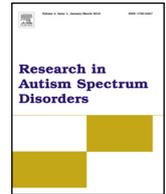




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A qualitative study of noise sensitivity in adults with autism spectrum disorder[☆]

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ABSTRACT

Background: Individuals with autism spectrum disorder (ASD) may respond to environmental stimuli more intensely and less conventionally than typical peers. Research has generally focused on sensory sensitivity broadly, rather than individual modalities. Thus, experiences of noise sensitivity (NS) have not been specifically documented in detail. This study documents the experiences of NS in adults with ASD.

Method: Semi-structured interviews were undertaken and recorded with 10 participants. The resultant data were analysed using a descriptive thematic approach to summarise the patterns in the participants' experiences.

Results: The analysis identified four themes emphasising the unique way those with ASD experience sound, and the impacts of noise sensitivity on them.

Conclusions: Documenting experiences such as these is an important early step towards a better understanding and hence supporting those negatively experiencing sound. The present results are both useful for those affected and those working with them, in terms of developing improved methods of coping and clinical interventions. The results are also consistent with recent neurophysiological research.

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1. Introduction

Until very recently autism spectrum disorder (ASD) was described as a constellation of deficits across three core domains: language and communication, prosocial behaviour, and restricted interests and repetitive behaviours (APA, 2000). It was not until the release of the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) that sensory issues, first described by Asperger over 70 years ago, were considered in the clinical diagnosis of ASD. In the DSM-5 (APA, 2013) the 'fixated interests and repetitive behaviour for ASD' criterion was broadened to include hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment. It is not known whether sensory issues manifest as a core trait of ASD, or as core traits of comorbid disorders (e.g., anxiety), and as such they are treated as correlates of ASD traits (Horder, Wilson, Mendez, & Murphy, 2014). However, Hazen, Stornelli, O'Rourke, Koesterer, and McDougle (2014) report sensory symptoms are increasingly being viewed as core features of ASD, sharing common aetiological mechanisms and contributing to the broader developmental and behavioural issues.

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Miller, Anzalone, Lane, Cermak and Osten (2007) noted that sensory symptoms associated with ASD could be grouped into three categories of 'sensory modulation', each associated with maladaptive responses to sensory stimulation. Those categories were 1) sensory over-responsivity/hyper-responsivity (negative response to sensory input), 2) sensory under-responsivity/hypo-responsivity (less pronounced or delayed response to sensory input), and 3) sensory-seeking behaviour (unusual cravings for certain sensory experiences). These categories are not mutually exclusive and those with ASD may experience a combination of sensory symptoms, commonly being both under- and over-responsive (Hazen et al., 2014; O'Neill & Jones, 1997). Considering the auditory modality, Stiegler and Davis (2010) added hyperacusis, though this condition is associated with inner ear or vestibular damage and is unlikely to be related to ASD. Without reference to specific sensory modalities, estimates of the prevalence of sensory issues in ASD vary widely, research indicates that sensory issues differentiate children with ASD from neurotypical controls and children with other intellectual disabilities (Dahlgren & Gillberg, 1989). Mazurek et al. (2013) report that estimates of sensory over-responsivity in children with ASD range between 56 and 70%. Others have noted high rates of sensory over-responsivity across the breadth of the autism spectrum (Hazen et al., 2014), and there appears to be no link between intellectual functioning and sensory reactivity in those with ASD (Elwin, Ek, Kiellen, & Shröder, 2013).

Robertson and Simmons (2013) identified a positive relationship between ASD traits and sensory processing difficulties. Pertinently, their data also indicated variability in sensory issues across the five modalities, with the auditory modality associated with the highest levels of sensory-related disturbance. As this is not an isolated finding (see also Talay-Ongan & Wood, 2000) it would be useful to examine the modalities in isolation. The present research focuses on the auditory modality and, in particular, hyper-sensitivity to sound. Hyper-sensitivity to sound is common to many psychological disorders, albeit with a different label: *Noise Sensitivity* (NS), and this standardised term is adopted here. Examples of clinical conditions associated with NS include tinnitus (Schwartz, Leyendecker, & Conlon, 2011), Traumatic Brain Injury (Dischinger, Ryb, Kufera, & Auman, 2009), schizophrenia (Tregellas, Smucny, Eichman, & Rojas, 2012), Lyme disease (Coyle & Schutzer, 2002), Williams syndrome (Barozzi et al., 2012), anxiety (Hadjipavlou, Baer, Lau & Howard, 2008) and depression (Stansfeld, 1992). In both the clinical and epidemiological literature the definition of NS is relatively homogenous, with noise sensitive individuals more likely to attend to sound, evaluate sound negatively, experience enhanced emotional reactions to sound, and subsequently have greater difficulty habituating to sound (Stansfeld, 1992). This definition mirrors that found in the ASD literature, albeit with reference to broader sensory processing abnormalities (e.g., Chamak, Bonniau, Jaunay, & Cohen, 2008; Elwin et al., 2013).

As with other clinical conditions, with the exception of tinnitus, NS in ASD individuals cannot be explained by peripheral hearing abnormalities, such as hearing loss or over-sensitive hearing (Gravel et al., 2006; Tharpe et al., 2006). Elwin et al. (2013) ascribed NS in ASD to deficits in core cognitive processes, such as selective attention or sensory gating (Marco, Hinkley, Hill, & Nagajaran, 2011). Gomes, Rotta, Pedroso, Sleifer, and Danesi (2004) appealed to psychological mechanisms, arguing that NS in individuals with ASD emerges from anxiety. In support, White and colleagues (White, Oswald, Ollendick, & Scahill, 2009; White, Ollendick, & Bray, 2011) reported that anxiety is a common comorbidity in ASD, which in children seems to co-vary with sensory hyper-responsivity (Lane, Reynolds, & Dumenci, 2012). Furthermore, in an epidemiological sample, Persson, Bjork, Ardo, Albin and Jakobsson (2007) found significant associations between NS and anxiety. However, Horder et al. (2014) reported robust relationships between ASD traits and sensory processing abnormalities even after controlling for anxiety, though they did not report associations with individual sensory modalities.

The neurobiological origins of NS in individuals with ASD remain to be identified (Hazen et al., 2014; Horder et al., 2014). Stiegler and Davis (2010) argued there was "virtually no evidence of true physiological differences in auditory systems of individuals with ASD" (p.67). However, recent evidence shows some differences in functional anatomy (Courchesne, Campbell, & Solso, 2011; Courchesne, Redcay, & Kennedy, 2004), connectivity (Alexander et al., 2007; Pryweller et al., 2014; Shukla, Keehn, Lincoln, & Müller, 2010), the planum temporal network (Kulesza & Mangunay, 2008; Rojas, Bawn, Benkers, Reite, & Rogers, 2002; Rojas, Camou, Reite, & Rogers, 2005) and brainstem architecture (Kulesza, Lukose, & Stevens, 2010) in ASD compared to typically developing individuals, and that these morphological differences in ASD brains contribute to dysfunctional auditory processing. Furthermore, neurophysiological studies (see Hazen et al., 2014; Horder et al., 2014; Iarocci & McDonald, 2006; Marco et al., 2011) show behavioural and electrophysiological differences between individuals with ASD and typically developing individuals. A review by O'Connor (2012) suggests that individuals with ASD have deficits in processing complex auditory information that is vital to successful social interaction and communication, but appear to have spared or enhanced processing of simple auditory stimuli.

The clinical treatment of health conditions is enhanced by precise aetiology, which is usually developed from quality clinical descriptions. In the broader domain of ASD-related sensory processing deficits, the existent explanatory frameworks can be considered conjectural. Thus, future model building would benefit from richer descriptive data pertaining to experiences along single sensory dimensions. Currently, and across clinical conditions, NS is often treated by practitioners as a neurotic trait, specifically negative affectivity. This often leaves those with sound-related difficulties feeling belittled, ignored or humiliated (Landon, Shepherd, McGarry, Theadom, & Miller, 2016; Landon, Shepherd, Stuart, Theadom, & Freundlich, 2012). Autobiographical sources indicate that for individuals with ASD, NS reduces health and well-being, and professional awareness is essential if educational, social, and vocational outcomes are to be improved (Ashburner, Ziviani, & Rodger, 2008; Stiegler & Davis, 2010). Furthermore, the development of effective treatments is of clinical importance given the high prevalence of sensory processing deficits within ASD individuals (Billstedt, Gillberg, & Gillberg, 2007; Mazurek et al., 2013). Current treatment approaches are few, with sensory integration therapy common. However, this approach cannot be

considered evidence-based (Barton, Reichow, Schnitz, Smith, & Sherlock, 2015; Lang et al., 2012), and new approaches are required (Hazen et al., 2014).

The addition of sensory processing deficits to the DSM-5 emphasises the impact of these symptoms on individuals with ASD. However, sensory-related research has been neglected relative to other core ASD traits (McCormick et al., 2014; O'Neill & Jones, 1997), despite its impact on everyday functioning. Further understanding of sensory experiences in ASD may lead to more refined diagnostic tools, whereby subjective measures can complement existing observation-based measures (Horder et al., 2014). To date, few studies have adopted qualitative methods to explore the subjective experiences of sensory hyper-responsivity in ASD, and they have focused on sensory modalities broadly (Elwin et al., 2013; Jones, Quigney, & Huws, 2003; Robertson & Simmons, 2015). Filipek et al. (2000) specifically appealed for further research into sound-related sensory processing abnormalities in ASD individuals. However, beyond a review paper (Stiegler & Davis, 2010) it appears this remains a gap in the literature. Furthermore, most of the research into ASD-related sensory experiences have involved child participants with few exceptions (but see Crane, Goddard, & Pring, 2009; Elwin et al., 2013; Kirby, Dickie, & Baranek, 2015). Thus, the aim of the present study is to describe experiences of NS in adults with ASD.

2. Method

2.1. Participants

Ten participants took part and gender appropriate pseudonyms are used to protect their identities. They were recruited through advertisements placed within a range of ASD-related community networks. Participants contacted the researchers directly and needed to be aged 20 or older, have a formal diagnosis of ASD or Asperger's syndrome from a clinical psychologist or paediatrician, in addition to self-reported experiences of NS. The participants' clinical diagnoses were not independently confirmed prior to their participation in this study and no assessments of current intellectual functioning were undertaken. Prior to being interviewed, the participants were provided with information about the research, and any questions they had were answered. Once they were comfortable, they confirmed their consent to participate by signing a consent form. Six male and four female participants ranging from 20 to 68 years old (mean = 39) were interviewed. All were living independently, and their demographic details are shown in Table 1. All participants except one (Chris) reported first noticing issues with noise from their childhood.

2.2. Procedure

Semi-structured interviews were undertaken using an adapted interview schedule (Landon et al., 2012, 2016) that included open-ended questions focused on experiences of NS. Discussions began with a brief overview of the participant's history of ASD and NS, and then focused on their day-to-day experiences of sounds. Broad questions were used to explore the participants' experiences of sounds (e.g., "can you tell me about your experiences of sounds?"), and the context of sounds generally (e.g., "can you talk about a typical day and how sounds affect you?"). Specific events were explored in more detail, as were the sources of sounds, and their nature (e.g., "are some sounds more problematic for you? Can you tell me about them?"). Successful and unsuccessful coping strategies were explored, and the interviews concluded with a general question about the significance of noise sensitivity to the participants. Interviews were recorded, lasted approximately 70 mins, and participants were free to stop at any stage. The recordings were later transcribed verbatim and participants offered the opportunity to review them. This research was approved by the Auckland University of Technology Ethics Committee (Approval number 14/79).

Table 1
Pseudonyms and demographic characteristics of participants.

Participant	Age	Gender	Marital Status	Ethnicity	Diagnosis	Co-morbidity
Andrew	26	Male	Not married/single	European	ASD	No
Darren	35	Male	Not married/single	European	Asperger's	No
Bryan	34	Male	Married	European	Asperger's	Anxiety
James	46	Male	Married	Japanese	Asperger's	No
Patricia	68	Female	Not married/single	European	Asperger's	No
Elizabeth	33	Female	Not married/single	European	Asperger's	No
Nicole	23	Female	Not married/single	European	ASD	No
Alicia	20	Female	Not married/single	European	Asperger's	Anxiety
Chris	51	Male	Married	European	ASD	No
Mark	52	Male	Divorced/single	European	ASD	PTSD

2.3. Analysis

The data were analysed using a thematic analysis (Aronson, 1994). The analysis was descriptive in approach involving minimal interpretation, with the objective being to summarise and present the key aspects of the participants' experiences accurately as they described them (Sandelowski, 2000).

The data were organised into themes identified from the transcripts using the steps described by Braun and Clarke (2006). The analysis began with reading and annotating the data. The first author developed initial codes, and then refined them by grouping data with similar or related codes to produce preliminary themes. All authors then independently checked and rechecked the themes against the original data to ensure an accurate representation of the participants' experiences. Direct quotes from participants were used as theme titles to emphasize the content of each theme, and further quotes used to illustrate the themes themselves.

3. Results

Analysis of the data resulted in four themes: 1) I feel it in my head; 2) It overloads you; 3) Sounds that can make you fall apart; and 4) I'm quite a hermit. Each theme is described in turn.

3.1. I feel it in my head

The participants discussed a range of problems they experienced with noise in a range of contexts. All participants reported high-pitched or sharp sounds and children crying or screaming as particularly problematic for them.

Cars that go through the rain when the road is wet . . . cars are going through and it's hissing. It's the hissing because it's very high and sharp . . . kids screaming, you know how they scream ear piercing sounds those kinds of sounds. (Elizabeth)

Several participants associated these sorts of sounds with a degree of physical discomfort, or 'feeling' the sound, beyond simply hearing them.

It's funny because it's a cross between hearing a sound and feeling the sound . . . it's hard to explain but when I hear something umm certain levels I feel it in my head as well as hear it. (Mark)

The feeling is so intense it feels like pain, I know it's not pain but it reminds me, it's very very similar to physical pain. (Elizabeth)

In addition to loud sounds, the participants also report hearing, attending to, and being affected by sounds that others did not seem to notice. These sounds seemed to draw their attention, and the participants described a degree of irritation, annoyance, and in some cases confusion, in response to them.

I think they do hear them but to them it's not significant. To me for some reason it is . . . the sound and it affects me and my heart's going; and everyone else is just like no reaction and I am just like "really, why did you not hear that am I like Superman now or something? (Elizabeth)

Definitely electronic things, like the computer and the buzzing light umm . . . umm buzzing fluorescent light, umm ticking, clocks and things umm, yeah so I guess those repetitive things that don't stop and umm yeah things that are kind of quiet and insidious. (Alicia)

3.2. It overloads you

The participants consistently discussed being distracted by sounds of all sorts, even in very quiet situations several sounds might be competing for, or demanding, their attention.

I am really easily distracted by noise . . . even now my attention is going to the birds singing. (James)

If you imagine trying to focus on something and you have a sound coming in from another channel . . . it interferes and in a way if you think of it as signals interfering with one another or the thing that manages all the signals having to manage too much at once . . . it's always an issue because it overloads you . . . all this stuff coming in at once and it's coming too fast for your brain to handle. (Darren)

A range of specific examples was provided. Several participants highlighted the difficulties they experienced in what might be considered relatively innocuous work-related situations.

I'm currently working in a building on the 4th floor and on windy days I can't concentrate on my work. (James)

One time we had a meeting in there and I needed to be attentive . . . but there was music playing, people making coffee, people talking and so much noise and the lights were bright and there was just too much I couldn't concentrate. (Nicole)

Consistent with Nicole's comments, the most frequently discussed contexts in which problems occurred were those involving interactions with others. Participants frequently reported background noises and multiple voices making it very difficult for them to communicate with others in both professional and social settings.

It's an amazing problem. I can't really communicate very well in a setting of large numbers of people in general. I'm not good at that at all. So noise is a problem in a sense that there's too much. And I can't cope with it all. (Bryan)
It's more like a jumble, so many conversations, so I can hear the noise and I can hear speech but I can't isolate the person next to me. It's just as loud as everything else and I can't isolate one person speaking. (Patricia)

The participants described the efforts required to engage in conversation when there was background difficulties in these scenarios were described as effortful and tiring.

Even if someone is in front of me and we are having a conversation, I have to go 'what?' . . . I have to focus on one point if I want to listen to a conversation. I have to make an effort to focus otherwise it's all just noise. (Elizabeth)

3.3. *Sounds that can make you fall apart*

A range of emotional reactions was discussed in response to noise. The most common was anxiety which was discussed explicitly, and sometimes alluded to in the context of sounds. In most cases this was as a reaction to noise or the difficulties caused by NS, frequently in a social context.

Lots of people talking and not being able to pick up the voices is more likely to make me anxious. (Alicia)

For some participants anxiety and emotional distress were evident in other non-social contexts. Sometimes specific sounds were linked to distress, in some cases this seemed to be due to properties of the sounds themselves, and in others due to uncertainty.

There are sound that can annoy you but there are also sounds that can make you fall apart as well, you'll feel you know feel unstable or unsafe. I had an experience with the power lines and the distance between the power poles they would vibrate and that caused me a lot of distress and sounds coming out of the mains board, frequency used come out of that and they are . . . a really unsafe feeling about them because other people couldn't hear it. (Mark)

Last night I didn't like it when the hail came. Because I'd only heard a little bit of rain – it hadn't been much. And then all of a sudden, and I wasn't sure if it was someone throwing stones on the roof of the veranda or if it was hail. (Patricia)

Some participants also reported that pre-existing feelings of anxiety acted to exacerbate their sensitivity to noise. This was evident in participants reporting a co-morbid anxiety disorder.

I think definitely if I'm in a more generally anxious state I notice I am more sensitive to sounds. So like last year I was very very anxious and I was very sensitive to sound so that's why I couldn't have my bedroom light on for example. Or like that's when I stopped wearing my watch. (Alicia)

Additionally, it was also evident among participants not reporting a co-morbid anxiety disorder.

I think it can be worse depending on mood. If you're anxious you notice it more . . . so it gets worse. (Darren)

Other emotional reactions such as frustration and irritability were discussed by all participants. Problematic sounds tended to lead to irritability, sometimes via anxiety, and sometimes directly.

I generally just get pretty irritable. Just makes me upset . . . unnecessary conversations are the worst. People just speaking nonsense that's kind of more frustrating to me. (Nicole)

Several participants reported a range of behavioural responses, including a general fidgetiness or restlessness and engaging in self-stimulatory behaviours in response to sounds they found problematic.

I can't doing anything there is all this energy racing around inside me out of irritation and thinking about these things and if I can just fiddle with my sleeve or something then at least I am doing something physically. I don't know how else to explain it . . . yeah its building up inside and you can't let it out, you can't go "ahhhhh be quiet" or whatever and can't be jumping up and down or doing anything you just fidget. Like oh this will be over soon or oh is there any dirt under my fingernails, I hope so because I need to do something. (Elizabeth)

Sometimes I feel hot . . . my legs get restless it's hard to explain . . . I get squirmy if it's loud enough like even if it's more than a minute or two. (Alicia)

If it is like a cocktail party type situation because that makes me anxious there things like feeling a bit ill or like kind of stimming, just like hand movements and stuff. (Nicole)

Mark discussed an unexpected sound that caused him to physically break down, illustrating extent of his despair in response to that sound, and the potential impacts.

I was actually outside telling my scout group what was going to happen during the course of the day and there was a camp site across from us and they had a steam kettle on the fire and I've never had this happen before. This whistle went off and it must have been a flute kind of pitch but all of a sudden I just covered my ears and broke down crying in front of my troop. (Mark)

The responses were often observable so most participants were careful to avoid unwanted attention given the hidden nature of their issues with sound, and the lack of understanding common among others.

I spend most of my time being irritable and trying not to react and draw attention to myself because it's really embarrassing and also people don't really understand if you get upset over sounds. Just like calm down or something like

that and then you know you can't calm down. Being told to calm down makes it worse because you are being told to calm down. (Elizabeth)

3.4. *I am quite a hermit*

The predominant approach to dealing with noise was avoidance of any situations in which the participants anticipated issues. Often this avoidance was centred on social occasions.

I tend to avoid those things. I am quite a hermit these days because I avoid being in those situations if I can, even family get togethers I'm not normally there too long. (Mark)

Well usually I would avoid the situation all together and I would think to myself – is there going to be loud music “oh sorry I can't go I have to do something.” (Elizabeth)

For the most part the participants did not feel they were 'missing out' as socialising was not often of significant importance to them. Some noted the link to ASD, and the fact that it was convenient as they did not have to 'fit in'.

Now I just don't go umm I don't do social functions of that sort, the only things that I do is have family friends come over and that's very occasional, one or two people at a time and that's it . . . I don't do social, don't need, I don't find its very satisfying. (Bryan)

Yeah the thing of being on the spectrum that you generally don't fit in with the general population anyways so I don't really feel like I have to do what other people are doing [laughs] just used to missing on normal things but you're not really in to what normal people are into anyway. (Nicole)

There was an example in which the avoidance had a very disruptive effect. Alicia's avoidance extended to not turning the light on in their room for several months.

So for example last year I was very much, I had a fluorescent light in my room, the buzzing was so annoying that it got to the point where I couldn't turn it on. So I sat there in the dark in my room for half the year because I couldn't turn the light on. So yeah so I kind of did that sort of removing the noise but like I couldn't remove myself from the room, so I removed the noise from the room. (Alicia)

Escaping from potentially problematic situations was also common. For the most part this was not planned, rather it was reactive once issues were encountered.

Usually I would want to get away from the source of the sound, like walk away from it in the mall and try to find somewhere quiet like a shop and pretend to browse. So I can calm down a bit. (Elizabeth)

If I am ever forced to go to a cocktail party or anything I tend leave it fairly early [laughs] or sit in the bath room or whatever. (Alicia)

Some participants were more proactive in their attempts to cope with noises. They discussed planning potential escape from situations they thought would cause problems, advising others of their issues, and using ear plugs.

Establishing my exit plans and everything and I can go in there and feel a lot better but the noise aspect of things especially when people are talking and the stereo is going and all that sort of stuff. It's quite distressing you know I feel very uncomfortable. (Mark)

Nicole reported positive experiences from making others aware of their problems, even if no tangible result was likely. The best thing for my anger was to do something constructive and to let someone else know how much it annoyed me . . . I made a complaint to the bus company a few weeks ago about all the sounds that the buses make that annoy me. The doors squeak. The indicators make a noise even sitting at the back you can still hear indicators. The buzzing sound when the doors open um the stop bell has a really sharp sound and when you're outside the bus when it drives past the noise it's very painful. (Nicole)

Ear plugs were used by several participants to ameliorate the impacts of noise, with varying degrees of success. Some found them problematic in themselves, or unhelpful as they merely altered the nature of their problem.

I feel that ear plugs or even cotton balls in my ears or anything like that builds up the pressure in my head and then I get a headache so I can't really do that. (Nicole)

Ah ear plugs, but sometimes it just makes the sound quieter and sometimes when they get quieter they actually get worse. (Darren)

However, others found earplugs useful in a range of situations as a relief from problems.

It's a bit like you don't know almost like a damp towel on a hot day or something. Yeah it's just takes away some of the discomfort. (Chris)

Elizabeth, in particular, found earplugs particularly useful to help her cope in a range of situations.

I'll bring ear plugs with me you know the one that you twist and . . . soft ones you stuff them right in there. I will just put them in my bag and I don't care if anyone thinks I am weird . . . they make me feel a lot more safe for some reason, it's because I know what they do so I kind of trust them to soften things for me. It seems that all I need, that seems to be the

answer because even high pitch sounds it takes away a lot of the sharpness and it mutes everything, softens it you know? It doesn't take away the sound, doesn't make me deaf, it just makes everything a little easier to hear. (Elizabeth)

Two participants discussed an improvement in how they reacted to noises; one in the context of a deliberate attempt to respond differently, and the other as a result of professional support.

I've probably have lost a bit of sensitivity as I have gotten older but a I think the change has happened with me rather than, just the way that I deal with things, see . . . things, the way that I look world is different than when I was younger . . . actually, it's changing the way I respond to things. You're going to overcome it by adapting yourself . . . that means a change in attitude and yourself. (Mark)

I've learnt to tolerate things, part of it might be reduced anxiety because I've been on medication to reduce anxiety . . . and I've learnt behavioural skills to help me manage, which is like debriefing, so I am a lot more relaxed person as well. (Darren)

4. Discussion

NS has been frequently discussed in the context of ASD amongst a range of sensory sensitivities. Thus, specific first-hand accounts of NS in people with ASD remain scarce, despite the prevalence of these issues and the importance of documenting these experiences, both for those affected and practitioners working with them (Hazen et al., 2014; Kern et al., 2006). The present study presents direct accounts from participants explicitly asked about their experiences with sounds. The resultant themes summarised key experiences and provide insights useful for those dealing with these issues, and for their clinical management.

The participants consistently referred to loud piercing noises causing issues, but also quiet noises which others around them did not appear to notice. These experiences are generally consistent with notions of hyperacusis (Baguley, 2003). However, in addition to this general exaggerated acuity and increased response to sounds, the participants also noted specific sounds, characteristic of specific sound intolerance (Hadjipavlou et al., 2008), and/or contexts, that were problematic for them. In the most extreme example one participant referred to events where specific sounds elicited overwhelming emotional responses in him. Whilst the most frequently discussed contexts were social ones – these situations combined multiple sources of sound with social interactions, both of which could be problematic for the participants. These responses in specific settings or to specific sounds are more consistent with NS.

The participants identified anxiety as a key component of their NS, irrespective of any comorbid anxiety disorder. Anxiety was discussed as a response to noise, but also as a condition which exacerbated NS – either because of its presence generally, or in specific contexts (notably social ones, but also uncertainty). Anxiety disorders are highly comorbid with ASD (White et al., 2009, 2011), and research has been investigating the relationship between sensory sensitivities and anxiety. NS has previously been attributed to hypervigilance to noise sources due to fear and anxiety (Miedema & Vos, 1999), usually in relation to a specific noise source (e.g., aviation noise). However, Green and Ben-Sasson (2010) proposed three theories supporting links between general sensory sensitivity and anxiety, essentially they were i) that sensory sensitivity is caused by anxiety; ii) that anxiety is caused by sensory sensitivity; and iii), that they are causally unrelated but associated through a common risk factor or diagnostic overlap. The first two are consistent with the participants' accounts in that their descriptions suggest the relationship is potentially bi-directional. Notwithstanding the neurophysiological links between NS and anxiety, psychological or pharmacological interventions for anxiety issues might hold some promise for reducing the impacts of NS, both by reducing susceptibility and improved coping. The participants' accounts evidenced some very strong emotional consequences of exposure to noise. Given that in some cases these issues were sporadic, psychological approaches may have advantages. Two participants receiving treatment for an anxiety disorder (Darren and Alicia) discussed some associated benefits in terms of coping with noise.

Coping with NS was largely through avoidance or escape. To a degree this was consistent with NS studies on other clinical populations (Landon et al., 2012, 2016). However, in those studies (participants with traumatic brain injury and schizophrenia, respectively), there was more evidence of problem-focused, or planned approaches to coping. By comparison, these were notably limited in the present study. The present participants also reported self-stimulatory repetitive behaviours as a response, perhaps as an escape or an attempt to ameliorate anxiety. McCormick et al. (2014) found no associations between sensory sensitivity, repetitive behaviours and physiological arousal in children with ASD. That result, together with the present participants' experiences might perhaps suggests that in this context the participants' repetitive behaviours might serve a behavioural or cognitive escape function.

Some participants discussed plans, and one (Nicole) discussed some satisfaction with making others aware of their problem, albeit not in a way that would be likely to result in any tangible benefit to her. Coping strategies and adaptive behaviours are often lacking in individuals with ASD, thus they are often a focus for clinical interventions (e.g., Lang, Regerster, Lauderdale, Ashbaugh, & Haring, 2010; Tantam, 2000). However NS is seldom, if ever, a treatment focus, as those affected seldom feel comfortable discussing it and it is not an overtly observable issue. It is likely that specific problem focused strategies would be useful, and hence lessen the less reliance on avoidant/escape strategies (Stallen, 1999). Furthermore, evidence suggests the degree of annoyance and distress experienced is related to the degree to which individuals perceive they can cope (Stallen, 1999), thus the benefits could be substantial. Supporting this, Darren discussed

skills learned during his treatment for his anxiety problems, and Mark talked about a general maturation process by which he came to alter his emotional reactions to noise. Although not referring to deliberate efforts such as those reported by Mark and Darren, Kern et al. (2006) have suggested that sensory abnormalities have the potential to improve.

Accounts of being overloaded by auditory stimuli were common, along with particularly effortful attempts to retain control over attention. Noise has more disruptive effects when individuals are focused on a task (Nowakowska-Kotas, Pokryszko-Dragan, Brodowski, Szydło, & Podemski, 2015), consistent with the present accounts. Teder-Salejarvi, Pierce, Courchesne, and Hillyard (2005) showed that individuals with ASD had difficulty attending to target auditory stimuli amongst background noise, evidenced by diminished event-related potentials (ERP). They suggested that in complex auditory scenes, top-down mechanisms involving auditory attention appear impaired in individuals with ASD. In children with ASD, diminished ERPs are a common finding in active attention-based tasks (Orekhova et al., 2009), and similar results have been found in passive attention tasks (Bruneau, Roux, Adrien, & Barthelemy, 1999).

Alternatively, these findings could indicate a problem with general low-level perceptual segregation abilities in individuals with ASD. Lepistö et al. (2009) found reduced ERP amplitudes for children with ASD in response to loudness changes in a multi-stream segregation task. The auditory scene analysis model (Bregman, 1990) has also been used to investigate auditory processing abilities in people with ASD (Lodhia, Brock, Johnson, & Hautus, 2014, Teder-Salejarvi et al., 2005). Perceptual processing deficits in the auditory domain have been identified, for example, Lodhia et al. (2014) investigated auditory segregation abilities in young adults with ASD and found they exhibited diminished ERPs in response to pitch, compared to matched controls. They concluded that individuals with ASD had a low-level deficit associated with processing timing information when they need to extract individual sounds in a noisy environment (e.g. focusing on a speaker). The difficulties experienced by the present participants could be related to these deficits.

Given the methodology used, the present study has limitations. The design necessitated a small sample of adults, thus any generalisations should be undertaken with caution. However, noise sensitivity seems rather similar across ASD, as such experiences such as these should contribute to the understanding of sensory reactivity across ASD. O'Neill and Jones (1997) previously noted the difficulties in obtaining accounts from individuals with lower levels of functioning and communication difficulties, as such they are often obtained via parents or caregivers. The present study has the advantage of obtaining first-hand accounts from the affected individuals. The aim was simply to explore and describe personal experiences of NS in adults with ASD, and contribute to the growing understanding of sensory disturbances in ASD using first-hand accounts from those affected. The study could also have been enhanced by independently confirming the participants' clinical diagnoses using an instrument such as the Autism Diagnostic Observation Schedule Module 4, and assessing other aspects of intellectual functioning. However, given the nature of the study it was concluded that additional assessments might add unwarranted burden to the participants and reduce their openness during the interviews.

4.1. Implications

Mental health professionals require a better understanding of NS and its presence in a range of conditions (e.g., Landon et al., 2012, 2016; Stansfeld, Haines, Burr, Berry, & Lercher, 2000), and more pertinently as an ongoing issue for many individuals with ASD (e.g., Hazen et al., 2014; Kern et al., 2006). Whilst it is exploratory in nature, the present study provides accounts which should aid professionals in developing their understanding, and integrating NS issues into treatment plans. In the absence of support the predominant approach to coping is often avoidance or escape, but first-person accounts here and elsewhere (Landon et al., 2012, 2016) have suggested more proactive planned approaches can be beneficial and there is potential to develop effective interventions. Accounts such as these also provide insights for clinicians on how to pose questions around NS, and importantly validate responses. Moreover, accounts such as these can help those facing similar issues, and together with other research, shed some light, from an experiential perspective, on the nature ASD and its associated sensory issues.

Conflict of interest

The authors have no actual or potential conflicts of interest that could inappropriately influence, or be perceived to influence, this work.

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