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Decreased sound tolerance in autism: understanding and distinguishing between hyperacusis, misophonia, and phonophobia

BY ZACHARY J WILLIAMS

Decreased sound tolerance (DST) affects a significant proportion of autistic people throughout their lifetime and, as **Zachary J Williams** explains, it is important that clinicians are aware of the three distinct subtypes of DST when making a diagnosis.

Autism spectrum disorder (hereafter 'autism') is a heterogeneous, lifelong neurodevelopmental condition characterised by difficulties with social communication, repetitive behaviours, and atypical reactions to sensory aspects of the environment. Notably, an estimated 50-70% of autistic individuals demonstrate clinically significant decreased sound tolerance (DST, i.e. an inability to tolerate everyday sounds) at some point in their lives [1], often resulting in referrals of autistic children and adults to audiologists or other hearing health professionals. As DST in autism appears to represent multiple distinct yet often overlapping syndromes [2] (i.e. hyperacusis, misophonia, and phonophobia), it is extremely important that clinicians be aware of the differences between these conditions and feel comfortable distinguishing between them when making a diagnosis.

Hyperacusis (Figure 1) is a hearing disorder in which sound of moderate intensity is perceived as excessively loud, painful, and/or overwhelming [2]. Individuals with hyperacusis perceive everyday sounds, such as the sounds of



domestic appliances or electric hand driers, as uncomfortably loud or, in some cases, physically painful. Though frequently associated with tinnitus and peripheral hearing loss in the general population, hyperacusis in autism is thought to be neurodevelopmental in nature [2], and additional signs of peripheral auditory damage are frequently absent in this population. As in cases of hyperacusis not associated with autism, audiometric testing of uncomfortable loudness levels can support the diagnosis, although this test is typically only appropriate in adolescents and adults without significant cognitive or language impairment. While there is no consensus among professionals regarding the specific criteria used to make a clinical diagnosis of hyperacusis, operational criteria used by my research group to define hyperacusis are presented in Figure 1 to assist clinicians in making this diagnosis.

Misophonia (Figure 2) is a newly-described condition in which individuals

have excessive and inappropriate emotional responses to specific 'trigger' sounds (e.g. chewing, tapping, and sniffing), even when those sounds are not loud [2]. Anger, extreme irritation, disgust, and anxiety are the most common emotions, though some individuals may experience rage [3]. Misophonic triggers may evoke a 'fight or flight' response, including nonspecific physical symptoms such as muscle tension, increased heart rate, and sweating. Unlike in hyperacusis, in which the acoustic properties of a sound (i.e. intensity, frequency, and duration) strongly predict that sound's aversiveness, misophonic reactions are heavily context-dependent and may be diminished or absent if individuals with misophonia make the triggering sound(s) themselves [4]. Furthermore, despite large individual differences in specific trigger noises, reactions to those trigger noises, and degree of context-dependence, the majority of individuals with misophonia

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Operational Diagnostic Criteria for Hyperacusis

- A. One or both of the following, present for more days than not over a period of 6 months or longer
 1. Multiple commonplace sounds of low or moderate intensity are perceived as excessively and uncomfortably loud.
 2. Multiple commonplace sounds of low or moderate intensity cause pain in one or both ear(s) or the head, and this pain is significant enough to warrant clinical attention.
- Note:** Sounds that most individuals find loud and/or uncomfortable, such as a nearby car alarm, a baby crying, or a gunshot, are insufficient to fulfill criterion A (though these sounds may disproportionately affect individuals with hyperacusis).
- B. Unpleasant sound-evoked sensations of loudness and/or pain are present across multiple settings and do not occur solely during episodes of headache, stress/anxiety, bodily pain, sleep deprivation, or acute illness (even if exacerbated by those states).
- C. The individual actively avoids situations or activities that include loud and/or painful sounds, endures these situations with intense discomfort or pain, or requires ear protection (i.e., insert earplugs, supra-aural earphones, and/or active noise cancellation technology) to cope with these situations.
- D. Sound-evoked loudness/pain and/or avoidance of aversive sounds cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- E. The sound-evoked sensations of loudness and/or pain are not better explained by loudness recruitment, superior semicircular canal dehiscence, Ménière's disease, a primary headache disorder (e.g., chronic migraine), or the physiological effects of a substance (e.g., salicylates, sedative-hypnotic withdrawal).

Additional Features Supporting Diagnosis of Hyperacusis (not required for diagnosis)

- Sound-evoked symptom exacerbations (“flare-ups” or “setbacks”) lasting several hours or longer, in which previously tolerable sounds become excessively loud or painful
- Additional sound-evoked symptoms, including ear fullness, ear pressure, vertigo, middle ear myoclonus, hearing changes/distortion, and reactive tinnitus
- Onset after acoustic shock or other noise trauma (less common in autism)
- Loudness discomfort/pain demonstrates asymmetry between ears (less common in autism)
- Uncomfortable loudness levels significantly reduced across multiple frequencies

Figure 1. Operational Diagnostic Criteria for Hyperacusis. These criteria are used in an ongoing research study at Vanderbilt University Medical Center to standardise the clinical diagnosis of hyperacusis. Criteria A–E must all be met for a diagnosis to be given. This diagnosis of hyperacusis subsumes both “loudness hyperacusis” (criterion A1) and “pain hyperacusis” (criterion A2), particularly given the unclear distinction between the two subtypes in terms of underlying pathophysiology. For billing purposes, ICD-10-CM code H93.233 (“Hyperacusis, bilateral”) can be used.

Operational Diagnostic Criteria for Misophonia

- A. Presence of one or more commonplace “trigger” sounds that reliably elicit intense and inappropriate emotional responses, irrespective of sound intensity or perceived loudness.

Note: In accordance with the recent consensus definition of misophonia, these criteria do not require that the individual be triggered by chewing or other oro-nasal sounds.

- B. Trigger sounds reliably evoke feelings of extreme irritation, anger, rage and/or disgust that are clearly excessive, unreasonable, or out of proportion to the circumstances (whether or not the individual recognizes them as such).
- These emotional reactions may be dependent on the context in which the trigger is encountered (e.g., only occurring when the trigger is produced by a specific person), but the reaction should be easily reproducible within that specific context.

Note: Emotional responses to trigger sounds may be accompanied by fear, anxiety, or physical symptoms of sympathetic arousal (e.g., heart pounding, muscle tension, sweating, paresthesias), but in the absence of anger, irritation or disgust, these reactions are insufficient to meet criterion B.

- C. The individual actively avoids situations or activities that include trigger sounds, endures these situations with intense discomfort, or needs to block out potential trigger sounds (e.g., using earplugs, music, or white noise) to cope with these situations.
- D. If unable to avoid trigger sounds or stop them from occurring, the individual experiences a significant loss of self-control, potentially resulting in emotional outbursts or other extreme reactions (e.g., yelling/screaming, running out of the room, panic attacks, rarely physical aggression)
- E. The emotional reactions to trigger sounds are persistent, typically lasting for 6 months or more. Specific triggers do not need to remain constant over this period, but at least one trigger sound must meet both criteria A and B at all times over the preceding 6-month period.
- F. Emotional reactions to trigger sounds and/or avoidance of these sounds cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Additional Features Supporting Diagnosis of Misophonia (not required for diagnosis)

- Triggered by common oro-nasal or throat sounds (e.g., chewing, crunching, sniffing, slurping, breathing, coughing, or throat-clearing)
- Stronger reactions when the triggering sound is made by a family member or close friend
- Stereotypic misophonic reactions that occur in response to stimuli from other sensory modalities (e.g., “misokinesia” in response to repetitive movements)
- Inability or greatly reduced ability to cause a misophonic reaction with self-produced trigger noise
- Symptom onset in preadolescence or early adolescence with no clear causal event
- One or more first-degree relatives who endorses misophonia-like symptoms
- Uncomfortable loudness levels within normal limits or decreased only at specific frequencies that trigger misophonic reactions

Figure 2. Operational Diagnostic Criteria for Misophonia. Criteria are modified from the 2020 Revised Amsterdam Criteria [4], incorporating information from the 2021 consensus definition of misophonia [3]. Criteria A–F must all be met for a diagnosis to be given. These criteria differ from the Revised Amsterdam Criteria insofar as (a) oro-nasal sounds are not required for diagnosis and (b) misophonia can be diagnosed regardless of other psychiatric or neurodevelopmental conditions, provided that all diagnostic criteria are met. Although misophonia is not formally recognised within systems of medical billing, we suggest that the diagnosis be captured under the ICD-10-CM code H93.299 (“Other abnormal auditory perceptions, unspecified ear”).

report that they are triggered at least to some degree by oro-nasal or throat sounds (e.g. chewing, crunching, sniffing, slurping, breathing, coughing, or throat-clearing). A recent expert consensus paper proposed a definition of misophonia for use in clinical and research settings, although concrete diagnostic criteria were not specified [3]. To further support clinicians in making a diagnosis of misophonia, operational research criteria (adapted from the consensus definition [3] and the earlier 'Revised Amsterdam Criteria' for misophonia [4]) are provided in Figure 2.

Although the word ‘phonophobia’ has been used to refer to multiple symptoms and conditions within the medical literature (e.g. hyperacusis, episodic DST associated with headaches, and loudness disturbance due to facial nerve damage) the term here is used to refer to a marked fear or anxiety about specific sounds or situations in which a person might encounter unpleasant sounds [2]. In other words, phonophobia refers to a specific phobia of sound, as defined within the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* [5] and its upcoming text revision (Figure 3). Phonophobia can be circumscribed to very specific sounds or generalised to all sounds with specific qualities (e.g. loud sounds, high-pitched sounds, sudden/unexpected sounds, or sounds associated with a feared object/situation). However, in all cases, the diagnosis is only appropriate if the phobic sound/situation almost always provokes fear and/or anxiety and this fear/anxiety is out of proportion to the danger posed by the specific object/situation.

“Although hyperacusis, misophonia, and phonophobia are all present in the autistic population, there is a notable lack of evidence-based options for diagnosis and treatment of these prevalent and impairing conditions”

Operational Diagnostic Criteria for Phonophobia

A. Marked fear or anxiety about specific sounds or situations in which an individual may encounter unpleasant sounds.

Note: In children, the fear or anxiety may be expressed by crying, tantrums/meltdowns, freezing, or clinging.

B. The feared sounds or situations almost always provoke immediate fear or anxiety.

C. The individual actively avoids the feared sounds or situations, endures these situations with intense discomfort, or requires ear protection (i.e., insert earplugs, supra-aural earphones, and/or active noise cancellation technology) to cope with these situations.

D. The fear or anxiety is out of proportion to the actual danger posed by the specific sound or situation (including the potential to provoke other symptoms such as hyperacusis pain) and to the sociocultural context. Fear or anxiety should also be sufficiently more than would be expected for an individual's developmental level.

E. The fear, anxiety, or avoidance is persistent, typically lasting for 6 months or more.

F. The fear, anxiety, or avoidance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

G. The disturbance is not better explained by the symptoms of another mental disorder, including fear, anxiety, and avoidance of situations associated with panic-like symptoms or other incapacitating symptoms (as in agoraphobia); objects or situations related to obsessions (as in obsessive-compulsive disorder); reminders of traumatic events (as in posttraumatic stress disorder); separation from home or attachment figures (as in separation anxiety disorder); or social situations (as in social anxiety disorder).

Note: Although diagnoses of phonophobia can be made concurrently with diagnoses of hyperacusis and/or misophonia, this additional diagnosis is warranted only in cases where the fear and avoidance are excessive compared to the known risks of pain, hyperacusis exacerbations, or other distressing symptoms caused by the feared sound.

Additional Features Supporting Diagnosis of Phonophobia (not required for diagnosis)

- Significant anticipatory anxiety and avoidance of specific sounds in the absence of clear evidence of loudness disturbance, sound-induced pain, or excessive anger/disgust reactions
- Misophonia-like "fight-or-flight" reaction in the absence of reported anger, irritation, or disgust
- Frequent manifestations of extreme anxiety (e.g., panic attacks, selective mutism) in response to specific sounds
- Ability to tolerate loud sounds increases dramatically when sounds are predictable and under an individual's control
- Co-occurring diagnoses of multiple additional phobias or other anxiety disorders, often with childhood onset
- Uncomfortable loudness levels within normal limits or somewhat decreased due to anticipatory anxiety

Figure 3. Operational Diagnostic Criteria for Phonophobia. Criteria are slightly modified from the DSM-5 criteria for specific phobia [5], with additional information regarding the qualifier of fear out of proportion to the circumstances and the ability for ear protection use to qualify for the "avoidance" criterion. Note that for billing purposes, phonophobia should be coded using ICD-10-CM code F40.298 ("Other specified phobia").

Notably, phonophobia can develop secondary to other DST conditions such as hyperacusis or misophonia. However, in cases where feared sounds result in significant pain, auditory discomfort, or other physical symptoms, an additional diagnosis of phonophobia should be reserved for individuals who experience fear and anxiety to a much greater degree than would be expected for an individual with their same level of hyperacusis/misophonia symptoms. In particularly severe cases of hyperacusis, in which certain sounds may cause extreme pain that persists for multiple days after exposure, fear and avoidance of the aversive sounds is arguably not excessive or irrational, and phonophobia should only be diagnosed if an individual demonstrates the same marked fear of sounds that are not known to greatly exacerbate their hyperacusis symptoms.

Although hyperacusis, misophonia, and phonophobia are all present in the autistic population, there is a notable lack of evidence-based options for diagnosis and treatment of these prevalent and impairing conditions, particularly in young children and individuals with significant cognitive or language impairments. Nevertheless,

even with limited access to a patient's internal experiences, knowledgeable clinicians may be able to make a clear distinction between different subtypes of DST based on consideration of the sounds the patient finds aversive, the degree to which context modulates their reactions, and the presence of observable fear or anxiety in certain situations (see Figures 1-3). With regards to management, strategies should be individualised to the patient's and family's needs and can include modalities such as behavioural or cognitive-behavioural therapy (often with an exposure/habituation component), occupational therapy, sound generators, amplification, medications, use of ear protection in certain situations, and environmental modifications. Though there is insufficient evidence to strongly support any of these interventions for DST in autism, the treatment of this common symptom remains an area of great clinical need. Thus, additional basic and clinical research is desperately needed on DST in autism and other populations to improve the lives of the millions of individuals who experience these often-disabling sound sensitivity syndromes.

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