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## Parent Reports of Sensory Experiences of Preschool Children With and Without Autism: A Qualitative Study

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## Abstract

This study describes children's "sensory experiences", generates parents' perceptions and explanations of these experiences, and compares these experiences across children with and without autism. Parents of 66 preschoolers (29 typically-developing; 37 with autism) were interviewed using a Critical Incident Technique. Parents described a situation where their child had a "good" sensory experience, a situation where their child had a "bad" sensory experience, and their own perception of how these situations felt to the child. The most common unpleasant experiences for both groups related to sound; the most common pleasant experiences involved touch and movement. Children with autism were reported to have more extreme and/or unusual experiences, and negative food-related experiences than typically-developing peers. Parental explanations for children's responses focused on qualities of the child, stimulus, and/or context. Many parents had difficulty understanding the concept of sensory experiences as being sensory, and likely to attribute these responses to aspects of autism. Parents' positive response to the interview itself was an unexpected result with clinical relevance.

## Keywords

Autistic Disorder; Qualitative Research; Critical Incident Technique

A growing body of research supports classroom and clinical observations that many children with autism respond to sensory experiences differently from typically developing children. However, questions remain concerning how children with autism experience these sensory

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differences in the context of their daily lives. In this paper we report a qualitative study of parent descriptions and explanations of sensory experiences of preschoolers with and without autism, and propose the use of a focused interview with parents as one important source of information to aid relevant interventions for children with autism.

Sensory processing impairments are reported to be highly prevalent but not universal in children with autism (Baranek, David, Poe, Stone, & Watson, 2006; Liss, Saulnier, & Fein, 2006). Research shows that preschoolers with autism have higher rates of sensory processing problems compared to both typically developing children (Kientz & Dunn, 1997; Watling, Deitz, & White, 2001) and children with other developmental disabilities (Baranek, Boyd, Poe, David, & Watson, 2007; Baranek et al., 2006; Rogers, Hepburn, & Wehner, 2003). These impairments may impact upon occupational performance, social participation, and daily family routines, and may result in referrals to occupational therapy practitioners. The variability observed in a child's sensory processing profile and the extent to which impairments affect daily life may present challenges for practitioners (Watling & Deitz, 2007).

Research explicating specific patterns of sensory processing impairment (e.g., hyper- or hyporesponsiveness or sensory seeking) and effects of these impairments on occupational performance may help practitioners choose appropriate interventions. Research and clinical assessment of sensory experiences in young children, and especially young children with autism, recognizes that these children are unlikely to be able to respond to self-report measures of their sensory experiences. Thus, clinical assessments with this population often rely on direct observation of the child during natural or test conditions, and/or a parent report format. Parent report instruments are most often used in studies characterizing sensory processing difficulties. Rogers et al., (2003) used the Short Sensory Profile (Dunn, 1999), and demonstrated that parents of young children with autism (aged 25–41 months) reported problems with tactile sensitivity, taste/smell sensitivity, and under-reactivity in their children. Using the Sensory Experiences Questionnaire (Baranek, 1999), Baranek and colleagues (2006) demonstrated that 69% of young children with autism showed high levels of sensory processing problems, including hyper- and hyporesponsive patterns across sensory modalities.

Sensory processing differences and difficulties are experienced by children with developmental difficulties other than autism as well. Both parent-report and observational measures have shown that some sensory processing patterns are not specific to autism. For example, hyperresponsiveness occurs among children with autism and children with other developmental disabilities matched on mental age, whereas hyporesponsiveness is more likely to occur among those with autism (Baranek et al., 2006; 2007). Additionally, some researchers have identified a pattern of sensory seeking behaviors among children with autism that may or may not be different from comparison groups (Liss et al., 2006; Dunn, Myles, & Orr, 2002; Watling et al., 2001). Regardless of their specificity, there is anecdotal evidence from clinical reports that various sensory processing patterns may impact upon a family's ability to care for their child or participate in community activities. Thus, these sensory processing patterns have important implications for intervention, and require deeper investigation in systematic studies.

Each method of investigating sensory experiences of children with autism has inherent limitations, arguing for the use of mixed methods to study these phenomena. Among the commonly used approaches, observational methods often suffer from limited scope and ability to generalize to other contexts. Parent-report methods, on the other hand, tend to have good ecological validity but may be prone to inherent subjective biases (e.g., parents' recall of events; questions determined a priori), as well as restrictions in the number and type (e.g., closed-ended) of questions included. Furthermore, the ability of parents or other caregivers to adapt to their child's sensory processing problems can influence the number, type, or quality of shared

social experiences, both in a positive and negative sense and may facilitate or constrain engagement in daily family routines. Neither observational nor parent-report methods tend to inquire beyond the level of child symptoms, and thus are limited in their contextual understanding that is critical to occupational therapy practice.

Qualitative interviews supply rich descriptions of situations and contexts and may provide a useful supplement to standardized tools for clinical assessment or intervention planning. However, few qualitative studies that focus on the sensory experiences of individuals with autism exist. One exception is a qualitative study that reviewed websites containing personal accounts of persons with autism (Jones, Quigney, & Haws, 2003). While there are some methodological concerns with a study excerpting narratives from webpages, this study provides insight into how sensory experiences are personally described by some adults with autism. Other qualitative studies include descriptions of sensory processing functions as part of broader studies of family routines and coping strategies of parents of children with autism (e.g., DeGrace, 2004; Larson, 2006) or other developmental disabilities (e.g., Fox, Vaughn, Wyatte, & Dunlap, 2002; Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996). None of these studies uses a comparison group of typically developing children, and with the exception of Gallimore et al., sample sizes are small. Thus, qualitative studies can add to our knowledge of both autism and the sensory processing issues associated with it by providing rich description and insight into how associated behaviors affect the individual and his or her family in the transactions of occupational performance and social participation. In essence, qualitative studies may tell us why the sensory experiences of children with autism matter.

The specific aims of this study are to describe the experiences of children with and without autism related to sensory situations during their daily routines, to generate information about how their parents perceive and explain these "sensory experiences", and to compare these sensory experiences among children with autism and between children with autism and typically developing children. In addition, this study aims to explore the potential of relatively unstructured parent accounts to add to other research-based knowledge of the sensory experiences of children with autism.

### Methods

This qualitative descriptive study was conducted as part of an ongoing NICHD-funded grant, the Sensory Experiences Project (http://www.med.unc.edu/sep/), studying sensory features in preschoolers with and without autism. In this portion of the study, we interviewed one or both parents of children with and without autism, using an open-ended interview based on Flanagan's Critical Incident Technique (CIT) (1954).

#### Sample

Parents of 66 preschoolers (29 typically developing children and 37 children with autism) were interviewed. Participants with autism were recruited for the larger study using a university-based state-wide research registry. Typically developing subjects were largely a convenience sample, recruited through local day cares, university list-serves, and through word-of-mouth. The groups differed in terms of the educational level of the mother (more graduate degrees in the typically developing group, more high school degrees in the autism group), chronological age (the typically developing group has a lower mean and lower bottom end of range), and mental age (the autism group has a lower mean, and wider range at both extremes). Mental age was measured using the Mullen Scales of Early Learning (Mullen, 1995) and the Leiter International Performance Scale—Revised (Roid & Miller, 1997). Table 1 presents characteristics of the sample.

This study was approved by the University of North Carolina at Chapel Hill Institutional Review Board. Informed consent was obtained from the parents who participated.

#### **Critical Incident Technique**

We used a variation of Flanagan's Critical Incident Technique (CIT) (1954) for collecting data. The CIT, which has been used extensively since the 1940s, asks participants to provide concrete examples of behaviors that constitute the parameters of a phenomenon (such as job qualifications, performance characteristics, or personality types) being studied. Typically, these data were collected using a very large sample and analyzed with quantitative methods. Hasselkus and Dickie (1990, 1994) adapted Flanagan's technique in a quasi-phenomenological study of what occupational therapists found meaningful in their practice. That study demonstrated that the method elicited rich data that could be analyzed qualitatively. Because the method allows for a larger sample than is generally found in qualitative studies, it supports some generalization of findings and also permits deeper analysis of subgroups of subject responses (e.g., Hasselkus, Dickie, & Gregory, 1997). The advantages of this method of data collection are its focus on the specific phenomenon of interest, the gathering of concrete examples of behavior, its flexibility, and the ease of use with a relatively large number of subjects.

#### **Data Collection**

We conducted telephone or face-to-face interviews with parents, depending upon the preferences and availability of the interviewe. The interview consisted of two basic sets of questions. First the parent was asked to describe an incident during which the child seemed to have a good sensory experience, then to tell why he or she thought it had been a good experience for the child, and last to explain how it had made the parent feel. The same set of questions was then asked with respect to a bad or unpleasant sensory experience. If answers were very brief or described experiences that were not obviously sensory, the interviewer probed for more details, asking, for example, what aspects of the situation the parent saw as sensory, or even listing the senses to see whether or not the parent might come up with an example. Based on initial interviews, we found that it was helpful to define *sensory*, to a limited extent, while asking the first question, and added that feature to all later interviews.

Interviews were conducted by a graduate student assistant, the project coordinator, and several other graduate students trained in the process. Analysis was done by the first author, who was not an expert on autism and was not involved in any other parts of the SEP grant activities. While analyzing the interview data, the first author was blind to the data and findings from the larger study.

#### **Data Analysis**

Interviews were audiotaped and transcribed for analysis. We used the *Atlas.ti* (Muhr, 2004) software program for qualitative analysis to facilitate coding and sorting the data. Codes were initially developed over the course of several meetings of the research team, during which the early interviews were read by all team members and codes and/or themes developed through discussion. As analysis continued, monthly meetings with the research team and/or PI were used to discuss findings and refine the direction of the analysis.

Using a list of codes developed by the team, the first author coded the transcripts mixing the order of the typically developing and autism groups for the first half of the interviews, and coding the remainder in the order they were added to the data file. During the coding process (and following discussions at monthly research team meetings), codes were added to the code list. This process was consistent with the emergent nature of qualitative research methods (Charmaz, 2006; Lincoln & Guba, 1985; Schwandt, 2007).

The analytical process consisted of reading and re-reading the interview transcripts and "marking" units of text with one or more codes that described the contents. The codes *positive* or *negative* were attached to most of the units in order to sort by these qualities along with the more descriptive codes. For example, a unit might be coded as *sound* (the sensory factor the child responded to) and *negative* (identifying the experience as unpleasant for the child), and could be further coded with a descriptor such as *embedded* (meaning the sensory experience was part of a larger event). Following coding, material was aggregated by single code (e.g., all of the units coded as *what is sensory* were assembled as a single report), and/or by combined codes, using the Boolean operators of *and* and *or*. The operator *or* was used when two or more codes were thought to tap similar or related content. During this process, some codes were dropped from further analysis because they were rarely used and other codes seemed to cover the same content and were bundled together.

The reports generated through aggregating codes were then read and marked-up several times, in order to identify the dimensions of the topic. Final analysis took place during the writing of this paper. At times the differences or similarities between the two groups of subjects seemed striking, and in these instances we used a simple calculation of percent of responses by group in order to highlight the comparison. We recognize that most parents gave only the first example that came to their minds, and some gave more than one, and thus the percentages are relative and do not represent all of the examples that parents might have been able to provide. Therefore, the possibility exists that the differences between the groups might have been even greater than these numbers represent.

## Findings

Corresponding to the structure of the interview, data fall into two broad categories: the sensoryrelated experiences of children as described by their parents, and the parents' understandings of the concept of sensory experiences and of the manner in which their children responded to such experiences. The findings are organized by these two categories.

#### **Children's Responses to Sensory Experiences**

Some of the examples provided by parents for both good and bad sensory experiences were dominated by the sensory component – either as a single modality that elicited a positive or aversive response, or as multiple modalities occurring simultaneously with the child's response seeming to be to the total input. In other reports the sensory aspects were embedded in an account of a larger situation. Table 2 depicts the types of examples provided by parents according to whether the sensory component is dominant or embedded. The following section of the findings is organized by single and multiple modalities, with the dominant or embedded nature of the sensory stimuli discussed with respect to the modalities.

**Sound experiences**—Various sounds were frequent examples of stimuli that provoked unpleasant sensory experiences (reported for 28 % of typically developing children and 59% of children with autism). *Loud* and *unexpected* sounds such as fire alarms, toilet flushes in public restrooms, dogs barking, other children crying, fireworks, loud coughing or clapping, and microphones with acoustical feedback were the most common examples. In some cases, unpleasant sounds were predictable and both parents and children took measures to avoid or control the experience. For example, vacuum cleaner noise was a problem for some children in both groups, and parents avoided using the vacuum when the child was present. Television commercials were another potential problem, and one child was described as being quick to mute the television when a commercial was about to air.

Children expressed their discomfort with particular sounds in a number of ways. Many verbal children stated that they didn't like a sound or that it was too loud. One child with autism

reported to his parent that particular sounds "*scare*" his ears. Other children muted the television, sometimes for commercials, sometimes for particular shows, as this child with autism did:

...like with the "Wheel of Fortune" show, he will always run over and mute it and he won't let us watch it, and I think it's the dinging sound in it...And then you'll find certain commercials for awhile...he runs to mute and he would go **crazy** if he couldn't get the remote control.

This mother went on to state that the child's sensitivity to sounds varied, happening at "*certain times, with certain things.*" Some children covered their ears when certain sounds occurred. A mother of a child with autism reported that unexpected loud sounds "*really made her go into, like, you know, she started flapping and stuff, and it was bothering her, and she was trying to cover her ears.*". Another mother described her child's reaction to a dog barking:

It sets him almost into a tantrum. He cannot stand to hear a dog barking. He'll cover his ears and kind of put his head up under the pillows or he'll even go into the closet. ... It really upsets him.

In several instances, the parents were clear that it was the sound to which their child reacted, not the object or event that caused the sound. For example, even though a mother could not operate the vacuum in her son's presence, he would play with the vacuum cleaner when it was not turned on. A child might respond to other children crying or screaming, but the parent attributed this to the sound, not the fact that the other children were present. Parents said that *particular* television shows or commercials were problematic, but not all.

Parents tried to make sense out of their children's responses to sound. One mother speculated that most people are able to hear a sound and filter it out, but not her son, who has autism: "*Maybe his reactions are just a little brisker than most people….*" Being able to understand what sounds bother a child, under what circumstances, makes it possible for the parent to avoid the situations, prepare the child, or employ other strategies to diminish the impact on the child. For example, the parent in the above example copes with the child's sound sensitivities by altering her cleaning strategies to use a broom rather than vacuum in the child's presence. Enhancement of this dynamic systems understanding is thus an important goal for occupational therapy interventions.

Less frequently, auditory examples were described as positive sensory experiences, and some children had (different) auditory experiences in both pleasant and unpleasant accounts. Sound-related events were identified as positive sensory experiences for four of the typically developing children (14%) and nine of the children with autism (24%). Most of these events had to do with music.

The pleasant musical experiences were described as something children sought out. They frequently included active participation by the child through singing, moving, and/or dancing with the music. In some cases, this participation involved others, particularly parents, as, for example, in shared songs or ritualized movement sequences associated with a particular song. Some children had favorite children's songs or videos, while others liked particular musical groups or types of music. These experiences were similar in both groups when music was a pleasant experience.

Curiosity and a heightened awareness of sound were described in the cases where children had positive auditory experiences not associated with music. All of these children were in the autism group. One mother related that her son was "*interested in all kinds of sounds*. *If anything makes a sound, he's got to listen to it.*" Another described how the sound and movement of the water when the toilet was flushed fascinated her child, and … "he creates something extra to it. It's

not just flush and watch; it's not just flush and listen. He'll find an object, a soap dispenser or a tissue box or something to turn around and wave as the water is moving." Another parent interpreted the idea of a positive sensory experience to mean a sensory strength and reported "he hears everything." In each of these examples, the child's response to sound was presented as unusual, but the parent identified it as a positive experience from the child's perspective.

**Visual experiences**—Eight parents reported visual experiences as either positive or negative experiences. The three positive experiences were all related by parents of children with autism and were respectively, "*seeing everything*," loving to see "*bubbles and balloons and things that fly around*," and enjoying turning the light on and off. Four of the five examples of children having a negative visual experience (all children with autism) had strong reactions to bright light, and sunlight in particular. The other example had to do with the child watching videos and finding some of the images frightening. The sole visual experience reported by a parent of a typically developing child was a negative reaction to strong sunlight.

**Touch experiences**—Some aspect of touch was reported as a positive experience by parents of 24–29 % of the children in both groups. Touch as a negative experience was reported by four parents of children with autism and two parents of typically developing children.

The majority of the positive touch accounts for both groups had to do with interpersonal touch – cuddling or snuggling with a parent, having a back rub, being tickled, or engaging in rough play with an adult. Parents (usually parents of children with autism) sometimes explained these experiences using the jargon of therapy. For example, one mother of a child with autism reported, "anytime he has a hug, I think he gets a stim because he likes the deep pressure," and another spoke of "anytime we wrestle or he gets deep tissue sensation." But whatever the effects were for the child, in many interviews the parent obviously took great pleasure in these pleasant touch experiences. One mother related how her child now liked when she touched his face, which she interpreted as "sort of a way of accepting affection."

Other positive touch experiences were the feel of substances in the child's hands, and the feel of wind in the face. The negative touch experiences of children were related to the face and head – not wanting to have ears cleaned, wiping food off the tongue, having the face touched, and aversion to haircuts. One mother reported that her child with autism didn't like to have his head touched, and said, "*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.*"

**Movement experiences**—A quarter of the parents of children in both groups reported movement-related instances of positive sensory experiences. The type of movement experience did not seem to vary across groups – reports included children loving swinging, jumping, spinning, being upside down, going fast, climbing, or dancing to music. With respect to swinging, one parent of a child with autism reported "*[he] really loves to swing. So, basically, anytime he swings, he's very happy and he'll giggle out loud, almost hysterically sometimes,*" while a mother of a typically developing child said, "*he likes swinging, he loves being on a swing. Like when it was 25 degrees out and snowing, we were in the swing.*" Jumping was an experience emphasized by parents of children with autism. In some cases, the jumping was extreme, e.g. one boy's parent told how "*before we knew he was autistic, he bounced and bounced...*," and another parent said, "*he likes to jump. So he jumps a lot, and he seems to get pleasure out of that.*" Reports of pleasure related to movement usually involved speed, spinning, bouncing, and/or change of body position. The movements were repetitive during the event, and favorites across time.

**Food-related experiences**—Food-related experiences were given as positive examples for seven (21%) of the typically developing children and two (4%) of the children with autism. In

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, as well as aspects outside of sensory domains such as predictability, routine, and novelty. One mother of a child with autism reported that "*all mealtimes are stressful…it's probably the most difficult thing*."

Positive food experiences were briefly described in terms of taste (*sweet, sour, spicy*), temperature (*cold*), and/or texture (*crunchy, soft*). Parents of typically developing children generally described negative food experiences in terms of simple preferences, such as a child just not liking lima beans or strong flavors. One typically developing child was described by his mother as vegetarian – having always rejected meat from the time he was a baby (except for bacon and chicken nuggets). Negative food experiences for children with autism were described in greater detail, often including a description of the child's behavior in response to the food. The most extreme reactions were gagging, throwing up, or having a "melt-down." One child with autism could not stand the sight of ketchup and the family had devised a means of screening it from his sight at the dinner table. In several instances, parents described difficult mealtimes and a limited and often changing list of what the child would eat.

When parents described limitations in what their children would eat, even if these were not extreme, they also spoke of their own frustrations with the situations. In particular, parents were concerned with issues of nutrition, child development, and the quality of family mealtime experience.

**Oral experiences not related to food**—A small number of parents described oral experiences that were not related to food. Two children with autism were described as loving to chew on things. Face washing and oral hygiene were problematic for two children with autism and one typically developing child. Another child with autism was described as having serious problems with feeding, beginning from the age of 6 months when he "*basically weaned himself [from breast feeding] because he didn't like that closeness.*" This mother went on to say that the child never put anything other than his hand or bottle or nipple in his mouth.

**Issues related to self care**—Two parents in each group reported positive sensory experiences related to self care. Three of these had to do with children enjoying their baths, and one was a child who liked having his teeth brushed. In contrast, eight parents of children with autism (19%) and no parents of typically developing children reported negative sensory experiences linked to self care. These accounts included descriptions of child-parent struggles over teeth brushing, hair brushing, haircuts, and nail trimming.

**Unusual sensory experiences**—Reports of sensory experiences the parent perceived to be unusual were reported for 15 (36%) of the children with autism. Reports focused on behaviors such as hand flapping, having to chew on things, not responding to extreme cold, and as one mother said, being "*dull to things*." Parents described some of these activities as self-stimulation, and linked them to their child's diagnosis.

#### Parents' understanding of sensory experiences

**Uncertainty regarding the concept of sensory**—A number of parents seemed to have difficulty understanding the concept of a sensory experience as evidenced by asking for clarification and/or asking for confirmation that an example was sensory, and in responses that described a good or bad experience of their child, without making direct reference to anything sensory about that experience. Many of these responses focused on the child's total behavior

and experience, sometimes, but not always, suggesting a sensory component. For example, a mother of a child with autism reported "... *it would be nothing in particular but she would lick her finger and you know, touch the different pictures, or go up to the TV and touch the different characters* ... *little things she'll do for short periods of time that are bound to be sensory*." The following quotes are from parents of typically developing children: "Over the weekend he flew a kite. And then he really got excited about that." "Well, he just shut his finger in a door, so that was bad." "We go hiking a lot. And then I take him down to a stream and he loves to find rocks and sticks and he loves to hold sticks." "He likes to dance. He likes to dance around in circles, and then any time he is in the bathtub he is happy." Each of these examples contains an identifiable sensory experience – seeing the kite, feeling the pain, enjoying the texture of an object, responding to sound or movement or the feel of water – although the parent did not state that explicitly. In contrast, a response from one parent of a child with autism had no identifiable sensory aspect: "Well she really hates to be calmed down...and so, I had to calm her down, and that's consistent, anytime she's ever had to be reprimanded she's just, that's like a cardinal sin...to reprimand her.... Is that sensory?"

This confusion with the concept of "sensory" was not something we were expecting, and it persisted even as the interviewers began to define *sensory* and include mention of the specific senses when asking the questions. This suggests that parents do not typically deconstruct a child's experiences and reactions into components such as the sensory aspects. Instead, sensory elements are embedded in the whole situation. The uncertainty about what was sensory was more common with the parents of typically developing children (42%) than with those of children with autism (21%), which suggests that sensory aspects of experiences are often not noted unless they are unusual (as in having a child who is hyperresponsive to certain sensory situations), or attention has been drawn to them (e.g., through education about characteristics of autism, or by an occupational therapist reframing a child's behavior in sensory terms).

#### Parent's explanations for child's responses to sensory experiences

Parents were asked to describe what they thought their child was experiencing and why they were experiencing it in that way. The parent explanations of their children's response to sensory stimuli fall into three broad categories: qualities of the child, qualities of the stimulus, and the situational context of the event and response. In addition, there were some parents of children with autism who stated that they had no way of understanding or explaining their child's experiences.

**Qualities of the child**—Parent explanations often alluded to qualities residing within the child, such as the manner in which the child experienced the situation physically and emotionally, the child's preferences, and, in some cases of children with autism, aspects of the disorder that affected how the child experienced the sensory stimulus.

Parents in both groups frequently described pleasant sensory experiences as being calming for the child, producing a sense of security, and being relaxing. One mother said that swimming helped to "*recenter*" her son who had autism, though she linked this more to his developing confidence than to any sensory aspects. On the other hand, an unpleasant experience might be interpreted as stressful, terrifying, or even painful. For example, one father of a child with autism believed that his son experienced brushing his teeth as painful. Many parents in both groups described their child's response in sensory situations to personal preferences – particular sensations they liked and some they disliked, without any other significance attached to their descriptions.

Although parents in both groups described a child's experiences as reflecting preferences, parents of children with autism sometimes couched these preferences in terms of the child's condition. Thus, for example, one mother said, "*I know he has some sensory issues with his*"

face. I mean, he loves to be touched on his face." Another mother spoke of her child with autism having sensory needs that were somehow different from normal 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."

**Qualities of the particular stimulus**—Many parents reported that it was something about the stimulus – the loudness or shrillness of a sound, the specific flavor or texture of a food, or the type of touch, for example, that caused the child's response. One mother of a typically developing child reported that he "*likes strong physical sensations*."

**Situation or contextual issues**—Parents in both groups frequently identified the situation or context of a sensory experience as the key to explaining their children's responses and preferences. Predictability and novelty figured into both negative and positive sensory experiences. Unexpected, unpredictable, and uncontrollable stimuli were experienced as aversive by children in both groups. On the other hand, two mothers reported that *new* experiences were particularly pleasing to their typically developing children. A child's ability to control the stimulus (e.g., doing something by oneself, being able to terminate the sensory input, or having the freedom to guide one's own experiences) was often reported as the determining factor in how the experience unfolded.

One mother described how her child with autism got into situations where any additional sensory input was unpleasant:

I guess the way I envision it's just like you know all his neurons are firing and he's just like on overload; you know like a short-circuit type thing where he's just getting too much in and he doesn't really know how to filter out what he doesn't need at that point.

This description combines factors within the child (his ability to filter out) with an excessively stimulating situation. A father spoke of how confined spaces with a number of "*visuals*" were difficult for his son, and suggested that this would extend to "*any person with sensory issues*." Multiple accounts described situations with excessive stimulation, combined with a child's autism-related difficulty in handling multiple stimuli, as ripe for aversive responses.

**Being unable to explain**—A mother of a child with autism said, "*I have <u>no idea</u> why he likes things. I don't know if he's experiencing it in the same way I would? You know, because it's <u>fun</u> to jump on a trampoline...." This mother's attempt to understand the child's experience in terms of her own experiences was not unusual. "<i>I don't know what, <u>why</u> he <u>loves</u> music. And I can't think of a reason why. I know I like music, but...*" another mother of a child with autism reported. Unusual sensory experiences presented puzzles that parents tried to understand, sometimes putting themselves into their child's shoes as they did so, as illustrated by the reflection of this parent of a child with autism:

I mean, it's strange, why, 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, you know.... Like, I took his, his, he's got a chew tube that the occupational therapist gave him, and I took it and I chewed on it, and I thought, you know, that feels pretty good. (laughs) I don't know if you've ever done it....It actually feels pretty good, and I kind of understand it a little bit, but I don't need, I don't feel the need to do it constantly or anything, but... it's just the same thing, I mean, it felt good to me, so... I guess it feels good to him.

## Discussion

By comparing parent reports of children with autism and typically developing children we were able to see that sensory experiences overlapped between the groups. Children in both groups reacted negatively to some sounds (often loud, or unexpected), responded positively to movement, and disliked certain foods or sensory aspects of foods. We did, however, sense a qualitative difference in the way parents reported these experiences. Parents of children with autism were more likely to recognize elements in their children's experiences as being sensory, and likely to attribute responses to aspects of autism per se. And while some of the parents in both groups reported strong reactions to sensory input, such accounts by the parents of children with autism described more extreme responses, and sometimes included unusual behaviors.

These accounts were, of course, the parent's rather than the child's, and so they must be understood as an interpretive effort by parents rather than accurate portrayals of their children's sensory experiences. Augmenting parental report with observational and/or self-reports in future studies may shed light on the extent to which children with autism do or do not perceive sensory experiences more intensely than their peers. That notwithstanding, the accounts are what the parents chose to share about their understanding of their children and in that context offer insight about the parent-child experience of sensory situations. Across both groups, parents usually enjoyed their children's enjoyable experiences and desired to continue them, but were distressed by their child's negative sensory experiences, taking steps to avoid or alter sensory situations their children disliked. Although the overall approach to enjoyable versus unpleasant situations was similar in both groups of parents, we cannot deduce the extent to which the type or frequency of family accommodations were similar or different between groups. These occupational accommodations will be further investigated in future studies. The present study supported the occurrence of such accommodations, however, and suggests that occupational therapists may want to probe the nature and extent of such accommodations in their assessments of children with autism or other disabilities and their families.

Within the group of parents of children with autism, two other responses were evident – either to normalize or to pathologize behaviors. A number of parents incorporated extreme or unusual responses to sensory situations into their daily lives. At other times, parents used the jargon of therapy to describe children's behaviors that seemed to be fairly typical. Future research will compare the CIT interviews with other data from the project to examine these phenomena.

Did we find anything unexpected or different in this qualitative add-on to a quantitative study? The team, including those who were collecting the quantitative data from parental questionnaires and child testing, found the qualitative interviews to be perplexing at times and confirming at others. The CIT data added a unique and personal perspective of sensory experiences in children's daily functioning to a largely "quantitative" study, with the potential to triangulate data and deepen our understanding of contextualized sensory experiences.

## **Clinical Implications**

We speculate that this interview format provides parents with an opportunity to share stories about their children without being asked to make comparisons to other children or to a concept of normal. Parents may feel that some standardized assessments miss their child's subtleties and are, at times, not reflective of his/her behavior and skills in the home. In the CIT process, the interviewer provides an accepting environment where the parent is invited to *tell me about*.... This is an invitation to share experiences and talk about one's child on one's own terms, an experience that may be rare for parents of children with autism. In intervention situations, the use of the CIT may help to establish rapport with parents and give the occupational therapist an opportunity to better understand the child in the context of the family.

It can shed light on what the parents value in their child and in their family's life together while also identifying family stressors and/or adaptations associated with the child's sensory experiences. Thus, including qualitative interviews in addition to standardized evaluations of sensory processing may provide a more comprehensive assessment of children's sensory experiences in the context of their daily lives.

Many occupational therapy practitioners will experience a sense of recognition as they read these descriptions of parents' accounts of their children's sensory experiences. In gathering the stories in a consistent way from a large number of participants with autism and a comparison group of typically developing children, and by organizing the findings into themes, this study may provide a broader understanding of the phenomenon of sensory experiences than a single clinician might gain in hearing parents' stories. At the same time, we expect that our findings will validate the experiences of occupational therapy practitioners working with children with autism.

## Strengths, Limitations, and Future Directions

A notable strength of this study is the large number of participants for a qualitative study and the use of a comparison group, allowing for some ability to generalize the findings. The limited scope of the CIT questions allowed collection of a manageable amount of rich descriptive data, but also limited the breadth of responses. Since we inquired specifically about one good and one bad sensory experience, these procedures may have extracted the most salient experiences, but certainly did not elicit a comprehensive array of the frequency, type or intensity of sensory experiences that may have further distinguished the two groups. Furthermore, these data cannot tell us to what extent the sensory processing functions in children with autism are different from those of their typically developing peers, versus to what extent the children's understandings of the situations and/or ability to cope with the sensory experiences are different and may affect the nature of their sensory experiences as well as their parents perceptions of these experiences. We are continuing this qualitative study with more participants in these two groups, an additional group of children with developmental disabilities other than autism, and new questions about how the child's sensory experiences have affected family activities. Another new question, asking the parents to describe an unusual sensory experience, is a response to the relative absence of reports of hyporesponsive sensory patterns in this study that were expected on the basis of quantitative reports in the autism literature (Baranek et al., 2006).

Other limitations in the study included the use of a convenience sample of typically developing children which over-sampled more highly educated parents and the fact that this study is built upon parent reports, rather than reports of the children themselves. Future work with older children will include direct interviews with those who are able to participate in the process.

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## References

- Baranek, GT. Sensory Processing Assessment for Young Children (SPA). University of North Carolina; Chapel Hill: 1999. Unpublished manuscript
- Baranek GT, Boyd BA, Poe MD, David FJ, Watson LR. Hyperresponsive sensory patterns in young children with autism, developmental delay, and typical development. American Journal on Mental Retardation 2007;112:233–245. [PubMed: 17559291]

- Baranek GT, David FJ, Poe MD, Stone WL, Watson LR. The Sensory Experiences Questionnaire: Discriminating response patterns in young children with autism, developmental delays, and typical development. Journal of Child Psychology and Psychiatry 2006;47I:591–601. [PubMed: 16712636]
- Charmaz, K. Constructing grounded theory: A practical guide through qualitative analysis. London: Sage Publications; 2006.
- DeGrace BW. The everyday occupation of families with children with autism. The American Journal of Occupational Therapy 2004;58(5):543–550. [PubMed: 15481781]
- Dunn, W. Sensory profile. San Antonio, TX: The Psychological Corporation; 1999.
- Dunn W, Myles BS, Orr S. Sensory processing issues associated with Asperger syndrome: A preliminary investigation. The American Journal of Occupational Therapy 2002;56:97–102. [PubMed: 11833406]
- Flanagan J. The critical incident technique. Psychological Bulletin 1954;51:327–358. [PubMed: 13177800]
- Forrest, J. Visual aesthetics for five senses and four dimensions: An ethnographic approach to aesthetic objects. In: Browne, R.; Browne, P., editors. Digging into popular culture: Theories and methodologies in archeology, anthropology, and other fields. Bowling Green, OH: Bowling Green State University Press; 1991. p. 48-57.
- Fox L, Vaughn B, Wyatte M, Dunlap G. We can't expect other people to understand: Family perspectives on problem behavior. Exceptional Children 2002;68(4):437–450.
- Gallimore R, Coots J, Weisner T, Garnier H, Guthrie D. Family responses to children with early developmental delays II: Accommodation intensity and activity in early and middle childhood. American Journal on Mental Retardation 1996;101:215–232. [PubMed: 8933897]
- Hasselkus B, Dickie V. Themes of meaning: Occupational therapists' perspectives on practice. Occupational Therapy Journal of Research 1990;10:195–207.
- Hasselkus B, Dickie V. Doing occupational therapy: Dimensions of satisfaction and dissatisfaction. American Journal of Occupational Therapy 1994;48:145–154. [PubMed: 7517102]
- Hasselkus B, Dickie V, Gregory C. Geriatric occupational therapy: The uncertain ideology of long-term care. American Journal of Occupational Therapy 1997;51:132–139. [PubMed: 9124270]
- Jones R, Quigney C, Huws J. First-hand accounts of sensory perceptual experiences in autism: a qualitative analysis. Journal of Intellectual & Developmental Disability 2003;28(2):112–121.
- Kietnz MA, Dunn W. A comparison of the performance of children with and without autism on the Sensory Profile. American Journal of Occupational Therapy 1997;51:530–537. [PubMed: 9242859]
- Larson E. Caregiving and autism: How does children's propensity for routinization influence participation in family activities? OTJR: Occupation, Participation and Health 2006;26(2):69–79.
- Lincoln, YS.; Guba, EG. Naturalistic inquiry. Newbury Park, CA: Sage Publications; 1985.
- Liss M, Saulnier C, Fein D. Sensory and attention abnormalities in autistic spectrum disorders. Autism 2006;10(2):155–172. [PubMed: 16613865]
- Muhr, T. Atlas.ti (Version 5.0) [Computer software]. Berlin, Germany: ATLAS.ti Scientific Software Development GmbH; 2004.
- Mullen, EM. Mullen Scales of Early Learning (AGS Ed). Los Angeles: Western Psychological Corp; 1995.
- Rogers SJ, Hepburn S, Wehner E. Parent reports of sensory symptoms in toddlers with autism and those with other developmental disorders. Journal of Autism and Developmental Disorders 2003;33:631– 642. [PubMed: 14714932]
- Roid, GH.; Miller, LJ. Leiter International Performance Scale Revised. Wood Dale, IL: Stoelting; 1997.
- Schwandt, TA. The Sage dictionary of qualitative inquiry. Vol. 3. Thousand Oaks, CA: Sage Publications; 2007.
- Watling RL, Dietz J. Immediate effect of Ayres's sensory integration–based occupational therapy intervention on children with autism spectrum disorders. American Journal of Occupational Therapy 2007;61:574–583. [PubMed: 17944295]
- Watling RL, Deitz J, White O. Comparison of Sensory Profile scores of young children with and without autism spectrum disorders. American Journal of Occupational Therapy 2001;55:416–423. [PubMed: 11723986]

	Z	Race	Mother's Educational Level <sup>*</sup>	Chronological Age (months)*	Mental Age (months)
Typical	29	23 White	High school degree: 3 (10%)	Range: 11–81	Range: 12–86
		2 Black	Beyond HS, partial college: 4 (13%)	Mean: 42.3	Mean: 47.9
		1 Hispanic	College degree: 12 (41.4 %)	SD: 19.7	SD: 20.9
		3 >1	Graduate degree: 10 (34.5%)		
Autism	37	27 White	High school degree: 10 (27%)	Range: 28–83	Range: 4–108
		6 Black	Beyond HS, partial college: 6 (16.2%)	Mean: 53.2	Mean: 36.4
		2 Hispanic	College degree: 15 (40.5%)	SD: 18.2	SD: 27.0
		2 > 1	Beyond college: 1 (2%)		
			Graduate degree: 6 (16.2%)		

(p>.05) as appropriate.

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Table 1

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#### Table 2

Examples of parent reports of child behaviors in response to sensory stimuli

Sensory component dominates response:

- Pleasant: Child enjoys a favorite song or dances along to music.
- Unpleasant: Child has extreme reaction as if in pain to a loud sound or experiences a "melt down" at sight, smell, and/or texture of food.

Sensory component is embedded in a situation:

- Pleasant: Child participates in parent/child hugging or snuggling routine involving touch or enjoys a birthday party at a fast food restaurant.
  - Unpleasant: Child resists going for a haircut because of the buzz of the clippers, or "loses it" during a school event with lots of stimulation.