to help manage these emotions. The help of a co-regulator to manage environmental stimuli was described as an indispensable element in learning the child his/her own internal control strategies. Caregivers reported having developed these strategies in a very intuitive way, or with professional assistance.

3.2.4. Emotions regulation

Two aspects of emotion were identified in the *data extracts* ($n = 6$; 2.94 %). One highlights the impact of emotional dysregulation on the processing of sensory information, while the other describes emotion as a modulator of the ability to process sensory information. Overall, emotions appeared to be closely related to responses to sensory input.

3.3. Theme 3: impact on daily life

The final theme identified related to the behavioral consequences of SP ($n = 36$; 17.65 %). Difficulties in coping with change were the behavioral consequences reported by caregivers. Descriptions related to eating problems caused by SP specificities constituted the second category of this theme. Finally, Risk-taking behavior-related issues were identified. This last category is rarely described in the literature but represents a significant problem in the daily lives of families (Table 5).

3.3.1. Response to change

Difficulties in managing changes were identified in the *data extracts* in relation to difficulties in adjusting to new sensory stimuli ($n = 12$; 5.88 %). Several types of reactions were noted, including meltdowns in response to change, agitation, emotional distress, adjustment periods, and adaptation difficulty. The findings from these focus groups suggested that difficulties in managing changes may be intrinsically linked to the challenges in assimilating new stimuli.

3.3.2. Food/Diet

The caregivers described eating as a significant sensory difficulty ($n = 19$; 9.31 %). Most participants reported that their child was selective about textures, mixtures (separate food), seasonings, colors, and food repetitiveness (i.e. brand). In addition to food selectivity, the *data extracts* highlighted specificities in the interpretation of bodily signals such as hunger and satiety.

3.3.3. Risk-taking behavior

Three caregivers identified risk-taking behavior in their children ($n = 5$; 2.45 %). The *data extracts* addressed two aspects: either a lack of danger awareness or poor stimulus management. Although this category represents a small proportion of *data extracts*, it is important to note its impact of daily life because it required significant adaptation from caregivers. These descriptions also highlighted the link between the adequate integration and interpretation of sensory information to avoid risky situations for autistic people.

4. Discussion and implications

The aim of this study was to explore the characteristics of behavioral responsivity to sensory input in autism. Sensory experiences of 15 autistic people were collected from their parents. Thematic analysis revealed three main categories of description among caregivers: sensory input, sensory modulation and impact on daily life. Sensory input encompassed seven sub-themes, including the six senses and the special case of sensations with water, which represented a multisensory aspect. The second theme identified was sensory modulation, with four key processes noted: sensory overload, self-regulatory strategies, caregiver strategies and emotion regulation. The last theme summarizes the impact on daily life of sensory input specificities, including reactions to change, feeding problems, and risk-taking behaviors.

Drawing on the behaviors described by caregivers in response to sensory input, sensation-seeking and stimming emerged as frequently observed responses. These behaviors were associated with several sensory modalities, including touch, vision, proprioception/vestibular, and olfaction, as well as with the sub-theme of self-regulatory strategies. They could manifest through behaviors

Table 5
Illustrative data extracts for the 'Impact of daily life' theme.

Theme 3: Impact on daily life	
Response to change	
Meltdowns in response to change	'Just for clothes. She refuses to let me shower. It's a nightmare for me. I have been wearing the same dress for a week. […] You see, I have a green dress, and I've been wearing the same dress for a week. I can't shower while she is awake. I have to shower when she is asleep. If she wakes up at night and sees that I don't have that dress on, it's a nightmare.' (3–5 yrs) (3A)
Agitation	'He went with the recreation center last week, and it was very difficult for him because they didn't do it in the same direction as we usually do. They struggled a bit because he couldn't stay still. It was too much for him not to take the same path.' (3–5 yrs) (1A)
Emotional distress	'[…] He was in such an emotional state, being there all day with them.' (6–12 yrs) (4B)
Adjustment time	'For example, we went to the hairdresser this morning. […] And I know that tonight, he won't stop talking about his hair. The fact that they trimmed the back of his hair, he loves the very short aspect. And so he keeps rubbing the back of his head.' (6–12 yrs) (7B)
Adaptation difficulty	'His orthopedist has known him for two years. Every time we go to a session, it's like we're starting over with a different person. It's frustrating.' (6–12 yrs) (4B)
Food/Diet	
Food selectivity	'[…] He was a child who ate everything. He was a big fan of broccoli [silence] and from one day to the next, he decided that he would only eat pasta, ground beef, and green beans. But they had to be frozen, without butter, not canned. Especially not fresh, no seasoning, no salt, so there you go.' (3–5 yrs) (1A)
Food separation	'She always wanted it to be separate. We bring her plate by plate. She smells her plates.' (>18 yrs) (13D)
Taste preferences	He eats, he eats, he eats, a lot of fruit. He loves fruit; you always have to give him fruit at every meal. He really likes the sensation of fruit, I don't know why, the different tastes of the fruits.' (13–17 yrs) (11C)
Body signal	Ah, my son, he doesn't really have a sense of hunger.' (13–17 yrs) (11C)
Risk-taking behavior	
Lack of danger awareness	'In the street, he's not afraid of people, quite the opposite. I have to make sure he stays on his path. He moves forward like a tank. […]' (3 –5 yrs) (2 A)
Poor stimulus management	'For example, once he was on the sidewalk, he got scared, actually he crossed all of a sudden and we had to catch him. […]' (6–12 yrs) (4B)

such as flapping, rocking, and motor stereotypies, among others. These dimensions are well-documented in the literature, which highlights their adaptive function in sensory and emotional regulation (Joyce et al., 2017; Kapp et al., 2019; Lawson et al., 2014). The current study underscores the importance of exploring sensory specificities not merely in relation to discomfort but also in understanding the satisfaction that can be derived from an individual's SP. Stimming and sensory seeking behaviors provide rich information about the sensory functioning of the individual and do not always indicate a processing deficit (Jaswal & Akhtar, 2019). Given the potential risk of under-evaluating these behaviors deemed less problematic, it is crucial to reflect on how these dimensions can be integrated into evaluation questionnaires.

The sub-theme of sensory overload is another key finding highlighted in this study. Several triggers for sensory overload were identified, including noise, crowds, and difficulties in attention modulation. These overloads most often occur in urban environments, at school, or in new settings for the individual. Parents also reported the consequences of sensory overload, such as increased anxiety, distress, fatigue, difficulties in emotion regulation, learning challenges, dissociation, and sleep problems. Our data emphasized that sensory overloads most frequently occur in urban contexts. Therefore, rethinking urban spaces for autistic people, particularly based on findings from qualitative studies on this topic (Finnigan, 2024; MacLennan et al., 2023), and recommendations for designing autism-friendly built environments (Tola et al., 2021), could significantly improve the comfort and autonomy of autistic people.

Finally, self-regulation strategies and caregiver strategies represent the final key finding of this study. Self-regulation strategies can manifest in various forms, such as stimming through a preferred sensory channel, action, shutdown, reproduction, and repetition. These strategies serve as adaptive mechanisms that allow individuals to maintain sensory balance in environments or situations perceived as "overstimulating" (MacLennan et al., 2022). Their effectiveness also indicates strong executive functioning, particularly in emotional regulation and SP (Pastor-Cerezuela et al., 2020). Furthermore, they can predict behavioral issues and the ability to manage stressors (Fernandez-Prieto et al., 2020). Thus, they are closely tied to the quality of daily functioning. Parental strategies also play a crucial role in supporting regulation. Parents may implement tailored strategies to help their children cope with sensory challenges, such as applying deep pressure, using visual schedules, or creating environments adapted to their sensory needs. These strategies aim not only to mitigate immediate distress (Little et al., 2022; Schaaf et al., 2011), but also to encourage the child to adopt these strategies across various contexts, including urban and school environments (Little et al., 2022; Pfeiffer et al., 2017). The evaluation of self-regulation strategies and caregiver strategies would provide valuable insights into the overall sensory profile of autistic people and would facilitate the development of a personalized care plan.

5. Limitations

This exploratory study of behavioral responsivity to sensory input in autism has three limitations. First, the sample size ($N = 14$) is small, especially given the individual heterogeneity among participants. Due to this small sample size, we cannot be certain that all important themes have been captured. Second, the data analysis approach is a limitation. Given the nature of our data, we opted to conduct qualitative analyses, but a quantitative approach may be necessary to refine the results. Finally, autistic people were not directly interviewed in this study, and integrating their perspectives would be an interesting extension for future research.

6. Conclusion

In light of these results, three key points emerged from the present study. Firstly, regarding the theme of sensory input, the study highlighted that, beyond the traditionally described sensory input, self-stimulatory and sensory-seeking behaviors were frequently observed in the data extracts and were associated with multiple themes and sub-themes. Secondly, the findings related to sensory modulation emphasized the roles of sensory overload and emotions, as well as the contributions of self-regulation and parental strategies. Finally, the theme on the impact on daily life identified sub-themes of reactions to change, feeding issues and endangerment, which appeared to be related to SP. In a clinical context of autism assessment, the themes and sub-themes identified in this study could be evaluated through a pilot study to determine their relevance for integration into interviews and questionnaires.

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Sandra Brouche: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Natalie Rigal:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Fabienne Cazalis:** Writing – review & editing, Methodology, Investigation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data Availability

The data extracts are available through the link provided in the supplementary material.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.rasd.2024.102488.

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