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Sensory experiences of children with autism spectrum disorder: In their own words

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Abstract

First-person perspectives of children with autism spectrum disorder (ASD) are rarely included in research, yet their voices may help more clearly illuminate their needs. This study involved phenomenological interviews with children with ASD ($n=12$, ages 4-13) used to gain insights about their sensory experiences. This article addresses two study aims: determining the feasibility of interviewing children with ASD and exploring how they share information about their sensory experiences during the qualitative interview process. With the described methods, children as young as four and across a broad range of autism severity scores successfully participated in the interviews. The manner with which children shared information about their sensory experiences included themes of normalizing, storytelling, and describing responses. The interviews also revealed the importance of context and the multisensory nature of children's experiences. These findings contribute strategies for understanding the sensory experiences of children with ASD with implications for practice and future research.

Keywords

Autism spectrum disorder; child interviews; sensory experiences

Introduction

First-person perspectives of children are widely absent from empirical investigations of their experiences, especially when the child has a disability. Research involving children with autism spectrum disorder (ASD) is no exception and primarily represents the views of parents, professionals and researchers. This study accessed the perspectives of children with ASD to contribute to our developing understanding of their sensory experiences. Specifically, this article reports on the feasibility of the study and describes the manner in which children shared about their sensory experiences during qualitative interviewing.

Over the past two decades, researchers have identified pervasive differences in the behavioral responses of children with ASD to sensory aspects of their environments (i.e., sensory features) (Baranek et al., in press). The sensory features frequently seen in ASD are

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currently conceptualized to include hyperresponsiveness (an over-reaction to sensory stimuli), hyporesponsiveness (a decreased response to sensory stimuli), sensory seeking (behaviors aimed at pursuing intense or unusual sensory stimulation) and enhanced perception (acute awareness of sensory stimuli) (Baranek et al., in press). These behaviors are not mutually exclusive; indeed, many children exhibit groups of differing behaviors as suggested by recent studies identifying sensory subtypes (e.g., Ausderau et al., under review; Lane et al., 2010). Extant research involving caregiver interviews suggests that unusual sensory experiences impact the daily routines and functioning of children with ASD and their families (Bagby et al., 2012; Schaaf et al., 2011).

Questionnaires, caregiver interviews and observational measures have been the primary modes of data collection in sensory related research among children with ASD. Although these methods have been successful in describing sensory features, they do not provide adequate insight into the child's lived experience. Parent, caregiver and clinician perspectives are invaluable to describing and understanding these experiences, but these third person views should not replace—nor should they be confused with—the child's perspective.

Rather, to understand their perspectives, we can go straight to the source by interviewing children with ASD themselves. However, these perspectives may not be valued or taken seriously due to a lessened social stance related to being both children and people with disabilities. In 1986, a child sociologist expressed her frustrations that in our society, “To take children's ideas, beliefs, activities and experiences seriously as *real* and as embodying *knowledge* is to risk being taken for a fool” (Waksler, 1986: 71). Over two decades later, this remains a concern when one sets out to conduct research incorporating children's perspectives. Though this area of research has expanded, children's voices are still rarely heard or taken seriously in the academic arena. According to Waksler, “The absence of children's explanations is rarely missed because its very existence is not recognized” (1986: 73). Notable exceptions that *do* recognize child's perspectives can be found in the health sciences literature (e.g., Aldiss et al., 2009; Kortessluoma and Nikkonen, 2006; Sartain et al., 2000; Wilson et al., 2010). These authors have demonstrated the benefits and value of research incorporating children's viewpoints, and yet, the voices of children with disabilities remain notably absent from empirical work.

The perspectives of children with ASD, in particular, may be less-likely to be included in research due to the nature of the diagnosis. In particular, deficits in social skills and communication as well as restricted and repetitive interests (American Psychiatric Association, 2013) make daunting the prospect of interviewing this population. Nonetheless, a small body of literature incorporates perspectives of young people with ASD into investigations about their experiences. For example, Spitzer (2003) explored the meaning of daily activities of children with ASD and other developmental disabilities through participant observation. Huws and Jones (2008) used interview methods to study the personal meaning and impact of receiving a diagnosis as experienced by adolescents with ASD. Other researchers have successfully utilized interviews to examine friendships from the perspectives of individuals with ASD (Daniel and Billingsley, 2010; Howard et al., 2006). Recently, Ashburner and colleagues (2013) demonstrated the feasibility of

interviewing adolescents with ASD about their sensory experiences despite the abstract nature of these topics.

In summary, there is a need for more research incorporating the first-person perspectives of children with ASD. The aims of the present study are twofold. First, we aimed to determine the feasibility of interviewing children with ASD about their sensory experiences. The second aim was to understand how the children in our sample shared information about their sensory experiences during the qualitative interview process. Using a qualitative approach was appropriate to inductively explore these aims. Our methods do not allow for generalizability to broader populations of children with ASD, nor for drawing comparisons to other groups (e.g., children with typical development). However, they do provide previously-unidentified insights that can contribute to future research and practice related to the sensory experiences of children with ASD.

Methods

This phenomenological study explored the perspectives of children with ASD about their sensory experiences. Because this study was part of a larger federally funded project, there were several data sources in addition to the child interviews used during the research process. Figure 1 contains a flow chart illustrating how the child interviews fit-in with the larger project. A description of assessments relevant to this study is located in Table 1. This research was approved by the university's internal review board and followed all data security and informed consent/assent procedures. Participants received financial compensation for their participation in the larger project.

Participants

The participants were twelve children diagnosed with ASD, ages 4-13 (mean 8.3) years. A description of the demographics, sensory features and autism severity scores for the children are located in Table 2. A child's capability of participating in an interview was determined by the research team using clinical impressions; thus, there were no requisite assessment cut-off scores. Rather, over the course of at least two appointments, experienced research staff interacted with the children in both structured and casual interactions. Through these interactions, staff determined if each child was capable of focusing on a conversation and providing unprompted responses to open-ended questions about their experiences. For example, "What do you like to do for fun?" was one of the sample questions used.

Procedures

Face-to-face, semi-structured interviews were conducted in the children's homes by one of five research assistants—all graduate students with experience working with children with ASD—over a 30 month period. Interviews lasted between 25 and 50 minutes and were video-recorded and transcribed verbatim. The investigators followed a semi-structured interview guide developed by the research team (See Appendix). Each interview was individualized and adjusted according to the child's preferences. For the ten children with home video data, salient clips of their own recorded experiences were shown during the interview to facilitate discussion. Procedures were adapted for the children as needed; for

example, if a child seemed to have trouble participating verbally, the interviewers could write some questions down or offer the child a pen and paper to facilitate response.

Analysis

The analysis process began with repeated reading and discussion of the transcripts among the research team. Because the children often used gestures and facial expressions to accompany their verbal responses, each transcript was supplemented with detailed descriptions of the child's behavioral responses.

Coding procedures were derived from recommendations by Coffey and Atkinson (1996) and Rubin and Rubin (2005). Using an iterative, inductive process, we approached coding the data with the research question: How did the children share about their sensory experiences? Portions of the data that did not address a sensory experience were not coded and segments could be coded with more than one description. First round codes were open and flexible in order to allow for development throughout the process. When a new code was revealed, previously-coded interviews were reviewed to determine if a similar code was present. There were over fifty codes after the first round. We used matrices to visualize early codes and determine patterns of codes among participants (Miles and Huberman, 1994). The early, inductive codes represented researcher interpretations of how the children shared their experiences. They included descriptive labels such as “acts-out experience,” “internal dialogue,” and “sensory experience to feel better.”

Some codes reflected challenges related to stereotypical behaviors commonly seen in ASD. These were coded as “barriers” and consisted of responses that appeared contradictory, repetitious, overly literal, unclear, or nonsensical. Examples of these codes included: “scripting,” “repeating interviewer,” and “nonsense phrase.” The research team decided to set aside these segments of data as they masked the quality and meaning of the children's other responses. Happé (1991) described how, when analyzing the words of individuals with ASD, a more subjective approach is warranted to reduce false negative and false positive conclusions. Therefore, great care was taken in this study to highlight what appeared to be the children's statements and behaviors that truly responded to the questions asked.

The remainder of the codes were merged and grouped into interpretive categories. The transcripts were then re-read and re-coded, resulting in ten final codes which grouped into three thematic categories. Upon second round coding, if a specific type of response was explicitly prompted by the interviewer, it was not coded; codes were reserved for categories of response that appeared unprompted (i.e., not led by the interviewer) in the transcripts. This was done to highlight the manner in which the children chose to share their sensory experiences, rather than their ability to respond to a certain type of question. Examples of each of the ten codes appeared unprompted in at least two transcripts and all transcripts contained at least one final code.

The first author, responsible for the majority of the coding, brought the codes to the other authors for discussion and confirmation throughout the process. An audit trail, whereby all authors carefully reviewed documentation of each stage of the analysis process, was used to enhance trustworthiness in this study (Brantlinger et al., 2007; Schwandt, 2007).

Additionally, an external auditor—a sociological and educational researcher unaffiliated with the research project and expert in qualitative methods—examined and confirmed the findings were logical and grounded (Brantlinger et al., 2007; Schwandt, 2007). Researcher reflexivity was used throughout the analysis process to ensure trustworthy results through journaling and discussion of researcher biases among the authors and with the external auditor (Brantlinger et al., 2007). Furthermore, detailed descriptions and quotes used throughout the results section further demonstrate the soundness of the presented conclusions (Brantlinger et al., 2007; Creswell, 2013).

Findings

The first key finding from this study is that we did, indeed, find it feasible to interview all the children who were identified through our selection process and each interview contained data that contributed to the findings for the second aim. Three important steps in our process enhanced the feasibility of these interviews: utilizing video clips of the child's own behaviors to ground the conversations, individualizing the interviews to the child's preferences and experiences, and providing opportunities for the children to share their experiences in creative ways. Additionally, video recording the interviews and adding detailed behavioral descriptions to the transcripts facilitated more complete data analysis.

In response to the second aim, three themes emerged which addressed how the children shared about their sensory experiences: by normalizing, storytelling, and describing their responses to their sensory experiences.

Normalizing

A group of responses signified that the children either felt—or wanted to feel—‘normal.’ In this theme, the children described their experiences in terms of simple likes and dislikes, as changing over time and as just like other people's experiences.

Likes and dislikes—The children frequently framed their sensory responses as general likes or dislikes. Children may not recognize or care *why* they do or do not like certain things. In this study, they often merely declared their like or dislike. The following example is from an interview with a child whose parent had previously reported his sensitivity to clothing on questionnaires.

Interviewer (I): I noticed that you're wearing a short-sleeved shirt

Child (C): I like those shirts

I: Yeah, better than long sleeves?

C: Cause long sleeves are like, I don't like them.

Representing their experiences in this way suggests that children may experience their likes and dislikes as aesthetic choices rather than an internalized issue or response.

In addition, children's preferences were not self-described as ‘sensory’ in nature, but as a more holistic experience. For example, a child who stated, “I like ice cream” was not specific (despite prompts by the interviewer) about whether he liked the cold sensation, the

sweet flavor or the social milieu associated with experiences of eating ice cream. Another child mentioned multiple times that he did not like spinach and called it “bad food,” again refraining from identifying any specific sensory aspects.

Speaking about sensory experiences as likes and dislikes may have removed a layer of abstraction for the children. They could describe positive and negative experiences without specifying which sense was dominant or what aspects were problematic; they spoke of them, rather, as integrated experiences.

Change over time—Many of the children in this study discussed their sensory experiences as changing over time. For some, it was a matter of growing accustomed or adjusting to non-preferred stimuli over time or with intervention.

C: Um, I used to not like whistles, but I'm over it now.

I: You're over it? So what did you do to, to get over it? How did that change?

C: Well, what happened is people let me blow the whistle myself, and I thought, like, if I could blow it and I, and the whistle's near me, it's, figure it's not so bad after all.

Other children demonstrated that they believed their previous behaviors were child-like and they wanted to grow up.

[discussing hair brushing]

I: Tell me about a time when it was painful.

C: A time when it was so painful is when I was like four or five.

...

I: What's different now?

C: That I'm thirteen, and started the seventh grade

...

C: And (pause) and that's it.

I: And what's different about having your hair brushed now?

C: That I look beautiful.

Based on the video observations in the home, the above participant was still experiencing discomfort during hair brushing; she grimaced, closed her eyes and covered her face. However, she no longer cried or fought against having her hair brushed. She seemed to have reached a point at which she was no longer willing to let her sensory responses limit her.

For the children, change over time exemplified growth; they discussed moving away from symptoms and being motivated to increase their participation in ‘normal’ daily activities. The children primarily spoke about change regarding the lessening of aversive experiences. When such changes had occurred, the children seemed proud that while they may still be struggling with sensory sensitivities, they have overcome some of their challenges.

Same as others—In some of the interviews, the children explicitly stated that they were not different from other people. In the excerpt below, the child chose to answer the interviewer's questions with responses that seem 'normal' and then reinforced this by explaining that these are similar to what other people would say.

I: What about things that you don't like to touch or feel on your skin?

C: Um, sharp stuff.

I: Sharp stuff? (smiles) Yeah, exactly.

C: Um, like most people do.

I: Yeah.

C: Um, (pause) hot stuff.

I: Yep.

C: Like, burning hot, like pizza that just came out of the oven.

...

I: Do you have a favorite thing that you like to eat?

C: Uh, pizza.

I: Yeah? When it's not too hot, right?

C: Right. That's what most people say.

Another participant seemed to recognize a difference in his response to the experience, but not his engagement with the activity that elicited the response.

[discussing teeth brushing as a painful experience]

I: Tell me how you brush your teeth.

C: I brush them, I don't know. I think I brush them much like other people.

Even though this child brushes his teeth like others, he recognized that his experience of teeth brushing was distinct in that it was painful for him.

Storytelling

The children used a variety of storytelling techniques to share their experiences with the interviewer. Many children in the study struggled with directly answering questions about their experiences and so they used creative strategies to share descriptions. Sharing methods included anecdote, demonstration, internal dialogue and simile.

Anecdote—Speaking about a specific instance was a common way the children shared their sensory experiences with the interviewer. While this type of response was asked for directly in some of the interviews, often the child offered a story on his/her own.

I: Well let's talk about the blender. You said that was a bad sound. Tell me a little bit about that.

C: Well, it's really, it's just really loud, and the noise just, um, is horrible.

I: Oh, how does it make your ears feel?

C: Bad, and so I just have to cover them. [Demonstrates] One time, when I was at a theater camp, where the director reads a story and, and I'd be dressed up in costumes of the characters in the story and get to play them, and I played as many things. I played, I been, and one time, one director, she was a very old woman, was playing a vacuum. I just covered my ears.

Overall, the children seemed more comfortable speaking about specific instances rather than trying to generalize their experiences.

Anecdotes were used by the children to share specific sensory experiences that occurred in various aspects of their lives. These stories added depth to their accounts and provided the interviewers with information to guide further questions. They also highlighted the importance of context to a child's experiences; based on their descriptions, it seems the children feel that what others might identify as internal responses are closely connected with their situations.

Demonstration—The majority of the children used demonstration or imitation as a method to share their experiences. They frequently demonstrated strategies using their bodies—especially covering their ears. Another common use of this method was for explaining what kinds of sounds were bothersome.

I: Is there anything else that hurts your ears?

C: Um, (pause) Um, I think that's it.

I: What can you do to

C: [interrupting] I mean no, sometimes those scoreboards uh, when uh, when it sounds and it goes “Brrrrrrr” and it's louder, it's louder than my mouth.

In the example above, the participant used his mouth to imitate, but wanted to make it clear that he was not making the exact sound; the real sound is louder, and therefore more bothersome. Another child made a similar clarification for the interviewer, stating, “Like that, but bigger” after demonstrating loud gunshot noises at the state fair.

Other children used demonstration to convey positive sensory experiences.

C: Sometimes I like to think about little sounds as music. Like, besides the ones that are, like, real music. Like, for instance, (quieter) um, (pause) Well sometimes, you know when you get in the car and it turns on, it goes, ‘rum, rum’? I kind like to think of it as ‘rummmrummm’ (spoken rhythmically) [Uses his hands together to demonstrate].

Another common use of this method was for the child to imitate his/her reaction to a sensory experience.

Father: But why do you not wanna try vegetables?

C: Because I don't like it. I just like the juice in there.

Father: Yeah, well how come? You don't like it on your tongue? Does it make you feel

C: It's like Eeeeeugh! [sticks out his tongue and makes a disgusted face]

Acting out the experience seemed to come more easily to the children than explaining their perspective with words. It also proved to be a very effective storytelling method.

Internal dialogue—The children sometimes repeated dialogue that had been running through their head during a sensory experience. One participant who is bothered by the sound of toilets flushing stated, “I took deep breaths [breathes deeply] I was like, I was like, ‘K, that was it, no more flushing.’” Another child described his experience at a basketball game:

And I heard the buzzer and I started to have panic, like, ‘Ahh!,’ like the panic that my brain is going in, like ‘what should I do, what should I do? Ahh!’ It's kind of like bouncing off the walls in, um, my head, like ‘what should I do?’

The effectiveness of this method of storytelling caused us to prompt later participants to share their experiences in this way.

Simile—While simile was only used in two interviews, it is a thought-provoking storytelling method. Both children used simile to compare a negative sensory experience to a much more exaggerated one. One child likened eating spinach to eating grass (“it tastes like me eating grass”) and the other, loud voices to a lion's roar. These statements suggest an understanding that their experience of tastes and sounds may be exaggerated from those of other people. They also imply awareness that for someone else to understand, they need to compare it to something else—something more universally unpleasant.

Describing responses

The final theme identified in the data involved the children describing their responses or reactions to negative sensory experiences. For many children, their response to stimuli emerged as a salient aspect of the experience. Their reasoning for why something was a problem was often due to the reaction it caused, rather than the stimuli itself. These reactions included using strategies, uncontrollable physical responses and fear.

Strategies—The children frequently characterized a sensory experience by the reaction they had to it, and often their reaction was to incorporate a particular strategy. This was usually framed by the children as a *need*, rather than a strategy they had devised; for example, “I just have to cover [my ears]” and “I had to drink water.” These strategies were primarily in response to aversive experiences, with the most common being covering ears during a loud or unpleasant sound.

Another type of strategy the children endorsed was choosing not to participate in negative experiences. One child stated, “I decided to not, not to eat beans anymore,” since she had

experienced multiple episodes of gagging while eating beans. Another child identified that not all unpleasant sensations were necessary—or worth it—to endure.

C: Fireworks. They're one of my least favorite things. But people can take me out on fireworks, it's mostly optional.

I: Okay.

C: It's not like 'you have to eat your dinner,' or 'you have to eat your vegetables.' It's mostly like, it's supposed to be a pretty sight. I like to watch it, like, with the window.

As the child in the above excerpt noted, there were often ways to adapt an experience to remove the unpleasant aspect. Another participant had a similar strategy: "That's why I like to watch it on TV instead of in real basketball game."

Uncontrollable physical responses—It was also common for the children to talk about negative sensory experiences causing a bodily reaction. The most frequent response described was feeling pain during loud noises. Children also associated pain—and occasionally, resultant crying—with tactile experiences such as hair brushing, teeth brushing and stepping on sand. Some children discussed how movements such as spinning caused sensations of dizziness and nausea ("might throw up"). Foods were described as causing children to feel reactions such as "hurt," "itchy," "choke," "gag" and "vomit." Children often could not explain what was negative about the stimuli, but only their reaction to it. Many children also described feeling "good" after a negative experience was over.

Some children also described other physiologic changes associated with negative sensory experiences. For example, when describing his experiences with loud music, one child stated, "It feels like my heart is beating, and um, my, uh, my whole body's shaking. Mmm and, uh, and my eyes, uh, they start to blink a lot." This suggests how out of control some children may feel during a negative sensory experience.

Fear—The final type of response children discussed was fear. The children seemed to remember past negative responses and reported fear of re-experiencing those sensations. A child who described trying new foods stated, "I'm afraid it might, it might feel weird or, or taste bad." Another participant—who, according to her mother, is afraid of and avoids places with inflated balloons—reported, "Well, the balloons popped, they were really scary. Last time I found, last time I got a balloon out, (inaudible) throw it in the air and I pop it on the rocks." Another child described it as feeling like, "the unknown is gonna come." Hearing this perspective allows us to understand that sensory responses are not isolated incidences, but may impact other aspects of children's lives. For these children, fear or anxiety related to sensory experiences seem to be playing a role in limiting their participation in daily activities.

Discussion

In this study, we determined that despite barriers to the process, it is feasible to interview children with ASD about their sensory experiences. Previous research involving interviews

with individuals with ASD has typically targeted older individuals and/or those who are considered to have less autism severity (e.g., Ashburner et al., 2013; Daniel and Billingsley, 2010; Howard et al., 2006; Huws and Jones, 2008). In attempting to interview younger children with a range of severity levels, we encountered new challenges including maintaining children's foci and discussing abstract concepts during interviews as well as interpreting children's words during analysis. However, using the described methods, we derived meaningful results from interviews with children with ASD as young as four years old and across a broader range of autism severity scores (in fact, the full range according to Gotham et al.'s 2009 system).

Regarding our second aim, three salient themes addressing how the children shared about their experiences were identified in the data—normalizing, storytelling and describing responses. The first theme described illustrates the manner in which many of the children in our study seemed to frame their experiences as “normal.” This is contrary to what is expected based on previous research and clinical perspectives, which tend to highlight the abnormal. Children with ASD are so frequently described as being *different* that it appeared unusual to us when they spoke simply about their likes and dislikes and about their preferences as changing over time.

Discussion of likes and dislikes also suggested that the children viewed their experiences as multisensory. In contrast to literature which breaks sensory processing deficits down by modality (e.g., Tomchek and Dunn, 2007), the children in this study implied that they experienced stimuli in an integrated manner. This finding lends additional support for theoretical arguments to view sensory experiences more holistically (e.g., Iarocci and McDonald, 2006). Additionally, when describing changes in their sensory experiences, children suggested they were motivated to change in order to improve participation in daily activities and as part of growing up. Practitioners are encouraged to be mindful of how children view their sensory experiences and what motivates them when tailoring interventions.

Some children also explicitly stated that their experiences were similar to those of “most people.” This suggests that they may be experiencing some self-consciousness about their experiences and perhaps do not want their sensory features to make them stand out. These findings are contrary to previous research with adults that suggests there are deficits in self-consciousness among individuals with ASD (Toichi et al., 2002) as well as findings which suggest that people with ASD may not desire to be ‘neurotypical’ (Hurlbutt and Chalmers, 2002). Future research could further explore the ways that children with ASD view themselves and how they want to be viewed. In addition, future work could determine if these normalizing statements are consistent in other samples and when interviewing children about other topics.

We found that the children in our study were able to share their experiences with us using various storytelling methods. The methods described in the second theme—*anecdote, demonstration, internal dialogue and simile*—may be particularly relevant for practitioners aiming to understand children's sensory experiences as well as for future research. Table 3 contains these four storytelling methods along with prompts that could be used to elicit

descriptions from children with ASD. This theme aligns with previous work which suggests that children prefer alternative modes of communication (Curtin, 2001).

As evident with their use of anecdote, context was a salient aspect of children's sensory experiences. They did not discuss their experiences as abstracted interactions with sensory stimuli but rather as situated experiences occurring within a particular time and place. Future research should further explore the role of context in the manifestation of sensory features.

The use of simile as a storytelling method seemed to suggest a sort of perspective-taking that is not expected of children with ASD. Individuals with ASD are often described as being overly literal and unable to understand the perspectives of others (Happé, 1993). However, two of the children in the study provided non-literal descriptions of their experiences using simile, suggesting they were trying to provide a reference for the interviewer to understand their experiences.

The third theme addressed how children used descriptions of their responses to sensory experiences as a way to share their perspectives. Their responses included strategies, uncontrollable physical reactions and fear. It seemed that although the children may not know *why* they had a certain response (e.g., gagging while eating a new food or covering ears during a basketball game), they viewed their reaction as a particularly salient aspect of the experience. The children's discussion of fear is especially relevant to practitioners and researchers aiming to understand the behaviors and participation patterns of children with ASD. Pfeiffer (2012) recently questioned 'which came first?' regarding hypersensitivities and anxiety. These fears related to past negative sensory experiences may be leading to—or co-occurring with—anxiety which can impact children's participation in daily functioning; these topics warrant further exploration.

Limitations

Despite our efforts to address the challenges faced during this study, there are some persistent limitations that must be discussed. Generalizability to broader populations of children with ASD is not possible from this study due to the methods used as well as the limited size and diversity of our sample. Additionally, the lack of a comparison group limits the conclusions that can be drawn; thus, we cannot suggest that the presented themes were unique to children with ASD. However, the findings do enhance existing literature on this topic by exploring first-person perspectives on a topic that has already been well-described from others' perspectives and across groups (e.g., Bagby et al., 2012; Baranek et al., 2006; Dickie et al., 2009; Tomchek and Dunn, 2007).

Although we excluded children who were unable to answer open-ended questions, some still experienced difficulty with the question-answer process, especially given the abstract nature of sensory experiences. This led to the interviewers occasionally needing to use leading questions, suggest responses or consult with family members. However, the use of video clips as artifacts and inclusion of detailed non-verbal responses in the transcripts helped to alleviate these problems. Additionally, the use of semi-structured methods allowed us to adapt to and include children with a variety of preferences and abilities.

Though we included children within a broad range of autism severity scores as well as chronological and mental ages, children not competent with verbal language were excluded. Therefore, we have no sense of how children who have less verbal aptitude may share information about their sensory experiences. Future studies may benefit from experimenting with play-based interviewing techniques or the utilization of augmentative communication tools to reduce reliance on verbal descriptions.

Finally, we chose to exclude from our analysis those behaviors and verbal responses that we felt represented stereotypical behavior not responsive to the interview. Setting aside segments of transcripts from analysis is not generally recommended, but it was determined to be appropriate for these interviews in order to access the children's perspectives rather than merely reflect diagnostic characteristics. However, we cannot be certain that meaningful information was not lost in this process. Additionally, it is possible that with prolonged research engagement with the children, better understanding of the significance of these aspects of the interviews could be developed (see for example, Spitzer, 2003).

Conclusion

Prior knowledge of the sensory experiences of children with ASD has primarily been derived from third person views. Although accessing the perspectives of children with ASD can be challenging, especially regarding abstract concepts such as sensory experiences, this study demonstrates that using child interviews as a primary data source can be fruitful. We found success utilizing video clips to ground the conversations, individualizing the interviews to each child and providing an opportunity for them to share their experiences in creative ways. Additionally, video recording the interviews and adding detailed behavioral descriptions to the transcripts enhanced our process. With these methods, we learned that the children in our sample shared about their sensory experiences in three key ways—by normalizing, storytelling and describing their responses. Through exploration of *how* children share about their experiences, we can come to better understand those experiences. These first person perspectives can contribute to improving how we study, assess and address sensory features that impact daily functioning among children with ASD. Our findings can also inform future research aiming to access the perspectives of children with ASD on other important topics.

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Appendix

Basic Interview Guide

Each child's interview guide was individualized based on information from standardized caregiver assessments, parent interviews, and home video recordings. During the interviews, interviewers adapted questions as needed and followed the child's lead.

- Today I am here to talk to you about ways that we get information from the world around us—I want to ask you some questions about your senses. Do you know what your five senses are?
- Can you tell me about some things that you [see with your eyes, hear with your ears, etc.]?
- What do you like to [see, hear, eat, smell, etc.]?
- What do you like about [child-provided example]?
- Are there some things that you do not like to [taste, touch, etc.]?
- Tell me about a time when you [heard a noise, tasted something, etc.] that you did not like.
- What are you thinking while this is happening?
- What does it feel like on your [ears, skin, etc.]? ...in your body?
- What do you do when you [hear a loud noise, smell something, etc.] that you don't like?
- Are there other things that you can do that make it better?
- Are there some [smells, noises, etc.] that are worse than others?
- Tell me what you don't like about [child-provided example].
- How about when you were younger? Did [child-provided example] bother you when you were little?
- How is your life different from other kids who don't mind [hearing loud noises]?
- What about other things that you do not like [to feel, to taste, etc.]?

References

- Aldiss S, Horstman M, O'Leary C, Richardson A, Gibson F. What is important to young children who have cancer while in hospital? *Children and Society*. 2009; 23:85–98.
- American Psychiatric Association. Neurodevelopmental disorders. In: *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed.. American Psychiatric Association; Arlington, VA: 2013. DOI: 10.1176/appi.books.9780890425596.514988
- Ashburner J, Bennett L, Rodger S, Ziviani J. Understanding the sensory experiences of young people with autism spectrum disorder: A preliminary investigation. *Australian Occupational Therapy Journal*. 2013; 60(3):171–180. [PubMed: 23730782]

- Ausderau KK, Furlong M, Sideris J, Little LM, Bulluck J, Watson LR, Boyd BA, Belger A, Dickie VA, Baranek GT. Sensory subtypes in children with ASD: Latent profile transition analysis using a national survey of sensory features. under review.
- Bagby MS, Dickie VA, Baranek GT. How sensory experiences of children with and without autism affect family occupations. *American Journal of Occupational Therapy*. 2012; 66(1):78–86. [PubMed: 22389942]
- Baranek, GT. Sensory Experiences Questionnaire (Version 3.0). University of North Carolina at Chapel Hill; 2009. Unpublished manuscript
- Baranek GT, David FJ, Poe MD, Stone WL, Watson LR. Sensory experiences questionnaire: Discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry*. 2006; 47(6):591–601. [PubMed: 16712636]
- Baranek, GT.; Little, LM.; Parham, D.; Ausderau, KK.; Sabatos-DeVito, M. Sensory features in autism spectrum disorders.. In: Volkmar, F.; Paul, R.; Pelphrey, K.; Rogers, S., editors. *Handbook of Autism and Pervasive Developmental Disorders*. 4th ed.. Wiley; Hoboken, NJ: in press
- Brantlinger E, Jimenez R, Klinger J, Pugach M, Richardson V. Qualitative studies in special education. *Exceptional Children*. 2007; 71(2):195–207.
- Coffey, A.; Atkinson, P. *Making Sense of Qualitative Data: Complementary Research Strategies*. Sage Publications, Inc.; Thousand Oaks, CA: 1996.
- Creswell, JW. *Qualitative Inquiry and Research Design*. 3rd ed.. Sage Publications, Inc.; Thousand Oaks, CA: 2013.
- Curtin C. Eliciting children's voices in qualitative research. *American Journal of Occupational Therapy*. 2001; 55(3):295–302. [PubMed: 11723970]
- Daniel LS, Billingsley BS. What boys with an autism spectrum disorder say about establishing and maintaining friendships. *Focus on Autism and Other Developmental Disabilities*. 2010; 25(4):220–229.
- Dickie VA, Baranek GT, Schultz B, Watson LR, McComish CS. Parent reports of sensory experiences of preschool children with and without autism: A qualitative study. *The American Journal of Occupational Therapy*. 2009; 63(2):172–181. [PubMed: 19432055]
- Dunn, W. *Sensory profile*. The Psychological Corporation; San Antonio, TX: 1999.
- Gotham K, Pickles A, Lord C. Standardizing ADOS scores for a measure of severity in autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2009; 39:693–705. [PubMed: 19082876]
- Happé FGE. Communicative competence and theory of mind in autism: A test of relevance theory. *Cognition*. 1993; 48:101–119. [PubMed: 8243028]
- Happé, FGE. The autobiographical writings of three Asperger syndrome adults: Problems of interpretation and implications for theory.. In: Frith, U., editor. *Autism and Asperger syndrome*. Cambridge University Press; New York: 1991. p. 207-242.
- Howard B, Cohn E, Orsmond GI. Understanding and negotiating friendships: Perspectives from an adolescent with Asperger syndrome. *Autism*. 2006; 10(6):619–627. [PubMed: 17088277]
- Hurlbutt K, Chalmers L. Adults with autism speak out: Perceptions of their life experiences. *Focus on Autism and other Developmental Disabilities*. 2002; 17(2):103–111.
- Huws JC, Jones RSP. Diagnosis, disclosure, and having autism: An interpretive phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual & Developmental Disability*. 2008; 33(2):99–107. [PubMed: 18569397]
- Iarocci G, McDonald J. Sensory integration and the perceptual experience of persons with autism. *Journal of Autism and Developmental Disorders*. 2006; 36(1):77–90. [PubMed: 16395537]
- Kortesluoma R, Nikkonen M. 'The most disgusting ever': Children's pain descriptions and views of the purpose of pain. *Journal of Child Health Care*. 2006; 10(3):213–227. [PubMed: 16940344]
- Lane AE, Young RL, Baker AEZ, Angley MT. Sensory processing subtypes in autism: Association with adaptive behavior. *Journal of Autism and Developmental Disorders*. 2010; 40:112–122. [PubMed: 19644746]
- Le Couteur, A.; Lord, C.; Rutter, M. *Autism diagnostic interview-Revised*. Western Psychological Corporation; Los Angeles: 2003.

- Lord, C.; Rutter, M.; Dilavore, P.; Risi, S. *The Autism Diagnostic Observation Schedule (ADOS)*. Western Psychological Corporation; Los Angeles: 1999.
- Miles, MB.; Huberman, AM. *Qualitative data analysis: An expanded sourcebook*. Sage Publications, Inc.; Thousand Oaks, CA: 1994.
- Mullen, EM. *Mullen Scales of Early Learning (AGS edition)*. Western Psychological; Los Angeles: 1995.
- Pfeiffer BA. Sensory hypersensitivity and anxiety: The chicken or the egg? *AOTA Special Interest Section Quarterly: Sensory Integration*. 2012; 35(2):1–4.
- Roid, GH. *Stanford-Binet Intelligence Scales*. Fifth edition. Riverside Publishing; Rolling Meadows, IL: 2003.
- Rubin, HJ.; Rubin, IS. *Qualitative Interviewing: The Art of Hearing Data*. 2nd ed.. Sage Publications, Inc.; Thousand Oaks, CA: 2005.
- Sartain SA, Clarke CL, Heyman R. Hearing the voices of children with chronic illness. *Journal of Advanced Nursing*. 2000; 32(4):913–921. [PubMed: 11095230]
- Schaaf RC, Toth-Cohen S, Johnson SL, Outten G, Benevides TW. The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism*. 2011; 15(3):373–389. [PubMed: 21430016]
- Schwandt, TA. *The SAGE Dictionary of Qualitative Inquiry*. 3rd ed.. Sage Publications, Inc.; Thousand Oaks, CA: 2007.
- Spitzer SL. Using participant observation to study the meaning of occupations of young children with autism and other developmental disabilities. *American Journal of Occupational Therapy*. 2003; 57(1):66–76. [PubMed: 12549892]
- Toichi M, Kamio Y, Okada T, Sakihama M, Youngstrom EA, Findling RL, Yamamoto K. A lack of self-consciousness in autism. *American Journal of Psychiatry*. 2002; 159(8):1422–1424. [PubMed: 12153838]
- Tomchek SD, Dunn W. Sensory processing in children with and without autism: A comparative study using the short sensory profile. *American Journal of Occupational Therapy*. 2007; 61(2):190–200. [PubMed: 17436841]
- Waksler FC. Studying children: Phenomenological insights. *Human Studies*. 1986; 9(1):71–82.
- Wilson ME, Megel ME, Enenbach L, Carlson KL. The voices of children: Stories about hospitalization. *Journal of Pediatric Health Care*. 2010; 24(2):95–102. [PubMed: 20189061]

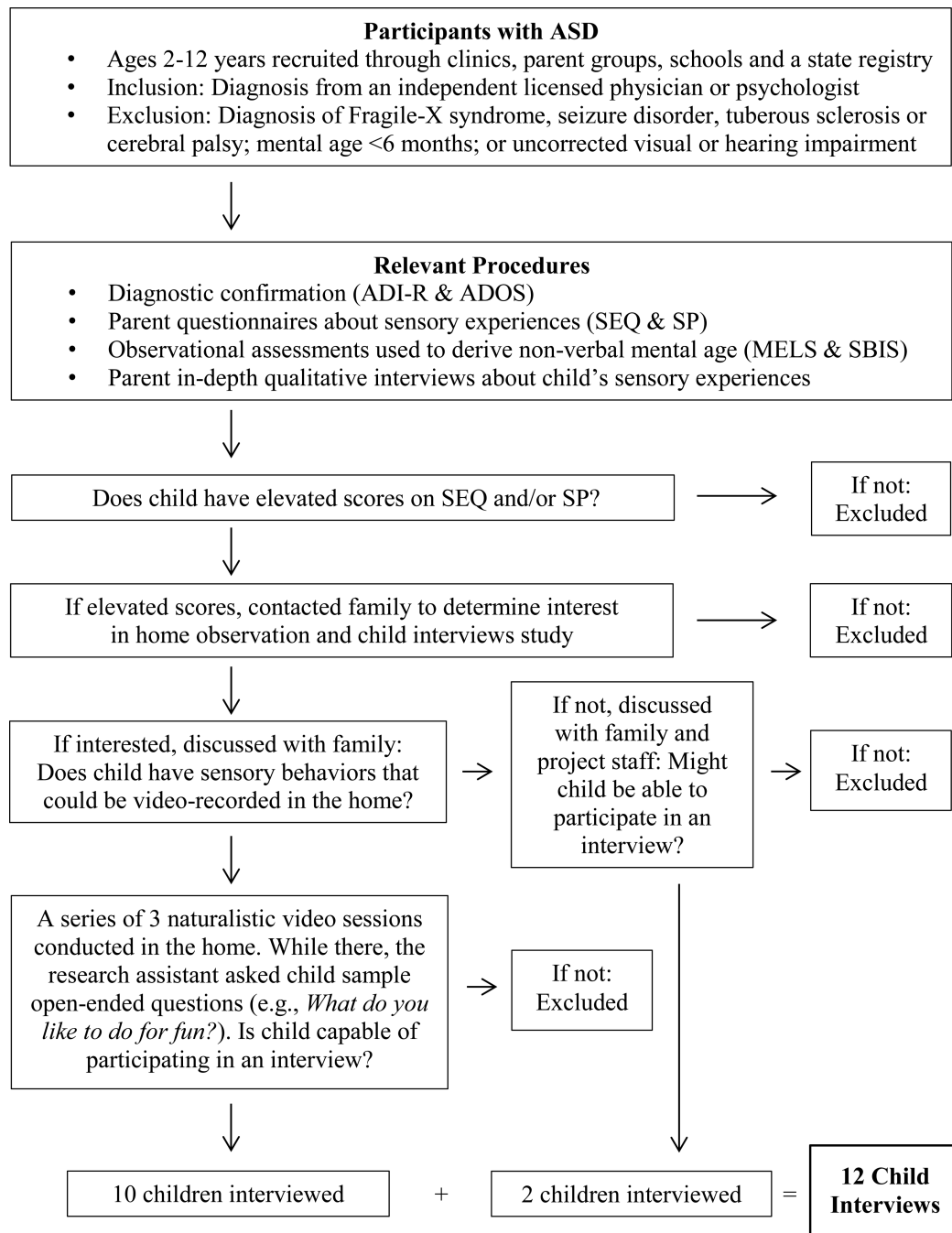


Figure 1.
Flow Chart of Participant Selection from Larger Research Project

Table 1

Assessments used to Inform Study

Assessment	Study Purpose
Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1999)	Diagnostic confirmation Severity score calculation
Autism Diagnostic Interview-Revised (ADI-R; Le Couteur et al., 2003)	Diagnostic confirmation
Sensory Experiences Questionnaire (SEQ; Baranek, 2009)	Screening Informing individualized interviews
Sensory Profile (SP; Dunn, 1999)	Screening Informing individualized interviews
Stanford-Binet Intelligence Scales (SBIS; Roid, 2003)	Non-verbal mental age calculation
Mullen Early Learning Scales (MELS; Mullen, 1995)	Non-verbal mental age calculation

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Table 2

Description of Participants

Age (years)	Sex	Race & Ethnicity	SEQ Results	Autism Severity	Non-verbal Mental Age
4	M	Caucasian	hyper ++ hypo + seeking +	8	5.75
6	M	Caucasian	hyper ++ hypo ++	9	7.25
6	M	Caucasian	hyper + seeking +	10	4.5
6	M	Caucasian	hypo ++ seeking ++	9	5.17
7	M	Asian	hyper ++ hypo ++ seeking +	7	6.58
9	F	Caucasian	hyper ++	7	4.92
10	M	Caucasian-Hispanic	hyper ++ hypo ++ seeking ++	4	11.83
11	M	Caucasian-Hispanic	hyper ++ hypo +	10	8.08
11	M	Caucasian	hyper + hypo ++	10	>15
13	F	Caucasian	hyper ++ hypo ++	8	7.25

Notes. SEQ results reflect hyperresponsiveness (hyper), hyporesponsiveness (hypo) and sensory seeking (seeking) as mildly elevated (+) or significantly elevated (++) . ADOS autism severity score ranges: autism (6-10), autism spectrum disorder (4-5), nonspectrum (1-3) (Gotham, Pickles, & Lord, 2009).

Table 3

Storytelling Methods and Prompt Examples

Storytelling Method	Prompt Examples
Anecdote	Tell me about a time when that happened.
Imitation	Show me what it was like.
Internal Dialogue	What was going through your mind when this was happening? What were you thinking?
Simile	Does that remind you of anything else? What else is like that?

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