Research Article

Understanding the sensory experiences of young people with autism spectrum disorder: A preliminary investigation

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Background/aim: Unusual responses to sensations can impact upon the daily activities for individuals with autism spectrum disorder. Current understandings of these sensory experiences have been drawn from the proxy reports from parents/caregivers, standardised self-report questionnaires and autobiographical accounts. As sensory experiences are intensely personal, the first-hand accounts of people with autism spectrum disorder may have greater validity than caregiver reports, but these have never been systematically researched. This study explored the utility of using a semi-structured interview protocol augmented with visual cues to facilitate our understanding of the way people with autism spectrum disorder experience sensory input, and use coping strategies to manage sensory issues that interfere with participation.

Method: A semi-structured interview augmented by visual cues was used to investigate the sensory experiences of three adolescent males with autism spectrum disorder. As is common in this population, two of the participants also had a diagnosis of Attention Deficit Hyperactivity Disorder and were taking stimulant medication.

Results: Participants shared a preference for expected, predictable and controllable sensory input, whereas unexpected, unpredictable and uncontrollable sensations were perceived as unpleasant. A heightened awareness of and difficulty filtering extraneous sensory input, high levels of movement seeking and an over-focus on salient sensory input were also described. Strategies employed to manage sensory challenges included avoiding, increasing predictability and control and meta-cognitive adaptations.

Conclusions: Further research involving a larger sample of participants is recommended to determine the utility of using a semi-structured interview protocol augmented with visual cues to understand the sensory experiences of individuals with high-functioning autism spectrum disorder.

KEY WORDS autism spectrum disorder, sensory processing, qualitative research.

Introduction

Autism spectrum disorder (ASD) is characterised by social and communication difficulties, and restricted, repetitive behaviours (American Psychiatric Association, 2000). In addition, children with ASD have consistently been found to exhibit atypical behavioural responses to everyday sensations as measured by caregiver questionnaires (Ben-Sasson et al., 2009). Their atypical responses to everyday sensations have been associated with many daily life challenges, particularly maladaptive behaviours in overstimulating environments (Schaff, Toth-Cohen, Johnson, Outten & Benevides, 2011).

Most commonly, individuals with ASD are described as experiencing sensory modulation disorders (SMD), which have been defined by Miller, Anzalone, Lane, Cermak and Osten (2007) as follows:

Sensory modulation occurs as the central nervous system regulates the neural messages about sensory stimuli. SMD results when a person has difficulty responding to sensory input with behavior that is graded relative to the degree, nature, or intensity of the sensory information. (p. 136)
Three subtypes of sensory modulation disorder include sensory over-responsivity, sensory under-responsivity and sensory seeking behaviours (Miller et al., 2007). A meta-analysis of sensory symptoms of children with ASD found that, in comparison with typically developing children, they demonstrated greater under-responsivity, followed by over-responsivity and then sensation seeking (Ben-Sasson et al., 2009).

Clinically, therapists can be confused when they come across complex combinations of under- and over-responsivity and sensory seeking even within the same modality for individual children. For example, children with ASD frequently express discomfort during hair cutting or face washing (over-responsiveness), and yet touch other people to the point of irritating them (sensory seeking). Similarly, they are often over-responsive to particular loud noises, and yet fail to respond when you call their name (under-responsiveness). Recent research confirms that under- and over-responsivity frequently coexist, and sensory-seeking behaviours are associated with both over- and under-reactivity in people with ASD (Lane, Young, Baker & Angley, 2010).

Findings with respect to physiological responses to sensory input (as measured by electro-dermal testing or heart rate responses) have been mixed and inconclusive. Some studies report physiological under-responsiveness among children with ASD (Miller, Reisman, McIntosh & Simon, 2001; Schoen, Miller, Brett-Green & Nielsen, 2009). In contrast, other studies have found that children with ASD demonstrate greater increases in heart rate responses to sensory input (Woodard et al., 2012), and stronger electro-dermal responses to auditory stimuli (Chang et al., 2012), as compared with typically developing peers. Schoen et al. found no association between physiological measures of sensory processing and the Short Sensory Profile (Dunn, 1999). Similarly, Woodard et al. found few correlations between physiological measures and the Infant/Toddler Sensory Profile (Dunn & Daniels, 2002). It cannot, therefore, be assumed that the behavioural responses rated in parent questionnaires are necessarily reflective of the child’s physiological responses to sensory input (although the heterogeneity of sensory responses in these studies may have impacted on these findings).

In their autobiographical accounts, many authors with ASD describe sensory processing issues that cannot be readily pigeonholed into the categories of over-responsivity, under-responsiveness or sensory seeking. For example, they often describe a need for predictability and control in many areas of their daily life, including incoming sensory input. Gerland (1997) describes her fear of eating unknown foods:

I didn’t find it dull eating the same thing all the time, though should it start to become so, that was nothing compared to the mortal danger of risking unknown food.... The consistency of some foods could be unpleasant, giving me a horrible feeling all over. With unknown food you never knew what might happen. (p. 14)

The findings of Gomot and colleagues may shed some light on this drive for sameness and predictability (Gomot, Belmonte, Bullmore, Bernard & Baron-Cohen, 2008; Gomot et al., 2010). They found children with ASD to be significantly more sensitive than typically developing children to minor changes in the sensory features of their environment, as evidenced by more rapid detection of small changes and more widespread activation of brain regions. These findings were more pronounced in children with the greatest difficulty tolerating change. On the basis of these findings, Gomot and colleagues speculated that people with ASD may cope with an underlying sensitivity to minor changes by actively avoiding novel stimuli and insisting on sameness. They also hypothesised that the repetitive and stereotypical behaviours often exhibited by people with ASD may be adaptive responses aimed at ensuring that incoming sensory input is self-generated and therefore predictable.

People with ASD also frequently describe a heightened sensitivity to irrelevant detailed input such as background noise or flickering fluorescent lights, coupled with difficulties in filtering relevant stimuli from competing stimuli (Grandin, 1992; Williams, 1996). For example, Grandin stated:

My hearing is like an open microphone that picks up everything. I have two choices: turn the mike on and get deluged by sound, or shut it off... I am unable to talk on the phone in a noisy office or airport... If I try to screen out the background noise, I also screen out the phone. (p. 107)

Individuals with ASD often fail to notice others speaking to them, and one of the most consistent indicators of autism in infants is not responding when his/her name is called (Allison, Auyeung & Baron-Cohen, 2012). An atypical ‘Auditory Filtering’ score on the Short Sensory Profile (Dunn, 1999) has been found in 93% of children with ASD (Lane et al., 2010), and differentiates their sensory responses from those of typically developing children to a greater extent than other sensory issues (Tomchek & Dunn, 2007).

People with ASD also often speak about an overly narrow focus on particular sensory stimuli. For example, Williams (1992) described her ability to become absorbed in certain forms of sensory input as a retreat from an overpowering world: “I learned eventually to lose myself in anything I desired – the patterns on the wallpaper or the carpet, the sound of something over and over again, the repetitive hollow sound I’d get from tapping my chin” (p. 3). On the basis of their findings
of significant associations between sensory hyper-sensitivity and over-focused attention, Liss, Saulnier, Fein and Kinsbourne (2006) hypothesise that an exaggerated focus on the sensory properties of objects may trigger an over-reactive response in a subgroup of individuals with ASD. In some instances, they speculate that over-focus on one unchanging element in the environment may be compensatory, as it is used to screen out extraneous overwhelming input and avoid sensory overload. Liss et al. also suggest that difficulties in shifting attention may result in difficulties disengaging from salient sensory stimuli.

The majority of research to date has been based on proxy reports from caregivers, predominantly using caregiver questionnaires (Ben-Sasson et al., 2009). However, as these caregiver questionnaires rate behaviours that are not necessarily reflective of underlying physiological responses to sensory input, it cannot be assumed that they accurately mirror the child’s experiences in relation to sensory input (Schoen et al., 2009; Woodard et al., 2012). While the parents interviewed by Dickie, Baranek, Schultz, Watson and McCormish (2009) were able to identify sensory experiences to which their children with ASD responded positively or negatively, they sometimes struggled to understand what their child was experiencing: “I don’t know if he’s experiencing it the same way I would” (p. 179). They were also unsure at times about whether it was the sensory aspect of the experience that was invoking an emotive response. Hotz and Royeen (1998) found that children rated their sensory defensiveness as significantly more intense compared with parent reports. Studies involving the use of self-report assessment tools (e.g. Crane, Goddard & Pring, 2009) such as the Adolescent/Adult Sensory Profile (Brown & Dunn, 2002) impose a theoretical framework on their experiences, which may or may not be sensitive to ASD-specific sensory issues. Although autobiographical accounts and reviews of autobiographical accounts (Chamak, Bonniau, Jaunay & Cohen, 2008) have provided valuable insights into the sensory experiences of people with ASD, their experiences have never been systematically researched. As Williams (1996) advocated, there is a need to ‘hear the autistic voice’ to better understand their sensory experiences. As these experiences are intensely personal, it could be argued that first-hand accounts have greater validity than the reports of family members who attempt to interpret their behaviours. It may therefore be important to gather the perspectives of individuals with ASD on their sensory experiences, in addition to those of caregivers.

This study explored the utility of using a semi-structured interview protocol augmented with visual cues to facilitate our understanding of the way young people with ASD experience sensory input, and use coping strategies to manage sensory interests/aversions that threaten to interfere with participation. Visual cues were used because people with ASD are known to have relative strengths in visual processing (Quill, 1997).

**Method**

A descriptive case study design (Yin, 2002) was used as a means of advancing our understanding of the sensory experiences of young people with ASD in real life contexts.

**Participants**

Three adolescent males diagnosed with ASD were recruited through Autism Queensland and The University of Queensland using nominated sampling. Participants were required to have sufficient language and cognitive skills to participate in a semi-structured interview.

**Instruments**

1. The Autism Diagnostic Interview–Revised (ADI-R) (Rutter, Le Couteur & Lord, 2008) is a standardised semi-structured interview conducted with a parent/caregiver to assess the presence of autistic symptomatology. Ninety-three items address social interactions, communication and restricted, repetitive and stereotyped behaviours.

2. A brief demographic interview with parents/caregivers identified the participants’ age, school type and grade, diagnosis, age at diagnosis, medical speciality of diagnostician, medications and family structure.


4. A semi-structured interview protocol with visual cues (developed by the first author) facilitated discussion around experiences of sound, visual stimuli, smell/taste and body movement. Between eight and thirty pictures were included in each domain. Appendix 1 provides an example of the questions and visual cues in relation to sound.

**Procedure**

Ethical clearance was obtained from The University of Queensland Ethics Review Committee. Informed parent consent and adolescent assent were obtained. An accredited assessor (JA) administered and scored the ADI-R to confirm each participant’s diagnosis. The AASP was used to confirm that these participants’ sensory processing was atypical. Each adolescent engaged in a semi-structured interview, ranging from two and a half to three hours, conducted by one of the authors (S. R. or L. B.) (with or without parent present depending on each adolescent’s preference). The participants were asked to think about their reactions to sensory input, with the visual cues presented as prompts rather than
being referred to specifically. Interviews with adolescents were audio-taped and transcribed verbatim. Transcripts were deidentified and pseudonyms were used. Member checking the interview summaries by the adolescents and parents confirmed accuracy of the information. Data from post-interview discussions with parents were included where it augmented the data provided by the adolescents.

**Data analysis**

Content analysis was performed as transcripts were colour coded independently by two authors (S. R. and L. B.). An a priori coding system was used, highlighting pleasant, unpleasant and distracting sensory experiences and coping strategies. Where disagreement in coding occurred, discussion and re-reading of transcripts were undertaken until consensus was reached. Coping strategies were discussed and categorised according to the nature of response until consensus was reached.

**Results**

The participants’ age, educational setting, diagnosis, medical speciality of diagnostian, family structure and ADI-R results are detailed in Table 1. The ADI-R indicated that they had a history of normal language development (i.e. use of single words before 18 months and phrases before 30 months) and the ability to comprehend complex two-stage verbal instructions without non-verbal cues. Although individuals with high-functioning autism and Asperger disorder have pragmatic language difficulties (e.g. sustaining conversations, turn-taking and prosody), their language comprehension is relatively less affected (Rapin & Dunn, 2003). As all participants were also managing age-appropriate mainstream school curricula, they were judged to have sufficient language and cognitive skills to participate in the interview. Like many individuals with ASD, two participants also had Attention Deficit Hyperactivity Disorder (ADHD) diagnoses. The estimated prevalence of comorbid ADHD ranges from 45% to 87% (Ames & White, 2011). Mayes, Calhoun, Mayes and Molitoris (2012) found that the core ADHD symptoms are so common in ASD, that these symptoms can be viewed as part of autism. The Diagnostic and Statistical Manual of Mental Disorders 4th Edition Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000) recommends against comorbid diagnosis of ADHD, but

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Brendan†</th>
<th>Andrew†</th>
<th>Luke†</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>16</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td><strong>Grade at school</strong></td>
<td>11</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td><strong>Type of school</strong></td>
<td>Private co-educational high school</td>
<td>State primary school</td>
<td>Autism-specific school two days and state high school three days</td>
</tr>
<tr>
<td><strong>Age at diagnosis (years)</strong></td>
<td>4</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>ASD and Attention Deficit Hyperactivity Disorder (ADHD)</td>
<td>Asperger syndrome and ADHD (mild)</td>
<td>ASD</td>
</tr>
<tr>
<td><strong>Diagnosed by</strong></td>
<td>Paediatrician</td>
<td>Paediatrician</td>
<td>Paediatrician</td>
</tr>
<tr>
<td><strong>Current medication</strong></td>
<td>Methylphenidate</td>
<td>Methylphenidate, Melatonin</td>
<td>No current medications</td>
</tr>
<tr>
<td><strong>Family dynamics</strong></td>
<td>Lives with father, mother, sister (aged 18) and brother (aged 21) also diagnosed with ASD</td>
<td>Lives with mother</td>
<td>Lives with mother, father and sister (aged 15)</td>
</tr>
<tr>
<td><strong>ADI-R results</strong></td>
<td>Meets criteria for autism</td>
<td>Meets criteria for Pervasive Developmental Disorder-Not Otherwise specified (PDD-NOS)</td>
<td>Meets criteria for autism (given convention that scores clearly above the cut-off on at least 2 domains may miss out in the third domain by not more than one point) (Rutter et al., 2008)</td>
</tr>
</tbody>
</table>

†All names are pseudonyms.
acknowledges that many children receive an ADHD diagnosis prior to an Asperger Disorder diagnosis. As is also common in this population, two of the participants were taking stimulant medication (methylphenidate). Oswald and Sonenklar (2007) found 57% of children with ASD to be using psychoactive medications, with 27% using stimulant medication. The AASP results indicated that all three participants had atypical sensory processing in one or more quadrant (see Table 2), although there were individual differences in their sensory processing patterns.

The semi-structured interview findings are presented within two sections: (i) experiences of sound, vision, smell/taste, touch and body movement described by participants as being pleasant, unpleasant or distracting, and (ii) coping strategies used to manage everyday sensory challenges. Where relevant, information provided by parents in relation to these interview questions is included.

**Sensory domains**

All participants identified listening to music (radio/iPod) as enjoyable, as were computer game sounds (Luke and Brendan) and movie sounds (Andrew). Sound sensitivities included aversions to the sound of branches scratching on windows and people breathing (Andrew), other people typing and clocks ticking (Luke). Sudden high-pitched sounds such as the phone ringing and people whistling (Andrew), hand driers (Brendan) and babies crying (Luke) were also disliked. Andrew and Luke described these as ‘hurting’ their ears. All participants disliked extraneous noise such as background TV noise, working in noisy places and surrounding conversations. Andrew and Luke both described not noticing others talking to them, e.g. “Mum yells ‘Luke. I’m like what?’”

Visually, bright coloured lights (e.g. city lights, ceiling lights, firelight, computer screen) attracted Luke and Brendan’s attention and were enjoyable for all participants, despite firelight ‘hurting’ Luke’s eyes. Brendan disliked filtered light (light shining through blinds) as, “It’s just annoying because it’s dark but still light, it’s not either one” and the transition from a light room to darkness (e.g. light being turned off). Luke and Andrew disliked transitioning from a dark room into sunlight as this hurt their eyes, as did sunlight when in Luke’s field of vision. All participants found patterns (bright, coloured patterns, geometric patterns) both enjoyable and distracting, including patterns in numbers (Brendan and Andrew), tessellations (repetitive pattern), sports field markings, floor mats and dart boards (Luke). Luke commented, “Patterns never annoy me! The ones that are distracting are the ones that I like, pretty much all of them… Interesting to see how it works, how it fits together.”

Andrew said, “I love how different kinds of patterns are different shapes.” Pavements and store shelves were distracting for Andrew, “Different patterns in the wall, like when I’m trying to pay for something, it distracts me.”

Seeing passing traffic was described as distracting by Andrew and Luke. Luke also found looking at ceiling fans enjoyable but distracting, “Overhead fans, I could just follow them round and round and round all day.”

Luke enjoyed being in crowds as he described, “Moving amongst people – I just like seeing if I can get through gaps close to people before they close, without touching them.” In contrast, Brendan disliked ‘seeing all the people’ in crowds and feeling ‘closed in.’

Enjoyable smells included vanilla incense (Brendan), animal smells (Andrew), take-away and kitchen smells (Andrew and Luke) and barbecue smells (Brendan). Unpleasant smells included chemical smells such as cleaning products and chlorine (all participants), incense and cigarette smoke (Andrew and Luke) and garbage smells (Andrew). Brendan enjoyed a limited range of foods (e.g. sour lollies, juicy foods, take-away chicken), and disliked many specific food smells such as vinegar, cooking vegetables, strong cheeses and foods that tasted different each time (e.g. leftovers). Andrew and Luke enjoyed pizza, cheese, fruit, crunchy and juicy foods, and would eat pasta repetitively. Tastes which were disliked included chemical flavours such as toothpastes

<table>
<thead>
<tr>
<th>Adolescents/Adult sensory profile</th>
<th>Brendan</th>
<th>Andrew</th>
<th>Luke†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low registration</td>
<td>Similar to most people‡</td>
<td>Much more than most people ††</td>
<td>More than most people¶</td>
</tr>
<tr>
<td>Sensation seeking</td>
<td>Less than most people ‡</td>
<td>Similar to most people§</td>
<td>Similar to most people§</td>
</tr>
<tr>
<td>Sensory sensitivity</td>
<td>Similar to most people§</td>
<td>Much more than most people ††</td>
<td>Similar to most people§</td>
</tr>
<tr>
<td>Sensory avoiding</td>
<td>Less than most people‡</td>
<td>Similar to most people§</td>
<td>Similar to most people§</td>
</tr>
</tbody>
</table>

†Much less than most people = less than 2% of the typically developing standardisation sample. ‡Less than most people = between 2 and 16% below the typically developing standardisation sample. §Similar to most people = between 16 and 84% of the typically developing standardisation sample. ¶More than most people = between greater than 84% and 98% of the typically developing standardisation sample. ††Much more than most people = greater than 98% of the typically developing standardisation sample.
(Brendan and Luke), medicines (Andrew), vegetables, gnocchi and spicy foods (Luke) and tomato and spicy foods (Andrew).

Andrew enjoyed the feel of wool and rubbery things and would touch these repeatedly. Luke enjoyed the feel of heavy blankets, money, animals, sticky things and hugs. Brendan disliked the feel of certain fabrics (wool, cotton, shag rug), although “given the opportunity he’ll sit and hold something soft” (as reported by Brendan’s mother). Andrew disliked wearing uniforms with plastic stitching. Brendan and Luke disliked having their hair cut when younger. Brendan was sensitive to changes in temperature and disliked showering when younger as “right afterwards it was really cold.” Luke disliked getting caught in the rain, “It’s the combination of the feel of it and the cold, I don’t like it all… you can just feel it go tap, tap, tap all over you.”

All participants enjoyed jumping on the trampoline and moving fast (rollerblading, ice skating, riding roller coasters). Other enjoyable movement sensations included moving in water and balancing (Brendan and Luke), throwing (Andrew and Luke), swings and moving on a boat (Luke) and being tackled (Brendan). Andrew enjoyed spinning around, “I strap myself into a spinning chair and spin around… [for] two good hours.” Brendan and Luke disliked standing for long periods. Andrew and Luke disliked tripping and being tackled. Andrew disliked swinging as, “It makes my stomach turn a bit.” Luke disliked “moving when I can’t see where I’m going, that’s why when I’m playing Marco Polo with someone I don’t want to be it,” but stated, “although if I do know the area very well then it’s kind of fun.”

Coping strategies

Three common methods were identified by participants to manage unpleasant/annoying and distracting sensory information: avoid, increase predictability/control and metacognitive strategies.

Avoid

Annoying/unpleasant sensations and sensations that were enjoyable but distracting were managed using avoiding strategies: task avoidance, removal, alternate space and blocking out were preferred options. When aged 13–14 years, Brendon avoided showering for ‘weeks’ at a time, as he disliked the transition from hot to cold. From a young age, Brendan would avoid eating, “If I didn’t like the way it smelt I just wouldn’t eat it, like wouldn’t go near it.” Brendan was below the third percentile for weight during his childhood and nasogastric tube feeding was considered at age 13 due to severe food avoidance. Andrew would ‘put out the garbage’ and Brendan would ‘turn on the fan’ to remove unpleasant smells.

Luke described removing an annoying ticking clock, “If it’s a small clock, like in my nanna’s house there’s a room with all sheets and doonas and stuff, so I just open the door, stick it under them.” If stimuli could not be removed or controlled, participants would find an alternate space or remove themselves from the situation. Luke sought alternate spaces to avoid noise (e.g. moved bedrooms to avoid the sound of his neighbour playing piano). He describes his strategy to avoid surrounding conversations, “in high school you just pick up your bags and say come on and then they pick up their bags and come with you, no questions asked.” Brendan would use, “lots of his usual avoiding behaviours” to avoid crowds, for example, “he’d want to eat, he’d want to go somewhere else” (Brendan’s mother). To avoid smells, Brendan would “leave the room, go downstairs.” All three described blocking out unexpected/annoying noises by listening to music from an iPod or radio. Andrew would “put the shades down so that he can work” to avoid getting distracted by passing traffic. When younger, Andrew “used to put my ears under pillows” to block out the sound of the phone ringing. Where parents were aware of their child’s sensory aversions, preferred options were provided (e.g. Brendan’s mother carefully selected clothing, foods, cleaning and hygiene products, and Luke’s mother purchased children’s toothpaste).

Increase predictability/control

Sensory stimulus was preferred if it was expected, predictable and within the participant’s control. As Andrew described, “In races when I’m expecting a whistle it’s okay… if someone whistles and doesn’t tell me – not okay.” Luke was annoyed by the sound of others typing, “if it’s yourself you can normally cope with it, but if it’s someone else it’s different – because you know that sound is going to be made because you’re doing it.” The uncontrollable nature of rain was described as more unpleasant than the feel of it for Luke, “I can’t make it stop, it’s annoying initially and then the fact that I can’t make it stop makes it more annoying!” When asked, “If you could turn the rain on and off like a shower would you turn it on and walk around in it?” Luke replied, “If I knew I could turn it off then yeah definitely!” Requesting a change was helpful to increase control. Andrew described, “At my old school a person was constantly whistling, I constantly told them to stop and stop and he never did and I walked up to him and told him in a firm voice to stop – he stopped.” Brendan began preparing his own meals at age seven and began cooking the family dinner at 13 to increase control over food smells in the house. He described, “If I don’t like the smell of it, I won’t cook it.” To increase the predictability of sensations, Brendan smells foods during cooking, eats only specific brands, coats foods in barbeque sauce and does not eat leftovers that may change in taste. Brendan cooked and ate predictable foods, “Generally if I cook something she (Mum) has cooked it before.” Luke disliked foods that were different than expected (e.g. gnocchi), “Well
you’re eating pasta, that’s the taste you expect and then you don’t expect to taste potato!”

As unpleasant sensations became expected and predictable, Andrew and Luke described being able to ‘get used to it.’ Andrew described no longer being annoyed by the girl squealing next door, “She does it all the time, I’m used to it.” Brendan’s fear of hand dryers in public toilets disappeared when he was able to play and experiment with them (Brendan’s mother).

All participants identified needing body movement more than other people. Brendan’s mother supported this, “He still fidgets a lot…wriggling his toes and jigging the whole time.” Andrew described, “I need to move more, like when I’m like this (sitting) in a test for hours… I start to get restless”. He indicated that movement helped him concentrate. Luke described being frustrated by needing movement, “When I want to not move I’m fine, when I want to move I’m like, I want to move, I want to move and if I don’t it’s… [frustrating].” Luke managed this by: “….if I wriggle my toes nobody can see it… sometimes I pretend to drop my pencil just so I can get up and get it just so I can move a bit.”

Meta-cognitive strategies

Self-talk, focus, imagination and planning were used by participants. Brendan and Luke identified ‘talking’ themselves through to cope with unpleasant/annoying sensory input. Luke’s first coping strategy in response to annoying/unpleasant sensory information was to “try to ignore it.” When asked, “If an aeroplane or something goes overhead, does that bother you?” Brendan responded, “It does but you can’t do anything about it, and it’s going to be over in a couple of seconds, so you just keep working, doesn’t matter, you can’t do anything.” Luke managed places that smelled of cleaning products by thinking, “Go in, go out, as quickly as possible.” Brendan described identifying what you can and cannot control, as an important strategy to avoid frustration, “Some things you can do stuff about it, and other times you can’t.” When visually distracted by shelves in a shop, Andrew would “just focus on one thing and everything just goes away.” When a noise was unstoppable and uncontrollable (e.g. another person typing), Luke imagined stopping the noise, “I think of someone I don’t like, they are making the noise in my head and I’m like (punches hand) stop the noise.” Planning ahead to avoid unpleasant sensory experiences enabled Brendan to comfortably participate in activities (e.g. going to shops in quiet times to avoid crowds). Luke described his plan to prevent distraction by overhead fans in the classroom, “I’ve got to get on with my school work so I don’t even look at them in the first place.”

Discussion

Participants described many examples of sensory over-responsiveness (e.g. sensitivity to noises, smells and tastes) and sensory-seeking behaviours (e.g. feeling textures, seeking movement sensations) and a few examples of under-responsiveness (e.g. not noticing others talking to them).

Consistent with findings of Gomot et al. (2008, 2010), sensations that were expected, predictable, controllable and self-selected were more likely to be perceived as pleasant, whereas sensations that were unexpected and beyond the individual’s control were perceived as unpleasant. For example, changing or unpredictable stimuli such as filtered light, transitions from dark to sunlight or hot to cold, unpredictable tastes (e.g. leftovers that change in taste and texture) or unexpected stimuli such as a baby crying were described as unpleasant. Predictable, repetitive sounds such as music were enjoyed, whereas complex, unpredictable sounds such as surrounding conversations were disliked. All participants were fascinated by predictable, repetitive visual patterns. Visuo-spatial pattern analysis has been identified as an area of strength in this population (Howlin, Goode, Hutton & Rutter, 2009).

Kanner (1943) ascertained that control may be a key to understanding sensory aversion as “the child can happily make as great a noise as any that he dreads” (p. 245). The participants did not experience sensations as unpleasant if they were self-generated and therefore predictable (e.g. their own typing or whistling), but these same sounds were perceived to be aversive when they were generated by others and unable to be controlled. Some of their coping strategies effectively enhanced their control over incoming sensory input (e.g. Brendan began preparing the family meals at an unusually young age and coated foods in a familiar sauce). The qualitative study of parent reports by Dickie et al. (2009) concluded that a key factor determining a child’s response to sensory experiences was the extent to which the child could control the stimulus (e.g. being able to terminate the input, having the freedom to guide one’s own experiences). Similarly, Schaff et al. (2011) found that activities of families of children with ASD were often dictated by the need for familiar, controllable sensory environments and routines.

The participants described heightened perception of, and difficulty with filtering out detailed extraneous background stimuli, including people breathing, ticking clocks, branches scratching on windows, moving fans or passing traffic. The participants were both distracted by irrelevant background noise, and yet at times failed to notice relevant sounds such as others talking to them, which is consistent with previous findings in relation to auditory filtering difficulties (Lane et al., 2010).

Findings in relation to frequent movement seeking are consistent with previous research by Tomchek and Dunn (2007) who found that 70.5% of children with ASD in this study always or frequently sought movement to the extent that it interfered with daily routines, as compared to 2.2% of typically developing peers.
From a sensory modulation perspective, movement may be used to increase arousal (e.g. movement with changing speed and direction) or decrease arousal (e.g. linear, repetitive movement) (Dunn, 1991). The possibility that individuals with ASD enjoy movement sensations because they are usually self-generated and therefore predictable also warrants further investigation. Participants reported enjoying most movement experiences with the exception of less predictable experiences such as being tackled or tripped and “moving when I can’t see where I’m going” (Luke). Repetitive movements (e.g. swings, moving on a boat and prolonged spinning in a chair) were also enjoyed.

Some sensory stimuli were described as simultaneously enjoyable and distracting. For example, Luke enjoyed watching ceiling fans for hours and needed to consciously avoid looking at them to focus on his schoolwork. This suggests a difficulty disengaging the focus of attention from salient stimuli, as described by Liss et al. (2007). There was also some evidence of the use of intense focus on one unchanging element as a means of screening out overwhelming extraneous input. For example, Andrew will ‘focus on one thing’ when overwhelmed by too much visual stimuli at the shops, so that “everything else just goes away”.

Some of the parents reported that their children’s sensory responses had a pervasive impact when they were younger (e.g. avoiding foods or crowds). However, by adolescence they had developed some strategies that effectively increased their control over their sensory environment, including strategies to avoid aversive input (e.g. moving away from noise), to increase predictability (e.g. controlling food preparation) and meta-cognitive strategies (e.g. self-talk to cope with aeroplane noise). Although evidence suggests that children with Asperger Syndrome may have more difficulty with meta-cognition than typically developing children (Semrud-Clikeman, Walkowiak, Wilkinson & Butcher, 2010), meta-cognitive strategies have been successfully used with this population to accomplish self-chosen goals (Rodger & Vishram, 2010).

As these open-ended questions augmented by visual cues added substantially to the information provided by a standardised sensory processing assessment, this approach may be useful clinically. In some instances, however, the information yielded by interview and the AASP appeared contradictory. For example, Brendan was scored as ‘similar to others’ in sensitivity and ‘less than others’ in sensory avoiding. Nonetheless, some behaviours such as extreme pickiness in relation to the sensory properties of foods suggested significant sensory sensitivity. On the AASP, he rated the items “I add spice to my food” and “Most food tastes bland to me” as ‘frequently’, suggesting sensory seeking and low registration. However, the interview suggested that coating foods in barbeque sauce may be a strategy to make the taste more predictable.

Limitations and future research
Further research is required to determine whether the visual cues add to the information that could be gained through interview alone, rather than prompting responses to things that would not normally concern the interviewee. As this study reports views of three adolescent males with ‘high functioning’ ASD, generalisation is very limited. It is possible that other variables such as comorbid diagnoses, the use of medication, ages, gender and severity of autistic symptoms may have impacted on the findings. In view of the high levels of heterogeneity within this population, future studies should therefore include a larger sample of participants with high-functioning ASD.

Although it is important to acknowledge the authors’ previous backgrounds in autism research and clinical experiences as these may inform the theories and language of the research (Hammell, Carpenter & Dyck, 2000), author bias was, nevertheless, minimised through independent coding of transcripts by two authors, peer checking of key findings and member checking with participants. Although the participants gave many examples of sensory sensitivities and sensory-seeking behaviours, they described fewer examples of under-responsiveness. It is possible that they lacked awareness of their own under-responsiveness that may have been more apparent to others. There may therefore be some merit in including a more detailed semi-structured interview of parents in future studies.

Although the currently used categories of under- and over-responsiveness and sensory seeking are useful descriptors, they may not fully capture aspects that are crucial to a deeper understanding of sensory experiences of people with ASD. Rather than relying solely on standardised questionnaires which involve closed questions and a pre-conceived sensory processing framework, open-ended questions with visual prompts may be more effective in drawing out sensory-related issues that are unique to the individual and his or her context. This method may also elicit information in relation to possible ASD-specific sensory issues (e.g. preference for predictable and controllable sensory input, difficulty filtering out extraneous sensory input, a high need for movement and over-focus on salient sensory input). Further research involving a larger sample of participants is recommended to determine the utility of using a semi-structured interview protocol augmented with visual cues to explore the sensory experiences of individuals with high-functioning ASD.

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References


Appendix 1
An excerpt from the semi-structured interview protocol with visual supports: Sound sensory domain

**Sound**

- Think about your reactions to sounds (e.g. sudden loud noises such as the school bell or a fire alarm, people talking, traffic noise, babies crying, background music in shopping centres, music on the radio or stereo etc.).
- Think about how you react to sounds when you are trying to concentrate on something.
- Think about sounds in different places such as at the shopping centre, in the school grounds, in the classroom at school, at the movies, at home or on a sports field.
- Can you describe the way that you feel about these sounds?

**Probe questions**

- Are there any sounds that annoy you?
  - What do you do if sounds annoy you?
  - What do you do to avoid sounds that you find unpleasant/annoying/irritating?
- Are there sounds that you find very distracting or affect your concentration when you have a task to do? For example, schoolwork, homework.
- Are there sounds that you particularly like or listen to repeatedly?
- Are there sounds that you seem to notice more than other people? For example, planes or trains coming before other people notice them.
- Are there sounds that you seem to notice less than other people? For example, people calling your name.