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The interface of paediatric ENT and autism spectrum disorder: a complex conundrum for otolaryngologists

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Abstract

Objective. Autism spectrum disorder is a lifelong neurodevelopmental condition encompassing complex physical and neurological symptoms, including complex sensory symptoms. This review explores the interface between autism spectrum disorder and paediatric ENT.

Methods. Using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses ('PRISMA') guideline, a robust literature search and review was conducted by two researchers. Thirty-four papers were filtered into the final review.

Results. Published literature clearly demonstrates potential for autism spectrum disorder to present in the form of auditory and other sensory symptoms to ENT surgeons and audiologists who may not fully appreciate this complex condition. Despite this well-documented link, auditory symptoms, auditory processing disorders and hearing loss within autism spectrum disorder remain poorly understood.

Conclusion. Improved recognition and understanding of autism spectrum disorder by otolaryngologists could enable more effective diagnostic and management strategies for autistic children who present with auditory and other sensory symptoms. In light of the current 'autism epidemic,' there is an urgent need for further research on this theme.

Introduction

Autism spectrum disorder is an umbrella term encompassing various lifelong neurodevelopmental disorders. It has a roughly 5:1 male-to-female diagnosis rate.¹ Autism was first described in 1943, but was considered 'childhood schizophrenia' into the 1960s, and gained no official description until the 1980s.¹ Rates of autism spectrum disorder diagnosis have steadily increased, and are currently estimated to be as high as 1 in 54 children,^{2,3} a three-fold increase since the early 2000s.³ This has led to what some have called the 'autism epidemic',⁴ which is likely a result of better diagnostic tools and identification techniques.

Typically, autistic traits present around three years of age, but diagnosis is uncommon under the age of four years.⁵ This can be due to various reasons. Autism spectrum disorder can present with many complex physical and neurological symptoms, which can delay diagnosis. As a generalisation, these symptoms fall into two categories. Firstly, abnormal behaviour: a gain of skill such as highly developed interests or talents in specific subjects; a preference for social isolation and difficulty understanding emotions; or lack of verbal communication.⁶ Secondly, an abnormality in sensory processing: this can be auditory, visual or physical. These abnormalities in sensory processing can be hyposensitive or hypersensitive.

Auditory system abnormalities are a prominent problem affecting many in the autistic population. These range from hyperacusis and tinnitus to profound bilateral hearing loss, with a prevalence higher than the national average.⁴ Hearing abnormalities have been estimated in 33–46 per cent of confirmed autism spectrum disorder cases.^{4,7} Another study⁸ showed that 40 per cent of autistic children exhibit symptoms of sound sensitivity, with decreased sound tolerance having a lifetime prevalence of 50–70 per cent in autistic people.⁹ These symptoms can affect autistic people profoundly, from losing sleep to developing anxiety, and can severely interfere with school or work.¹⁰ Rosenhall *et al.* showed that auditory symptoms and hearing loss had similar rates throughout the autism spectrum disorder community, regardless of 'intellectual functioning'.¹¹

The recommended method to test autistic children for auditory processing disorders is to check for uncomfortable loudness levels, requiring minimal verbal communication, relying on facial expression and body communication.¹⁰ Although autistic children require more from healthcare systems, particularly in the otorhinolaryngology field, than their non-autistic counterparts, paradoxically they are less likely to have their needs met.¹² It has also been recognised that if an autistic child has hearing problems, this can delay the diagnosis of both conditions.³

Autistic children frequently present to ENT departments with non-auditory symptoms, including otitis media and allergic rhinitis.² Because of differences in

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Table 1. Definitions of terms used within this paper

Term	Definition
ASD	ASD is a neurodevelopmental disorder describing a collection of symptoms, affecting communication, behaviour and sensory processes. ¹³ It affects how people with the condition communicate, socialise, learn & behave. It can be diagnosed at any age, but symptoms must have been present since early life. While there is no cure, various treatments & services can relieve the burden ¹⁴
APD	The British Society of Audiology describes 3 APD categories: acquired, secondary & developmental APD. Acquired APD arises from a known neurological event, such as infection, trauma or stroke. Secondary APD results from a genetic cause or peripheral hearing impairment. More relevant to this scoping review is developmental APD, in which APD is present from birth, exists with normal audiometry & has no identified aetiology ¹⁵
Hyperacusis	Hyperacusis is a DST disorder, where normal or non-threatening sounds appear louder & intolerable. Depending on the person & severity, this sensation can be painful or frightening, or just unpleasant. Dislike or fear of specific sounds comes under the terms misophonia & phonophobia, respectively ¹⁶
Tinnitus	Tinnitus is another DST disorder, described as auditory perception of a sound despite the absence of an external environmental stimulus. It can present unilaterally or bilaterally, & to varying degrees, from only noticeable in quiet rooms to severely affecting daily life ¹⁷
Hearing loss	Hearing loss can be experienced unilaterally or bilaterally. It can be sensorineural or conductive in nature. Its prevalence increases with age, but it can be present from childhood or even birth ¹⁸
M100 latency	M100 latency is a measured magnetoencephalography response & is the expected delay in auditory evoked cortical response, representing 100 ms. This latency measurement can give an indication of white matter conduction & speed of transmission between synapses. This measurement is often used when checking cortical responses to different stimuli, mainly auditory ¹⁹

ASD = autism spectrum disorder; APD = auditory processing disorder; DST = decreased sound tolerance

communication skills, these conditions usually present later and more severely, leading to more hospital visits and surgical procedures.² There are numerous theories behind the physiological cause of autism spectrum disorder, with multiple papers contradicting each other. Mathew *et al.* discussed the 'early closure of neuroplasticity' in autistic children, proposing that early intervention for hearing loss can be vital to improving the outcome.³

This review aimed to explore the interface of autism spectrum disorder and paediatric ENT, with a specific focus on the potential for autism spectrum disorder patients to present to paediatric ENT clinics with sensory or other symptoms. There are several terms used within this manuscript, which are defined in Table 1.^{13–19}

Materials and methods

A pilot literature search demonstrated a heterogeneity of literature, unsuitable for incorporation into a systematic review. A scoping review approach was therefore adopted.²⁰

Publications were identified through PubMed and Ovid Medline databases, and Google Scholar web search engine, using the search terms: autism spectrum disorder, autism, autistic, neurodiverse, non-verbal, paediatric, childhood, early, ENT, otolaryngology, hyperacusis, tinnitus, auditory processing disorder, auditory hypersensitivity and deafness. The reference lists of manuscripts identified in the initial search were also screened. There was no limit on the publication dates of studies.

A total of 104 papers were initially identified, with 34 being selected for the final scoping review (Figure 1). The inclusion criteria included papers that addressed the themes of both autism spectrum disorder and ENT issues in children. Of those papers initially excluded, 48 were irrelevant and 2 were case studies. On inspection of the full papers, 19 were deemed irrelevant and 1 was a duplicate.

The included papers were analysed and categorised thematically. This formed the basis for the scoping review.

Results

Of 34 papers included, there were variations in study design. Five papers were descriptive reviews, two were retrospective case series, eight reported prospective research, eight were case-control studies, six were systematic reviews, four described qualitative research and one was a population study (Figure 2).

The manuscripts were classified thematically into exhaustive, exclusive categories. Three manuscripts addressed the concept of pre-existing autism spectrum disorder in paediatric ENT, 14 explored autism spectrum disorder and auditory symptoms, 10 addressed autism spectrum disorder and auditory processing, 5 came under the theme of autism spectrum disorder and hearing loss, and 2 addressed autism spectrum disorder and cochlear implantation (Figure 3).

Pre-existing autism in paediatric ENT

First described by Kanner in 1943,²¹ autism spectrum disorder has gone through various stages of recognition until the latest by the National Institute for Health and Care Excellence in 2013.²² With the rising incidence of autism spectrum disorder diagnoses, and with studies consistently demonstrating an estimated 40 per cent or more of diagnosed children showing symptoms of sound sensitivity,⁸ it is key for otolaryngologists and audiologists to recognise the condition.

Autistic children have also been shown to exhibit a higher prevalence of anxiety, which can be particularly challenging in healthcare settings.¹² Sensory symptoms can become a serious challenge for autistic children and their carers.² A study by Fahy *et al.*, in a paediatric ENT setting, concluded that healthcare professionals considered parents to be the 'experts' when it came to managing and understanding their autistic children's needs.²

Autism and auditory symptoms

A paper by Law *et al.*²³ found that the lifetime prevalence of auditory sensory issues (tinnitus, hyperacusis, misophonia and phonophobia) may be as high as 86.6 per cent in autistic populations.

Hyperacusis is common in autistic populations,¹⁰ and can affect individuals in different ways, from causing anxiety to loss of sleep and trouble concentrating.¹⁰ There are numerous papers theorising the aetiology of hyperacusis in autism

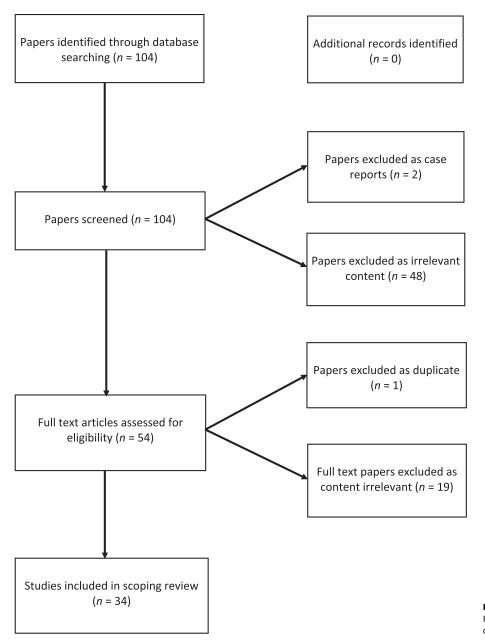


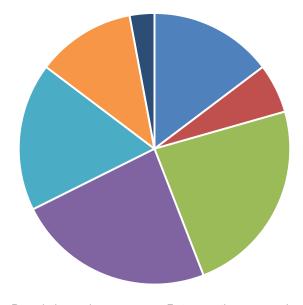
Fig. 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses ('PRISMA') flow diagram displaying the systematic search methodology.

spectrum disorder, from increased neural synchrony¹⁰ to a small or absent superior olivary complex.²⁴ Despite the evidently high prevalence of hyperacusis in autism spectrum disorder patients, the link remains poorly understood.²⁵ Studies conclude that the prevalence of hyperacusis in autistic children is generally around 40 per cent²⁶ (range, 29–69 per cent^{4,10,26,27}), with a lifetime prevalence of decreased sound tolerance in autism spectrum disorder individuals of 70–86.6 per cent.^{9,27} The general population incidence of hyperacusis is between 3.2 per cent and 17.1 per cent.¹⁰ One study found that, of 61 children with a diagnosis of 'troublesome hyperacusis', autism was subsequently recognised in 13 per cent.²⁸ which is higher than the current national average of around 1.9 per cent.^{2,3}

Scheerer *et al.*²⁹ discussed how hyperacusis in autistic children can be associated with multisensory integration. This may be due to sensory modulation differences, with the brain becoming overwhelmed, and unable to filter and process the intensity of the auditory stimulus.²⁹ This correlates with the recognised autistic trait of becoming overwhelmed in busy places.¹⁰ It has been demonstrated that a majority of

autistic children (59 per cent in a survey by Wilson *et al.*²⁶) are startled by loud noises, in comparison to 15 per cent of neurotypical counterparts.²⁹ Hyperacusis can lead to maladaptation in social and academic situations for autistic children, where avoidance and isolation can worsen social skills and anxiety, and create difficulties with school work carried out in a loud environment.²⁶

Tinnitus, an audiological problem that causes an individual to hear sounds without the presence of an external auditory stimulus,³⁰ is estimated to have a lifetime prevalence of 10–15 per cent in the general population.³¹ A survey of autistic children demonstrated that 35 per cent experienced tinnitus, with about half experiencing it in both ears.³¹ That survey used the Tinnitus Reaction Questionnaire, which assesses the associated psychological distress caused by tinnitus.³¹ The average Tinnitus Reaction Questionnaire score among autistic people with tinnitus was 27 (formal treatment is recommended for a score higher than 17), demonstrating a significant issue.³¹ Interestingly, in that study, 11 per cent of patients reported tinnitus even in the presence of background noise, which is not a classic feature of tinnitus.³¹



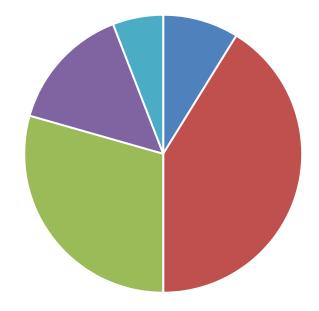
- Descriptive review
 Retrospective case series
- Prospective research paper = Case-control series
- Systematic reviews
 Qualitative research paper
- Population study

Fig. 2. Chart showing literature types included within the analysis.

Autism and auditory processing

Abnormal auditory processing in autism spectrum disorder has been previously proposed, though no definitive explanation has been identified.³² Bouvet *et al.*³³ considered that autistic people have more sensitive hearing, and are therefore able to detect changes in musical notes and pitch more easily than their neurotypical counterparts.³³ This pattern of cortical processing is thought to influence vision as well as interests, allowing autistic people to hyperfocus on tasks and hobbies, a well-documented autistic trait.^{33,34} A problem that autistic people often face is trouble hearing and understanding speech in the presence of background noise. This could be due to concurrent hearing problems, but might also be a result of the functioning aspect of the autistic mind. 'Failure of selective attention' is well documented in the autism literature, and can often be due to sensory overload.³⁵ Alcántara *et al.*³⁵ referred to 'auditory scene analysis' where, in the autistic mind, different auditory inputs are often grouped internally into different auditory 'objects'. Consequently, it becomes difficult for the mind to focus on just one of these auditory inputs.³⁵ This can become distressing for an autistic child, particularly within a loud classroom environment, putting them at an educational disadvantage.³⁵

A paper by Remington and Fairnie³⁴ attempted to contextualise hyperacusis with neural pathways, proposing that autistic people have an 'increased perceptual capacity relative to neurotypical individuals', allowing autistic people to be able to process information to a higher degree, making it easier to become overwhelmed.³⁴ This would coincide with a paper by Myne *et al.*,²⁸ where autistic people were reported to have a higher acuity for musical notes. Myne et al. discussed M100 (auditory evoked response) latency delays in autistic children being largely in the right hemisphere, which commonly processes sound and music.²⁸ These authors found that around 10 per cent of autistic children experienced rightsided hemisphere 10 ms M100 latencies compared with neurotypical controls.²⁸ M100 latency delays can be indicative of a disruption in the pathway encoding simple sensory information.³⁶ A paper by Matsuzaki *et al.*³⁷ also supports the theory of right-sided hemisphere bias in autistic people. These authors used magnetoencephalography to attempt to measure the neurophysiological mechanisms used for auditory language discrimination. They demonstrated auditory mismatch field amplitudes and latencies, largely in the right hemisphere.³⁷ The significantly increased rightward mismatch field amplitude lateralisation they noted in autistic adults is consistent with the paper by Myne et al.,²⁸ as well as other papers reporting structural and functional abnormal



- Pre-existing ASD in paediatric ENT = ASD and auditory symptoms
- ASD and auditory processing
- ASD and hearing loss

Fig. 3. Thematic analysis of the included literature. ASD = autism spectrum disorder

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- ASD and auditory processing
 ASD and cochlear implantation

hemispheric asymmetry in paediatric autism spectrum disorder. This indicates a differential path of maturation in the cortical auditory systems in autistic children.³⁷

Autism and hearing loss

Hearing abnormalities, of both sensorineural and conductive origin, are estimated to be present in 33–46 per cent of autistic children.⁴ The link between hearing loss and autism spectrum disorder, however, has sparse evidence to support it. Some studies estimate the hearing loss in autism spectrum disorder to be ten times higher than in the neurotypical population, with others documenting similar rates between autistic and neurotypical populations.³

Some of the stereotypical signs of autism, for example, toe walking, hand flapping or 'sustained odd play', can result in an earlier diagnosis. However, it has been shown that hearing impairment can delay the diagnosis of autism.³⁸ A study by Mandell *et al.*³⁸ included 382 autistic children and young adults aged under 21 years. The average age of autism diagnosis was 3.1 years. The authors demonstrated that if a child had hearing impairment, their average age at diagnosis was 4.1 years, and hearing impairment was the symptom most likely to delay diagnosis.³⁸

Identifying a true dual diagnosis of autism spectrum disorder and hearing loss can be challenging because of the nature of the symptoms of both conditions. Each condition complicates diagnosis of the other.⁵ Both conditions independently cause delays in language development, and, when concurrent, this can worsen the problem, hence early identification is key.⁵ Gillberg *et al.*³⁹ proposed that if deafness is suspected under the age of three years, this should also be highly indicative of autism.⁴⁰

Autism and cochlear implantation

Diagnosing a child with severe autism with profound sensorineural hearing loss can pose a challenge, specifically in determining whether the hearing test result is due to a true loss of hearing or communication differences associated with autism.⁴¹

In the twentieth century, it was generally thought that autistic children would not benefit from cochlear implantation, but in the past 20 years evidence has emerged suggesting that there is some benefit to be gained. A review article³ showed that of nine studies analysed, eight demonstrated that autistic children had an overall improvement in their speech expression following cochlear implantation, although the extent of this benefit was highly variable. It was also concluded that, in general, non-compliance was usually related to the severity of autism spectrum disorder.³

There is a move towards cochlear implantation at around the age of 12 months. Autism spectrum disorder diagnoses are usually made after the age of three years, and hearing problems in autism spectrum disorder are prevalent. It is therefore essential for the otolaryngologists and audiologists to whom children present with a profound hearing loss to be aware of the potential for a concurrent autism spectrum disorder diagnosis.³

Discussion

In the past 20 years, there has been a rapid increase in autism diagnoses, as healthcare professionals gain more understanding

of the condition. An autism diagnosis can benefit the child and the support system around them. Families can better understand the context of their child's symptoms and experiences, and learn how to deal with challenging situations. More autism spectrum disorder diagnoses will, however, put more pressure on primary and secondary care services.

Hyperacusis and tinnitus can cause elevated levels of anxiety in autistic children, leading to maladaptations that are detrimental to their education. Through recognition of the impact of hyperacusis, autistic children can receive the support and consideration they need. With such support, autistic children are far more likely to acquire literacy.¹³ As the recognition of auditory differences in autistic children improves, education systems will need to adapt accordingly.

The ENT and audiology problems that autistic children face are multiple and complex, and their true prevalence is often unknown because of the diagnostic challenges which the intersection of the two conditions presents. In non-verbal autistic children, unmanaged decreased sound tolerance can cause emotional and sometimes aggressive outbursts. If their autism is undiagnosed and decreased sound tolerance is not suspected, this can present a conundrum, and diagnostic delays can have a profound impact on a child's well-being and education. When these conditions are recognised and acknowledged, simple interventions can improve the child's quality of life. These might include cognitive behavioural therapy, use of noise-reducing headphones or simple removal of the auditory stimulus.¹⁰

Hearing loss in autism spectrum disorder remains poorly understood, with contradicting published evidence regarding its prevalence. Hearing loss is currently not a recognised symptom of autism spectrum disorder. However, if an autistic child has a concurrent hearing loss, this can delay the diagnosis of both conditions. Thus, there is a clear need for audiologists and otolaryngologists to be aware of this diagnostic conundrum.

The International Classification of Diseases 11th Revision ('ICD-11')⁴² diagnostic criteria were published in January 2022, to align with the US Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition ('DSM-5') diagnostic criteria. Within the International Classification of Diseases 11th Revision, there is no mention of auditory processing disorders, hearing loss, or other audiological or otolaryngological problems. There is brief reference to hypersensitivity or hyposensitivity to sensory stimuli, including sound, light, taste, smell, pain and touch, making this a vague reference, and underplaying the importance of auditory and hearing symptoms. Updated, more specific diagnostic criteria, which recognise the prevalence of auditory processing disorders and hearing loss, could help affected children. This would promote earlier diagnosis and management strategies.

There is an urgent need for further research, to enhance understanding of autism spectrum disorder in children, particularly concerning the link between hearing, auditory symptoms and autism spectrum disorder.

This scoping review has identified different key areas that are important in the interface between autism spectrum disorder and paediatric ENT, highlighting potential areas of research and education that could aid future recognition, diagnosis and treatment. We recommend the following: (1) robust studies to ascertain the true prevalence of hearing loss, auditory symptoms and auditory processing disorders, in autistic children; (2) ethical trials to identify the incidence of undiagnosed autism spectrum disorder presenting to otolaryngology and audiology professionals, in the form of sensory differences and auditory symptoms; (3) studies to clarify the effect that auditory symptoms, decreased sound tolerance and auditory processing disorders can have on autistic children, including psychosocial as well as educational metrics; (4) clarification of the aetiology of auditory symptoms in autistic populations; (5) training audiology and otolaryngology professionals to understand and recognise autism spectrum disorder, and to adjust their practices appropriately, especially when assessing children with unexplained hearing loss, auditory symptoms, auditory processing disorders and decreased sound tolerance disorders; (6) engagement with autistic advocates and populations, for enhanced insight into the complex interface of challenges and symptoms; and (7) more research into effective treatments for autistic children with auditory symptoms and hearing differences, with a multidisciplinary approach.

While Fahy *et al.*² recognise that healthcare professionals should consider the parents of autistic children to be the experts of their condition, there is a growing body of evidence to indicate that otolaryngologists also need to be experts. Autistic children's sensory abnormalities frequently present to ENT and audiology clinics, and would best be managed in the context of a neurodevelopmental disorder than a primary ear disorder. A multidisciplinary team approach to these cases is essential in order to provide the best all-round care.

Conclusion

This scoping review identifies key themes within the interface of autism spectrum disorder and paediatric ENT, highlighting areas for future research. Improved recognition of autism concurrent with auditory symptoms, auditory processing disorders, hearing loss and decreased sound tolerance would lower the average age of diagnosis of each condition, leading to better social and educational outcomes for these children.

A consistent approach or mandatory guide for checking auditory symptoms and hearing following a diagnosis of autism spectrum disorder could help with the recognition of concurrent issues. In the same manner, paediatric otolaryngologist and audiologist awareness of autistic behaviours, traits and presentations, and the potential prevalence of the overlap, would also be beneficial.

The diagnostic criteria for autism in the UK are evolving, but the most recent change does not acknowledge the importance and impact of auditory symptoms and hearing differences in autism spectrum disorder. Improved diagnostic criteria could be greatly beneficial for awareness and recognition, leading to better recognition, and more efficient diagnostic and management strategies.

With an increasing body of literature strengthening the link between the conditions, improvements in the way we recognise, diagnose, and manage hearing differences and auditory symptoms in autistic children, could change the face of autism spectrum disorder.

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Competing interests. None declared

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