



What's next for misophonia? Child and parent priorities for misophonia advocacy, treatment, and research

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ABSTRACT

Background: Misophonia is characterized by sensitivity to specific common sounds and associated visual stimuli. Despite a high estimated prevalence in the general population, “misophonia” as a term remains largely unknown by the general population, with research on misophonia treatment still in a nascent stage. This is especially the case in children and adolescents, despite misophonia most often beginning in this time. To guide the growing foundation of misophonia literature, this study seeks to inquire about advocacy, research, and treatment priorities from the perspective of youth with misophonia and their parents.

Methods: In this study, twenty youth with clinically significant misophonia (ages 10–17) and their parents engaged in semi-structured focused interviews. Interviews were transcribed and thematically analyzed using an inductive approach.

Results: Eight themes were identified, including *Advancing Awareness for Advocacy*, *Misophonia is Outside a Child's Control*, *Practical and Misophonia-Specific Therapies Needed*, *Understanding the Neurobiology of Misophonia*, *Defining Misophonia Beyond Sound Triggers*, *Understanding the Daily Impact of Misophonia*, *Uncovering the Misophonia-Mental Health Connection*, and *Long-Term Prognosis*.

Discussion: While some participants' ideas were distinctive to their experience, several themes, described above, emerged across interviews. These findings propose paths forward for future advocacy, research, and treatment development.

Background

Misophonia is characterized by strong emotional, physiological, or behavioral responses to specific sounds or sound-related stimuli [1]. The sounds and visuals, referred to as “triggers”, are most often human-made sounds such as chewing, pen-tapping, or breathing [2–5]. Retrospective studies among adults suggest misophonia most often begins in childhood [6,7], and new research suggests a similar clinical presentation in youth [8], though youth have been typically overlooked in misophonia research. Misophonia can cause tremendous suffering and impacts to quality of life in youth [8,9], and thus developing a better scientific understanding and providing effective treatment are critical priorities to the many individuals who struggle with this condition. To guide the expanding interest in misophonia, this study seeks to elicit the perspective of those affected by the condition. To our knowledge, this is the first qualitative study to inquire about advocacy, research, and treatment needs from the perspective of youth with misophonia and

their families.

Despite recent scientific progress in this field, the lay public generally lacks recognition of the term “misophonia” [10,11], although more people may be familiar with the symptoms without knowing the term [12]. Studies have explored the importance of public awareness of many health conditions including dementia [13], peripheral arterial disease [14], and endometriosis [15], to name a few. While the public may be generally unaware of the term misophonia, the body of misophonia literature has accelerated in just the past few years [16]. That said, there are still tremendous gaps, as basic questions related to the underlying neurobiology and natural course are largely unknown [17].

In line with misophonia being a recently recognized condition, it lacks well-studied or protocolized treatments, with the literature still in early stages [16,18]. Currently, misophonia treatment and management options have been tested across disciplines and include lifestyle modifications, audiologic treatments, psychotherapies, and medications [7,16]. Evidence for misophonia treatment is mostly based on case

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reports and is most abundant for various forms of cognitive behavioral therapy (CBT) [18–26]. The only randomized controlled trial for misophonia to date examined the efficacy of weekly group CBT and showed clinical improvement in misophonia symptoms compared to a waitlist control [6]. Several case reports have documented partial to complete remission of misophonia symptoms with selective serotonin reuptake inhibitors (SSRIs) and remission of misophonia symptoms with targeted pharmacologic treatment of comorbid conditions such as ADHD [27–29]. That said, results from a large survey suggest that parents of youth with misophonia and adults with misophonia are not satisfied with misophonia treatment received by and large, although there is a strong desire to receive treatment [30].

Given the gaps in misophonia knowledge and treatment, those in the misophonia community have the opportunity to inform next steps. The goal of this study was to use qualitative methods to understand the advocacy, treatment, and research priorities of youth with misophonia and their parents. These data center the patient and family perspective to provide a framework for prioritizing efforts to alleviate the impact of misophonia in youth.

Methods

Participants

Twenty parent and child dyads throughout the United States were recruited through postings in misophonia-specific social media groups, outreach to participants of previous research studies, and recruitment through practitioners treating misophonia. Inclusion criteria were: clinically significant misophonia determined using the Misophonia Assessment Interview [22], which was updated in this study to include recent consensus criteria [1]; English-speaking; child aged 10–20 years old and based in the United States. Exclusion criteria were: inability to answer open-ended questions (e.g., in the case of developmental delays) or need for immediate clinical attention due to active psychosis or suicidal ideation.

2.2. Ethical considerations

This study was approved by the Institutional Review Board, and consent was obtained from all parents and assent from all children participating.

2.3. Procedures

Interested participants were first screened for likely eligibility through a phone call. If they were determined to likely be eligible, participants then completed a video visit with a trained interviewer who worked through an informed consent procedure, administered the MAI, and collected demographic information. Next, the interviewer led the participant through a semi-structured interview with questions developed by the investigative team including psychologists with expertise in misophonia and qualitative methods. Interviews were recorded and transcribed with participant consent. Parents and children were interviewed separately in 30-to-60-minute interviews and given \$20 each as compensation for their time.

2.4. Data analysis

We employed a thematic analysis approach to analyze the interviews, using MaxQDA for code and data analysis management [31]. Interviews were analyzed using the following approach: 1) transcribing the interviews, 2) developing codes to identify recurring topics, 3) applying themes to codes, 4) reviewing themes, 5) defining and grouping themes, and 6) producing a report. Analyses were conducted using an inductive approach, i.e., in an exploratory fashion without pre-specified hypotheses or theoretical models. The second and fourth

author applied codes to the first four dyad interviews to measure consistency and refine codes until at least an 80 % overlap was achieved. Then, the authors proceeded to code the rest of the transcripts. A random selection of 20 % of the rest of the transcripts were double-coded to check for reliability and found 82 % agreement. The first author then reviewed excerpts from the “public understanding” and “research/treatment priorities” codes to identify themes (other codes are described in more detail in another manuscript [blinded citation]). Preliminary themes were identified and discussed in weekly meetings with the last authors before being summarized into memos with connections to exemplary quotes. These memos were reviewed with the last author, and subsequently shared with the broader research team for iterative feedback. A first draft of this manuscript was then shared with participants, who provided further input on interpretation and presentation of results.

3. Results

Participants

Youth participants (Age *M* (SD) = 13.45 (2.59)) were primarily female (80 %), White (100 %) and from high SES households (see Table 1 for complete demographics review).

3.2. Advancing awareness for advocacy

When asked what the public and medical community should know about misophonia, participants almost unanimously wanted others to recognize misophonia as a condition and be aware of its potential debilitating effects. One participant expressed:

I Think there’s a lack of awareness that it exists. I mean, even doctors don’t know that it exists. —P004

Table 1
Demographic Characteristics of Participants.

	Parent	Child
Gender		
Female	18 (90 %)	16 (80 %)
Male	2 (10 %)	3 (15 %)
Other	0 (%)	1 (5 %)
Age		
Age (SD)	45.84 (6.194)	13.45 (2.585)
Ethnicity		
Hispanic	1 (5 %)	2 (10 %)
Race^a		
White	19 (95 %)	20 (100 %)
American Indian or Alaskan Native	1 (5 %)	1 (5 %)
Other	1 (5 %)	1 (5 %)
Highest Education		
Some College, no degree	2 (10 %)	
Associate Degree	1 (5 %)	
Bachelor’s Degree	9 (45 %)	
Post Graduate Degree	8 (40 %)	
Relationship Status		
Married	17 (85 %)	
Widowed	1 (5 %)	
Divorced	2 (10 %)	
Employment Status		
Part-Time	5 (25 %)	
Full-Time	6 (30 %)	
Unemployed	8 (40 %)	
Missing	1 (5 %)	
Estimated Household Income		
\$20–29,999	1 (5 %)	
\$50–59,999	2 (10 %)	
\$60–69,999	2 (10 %)	
\$70–79,999	1 (5 %)	
\$80–124,999	4 (20 %)	
\$125,000 and over	10 (50 %)	

^a Participants could endorse more than one race

Participants commonly stated that others do not realize the daily functional impact of misophonia. Participants often expressed that others' lack of awareness leads to the trivializing of their sound sensitivity and underestimation of its impact on tasks such as attending school or spending time with family. One parent described the debilitating impact of sound sensitivity for their child who experienced both aggravation and pain in response to triggers:

It really can be life altering... it can be debilitating and when you hear something that aggravates you and [are] forced to be in an environment where something is literally causing you pain, for someone to just be like, "Oh well, it's not that bad. Just get over it, just deep breathe, or just put your headphones in," – it's sad. — P003

Because many people are not aware of misophonia as a clinically significant condition, participants expressed a reticence to ask for accommodations from those around them. They expressed that a general awareness of misophonia may help a parent of a child or individual with misophonia advocate for accommodations:

I Think there needs to be more awareness about it, so that people with misophonia can be open about it and explain it to people, and it's not like everyone gets all weirded out. So those people can feel comfortable being in public, [and] being like, "Hey, do you mind not eating in class. We're taking a test, I'm really trying to focus right now, this really bothers me." But, you know, I feel really reserved to say anything like that. — C006

3.3. Misophonia is outside the Child's control

Participants reported that others perceive reactions to sound triggers as voluntary and therefore manageable with self-control. For those with misophonia, this sets behavioral expectations beyond what they can meet when faced with a trigger. Many parents highlighted that this is especially the case for children, who should not be developmentally expected to independently manage such overwhelming sensitivities, as this parent describes:

I Would like them to know that it is something the kids cannot control, or the people cannot control. We tend to [view] it, like, 'It bothers me too, so, I control it, why [don't] they control it?' but we have a lot of people saying, "Oh, it's just lack of self-control from the kids." — P019

Parents also expressed that others may attribute reactions to sounds as caused by an external problem such as parental discipline, as this parent explains:

I Would want people to know that it's an involuntary reaction. And that it's not – Because my mom has thought – [that] she's having bad manners, or that I'm not disciplining her enough. It's very involuntary. You can't approach it in the midst of it. So, I think I want people to know it's out of their control. — P001

3.4. Practical and misophonia-specific therapies needed

Participants expressed enthusiasm for any effective intervention, including medications, psychological therapies, and coping strategies. Commonly, participants expressed that because misophonia affects many aspects of a person's day, practical therapies are needed to fit into the child's everyday activities. One parent expressed how a common coping method isn't easily incorporated into daily life:

I'd just like to see technology that really works, ... you're not walking around with these giant headphones on. And something that's discreet. — P017

While most participants generally wanted effective therapy without giving further specification, some expressed frustration at being treated with therapies specified for other conditions, as this participant describes:

It's currently being treated, in our case, as anxiety, and it's a very specific issue, that, I think, needs its own specific therapy. — P001

3.5. Neurobiology of misophonia

When asked about directions for future misophonia research, participants commonly inquired about the etiology of misophonia. Most often, participants wondered what makes the brain of a person with misophonia different than that of those without misophonia with the hope that this could lead to therapeutic innovation. One parent suggests:

Maybe functional MRIs and seeing what happens in the brains when they hear these sounds and compare and contrast with other people who don't have [misophonia]. — P013

Participants not only felt that understanding the etiology of misophonia could help direct therapies, but also serve a psychological benefit for patients and families, as this parent describes:

At least it's like, "OK." It's nothing that I did wrong when he was little or anything like that. — P019

3.6. Defining misophonia beyond sound triggers

While most associate misophonia with sensitivity to sound, several participants experience triggers to sound through other senses such as vision. For example, a person may have a reaction to watching someone chew even if they cannot hear the chewing sound. Several participants wanted more research into this lesser-known aspect of misophonia. As one parent questions:

She can still hear the sounds through the floor and stuff. I'm like, is it a sensation, is it visual? I know that there's another word for like the visual component of that... Is it feeling? Is it a combination of feeling and hearing and seeing? — P015

3.7. Investigating the daily impact of misophonia

In their interviews, most participants discussed the daily difficulties for a person living with misophonia. Some participants want more research into how misophonia affects daily functioning. One participant described this type of research as a top priority:

Really understanding what misophonia is and what a severe impact it can have on the quality of life for someone is the most important thing. — P018

Some participants also desired more research on how a person with misophonia affects the family unit with the hope that this research could lead to strategies for family-based interventions:

Help the family too. So, focusing on that, I think we have to start with the person with it, but then eventually work with the family too because it's huge. — P016

3.8. The misophonia-mental health connection

Participants frequently wondered about the overlap between misophonia and other conditions, having seen co-occurring symptoms. Some participants suggested another research direction for the connection between misophonia and mental health conditions, describing misophonia as causing mental health conditions due to the impact the condition has on quality of life. One participant described how misophonia has affected her mental health:

It really isolates you from society and it's like no one can relate to me. So, I think they really need to be looking into the anxiety and the depression that also comes with this because you get in your own head, and you're

like, “I’m so alone because no one understands what I’m going through.”
— C006

Research on prognosis

Lastly, some participants were interested in research into the time course and prognosis of misophonia. Participants felt that this anticipatory guidance may help families understand what the future could look like for their children with misophonia. One parent expressed their thoughts on their child’s future with misophonia:

Is this something that you can anticipate is going to get better with time, get worse with time? That data is something that if I knew as a parent, then I feel like I could help better prepare my child. — P009

A youth participant also conveyed interest in understanding the long-term course of misophonia:

How it affects you when you first thought about it, or noticed that it was happening, versus a year later, then three years. How it affects you ... throughout your life. — C003

4. Discussion

This is among the first studies assessing the advocacy, treatment, and research needs of youth with misophonia and their parents. Although some participants’ ideas were distinctive to their experience, several persistent themes pose scientific, advocacy, and treatment paths that may have meaningful positive impact on this community. These include the desire for public awareness of the experience of having misophonia, highlighting the lack of control associated with reactions to triggers and its potentially debilitating nature; practical and accessible therapies; research on non-sound triggers, the daily impact of misophonia, the neurobiology of misophonia, and how misophonia relates to other diagnoses; and anticipatory guidance for those with misophonia and their families.

From an advocacy perspective, participants overwhelmingly want the public to recognize the term “misophonia,” know the spectrum of severity (with an emphasis on the clinically significant end of the spectrum), and acknowledge the lack of control those with misophonia, especially children, have over their reactions to triggers. Studies on public awareness of misophonia indicate that most people do not yet recognize the term “misophonia,” although more may be aware of the clinical presentation without knowing the term [11,12]. These studies’ findings are consistent with the experience of participants in our study who described regularly encountering others who are unaware of misophonia and experiencing barriers because of this. Because misophonia reactions exist on a full continuous spectrum, it is likely that many individuals may not understand the potential severity of symptoms and expect that children should simply be able to control their reactions. For individuals with clinically significant misophonia, however, reactions are often perceived as completely outside their control. Recent studies have highlighted a high prevalence of misophonia in the general population, with estimates as high as 20 % when including subclinical populations [11]. Although this is certainly a meaningful step to raise awareness, there is a danger in including subclinical thresholds in this estimate, as it may undermine the experience of individuals with clinically significant misophonia, such as those included in this study, who certainly make up less than 20 % of the population. Because triggers for those with misophonia are often human-made sounds, general awareness of misophonia and adaptive accommodation by others may be crucial to the daily functioning of those with the condition. Efforts to enhance self-advocacy are a clear, immediate priority of the community. For example, the misophonia advocacy group soQuiet offers free misophonia information cards for those with misophonia to share with others [32].

While participants discussed general awareness as a factor in the functional management of misophonia, they also strongly desire accessible and practical treatment. For instance, studies indicate that most people with misophonia use other sounds such as music as avoidance strategies, yet the very high cost of discrete hearing aids that play white noise or music may preclude many from using these devices [2,6]. A few participants described frustration at the lack of misophonia-specific therapies, which contrasts with the transdiagnostic approach taken in some literature [22,33]. It is highly plausible that basic CBT-based strategies are effective for misophonia, though providers likely require more training in its specific application to the difficulties individuals with misophonia commonly face. For example, the only randomized controlled trial of misophonia treatment found significant but still modest efficacy of a misophonia-specific CBT protocol relative to a waitlist control, which included several cognitive behavioral strategies relatively specific to misophonia (e.g., behavioral experiments – a CBT technique applicable across many diagnoses – were used to test beliefs about eating norms) [6]. We also speculate that the sentiment for misophonia-specific therapies may reflect the ability of specific, proven therapies to validate a condition’s disabling effects, a need expressed by participants and previously discussed.

Regarding research priorities, participants’ suggestions largely mirrored those described from the perspective of investigators in Potgieter et al. [7] and Rosenthal, Shan, & Trumbull [34]. Participants frequently discussed interest in more research into the neurobiological underpinnings of misophonia. This is a burgeoning area of research [35–38], which one day may help aid in diagnosis and treatment. Additionally, objectively identifying associations between brain functioning and misophonia symptoms may help validate the experience of those with misophonia and their families by presenting evidence of neurologic difference [39]. Participants highlighted the importance of misophonia being recognized as a condition not attributable narrowly to a behavioral, personality, or parenting problem, which may be aided by neurobiological perspectives. That said, it is of utmost importance to continue to consider the psychological and social components misophonia to develop a well-rounded understanding and avoid the pitfalls of a neuroreductionist perspective.

Participants also expressed interest in expanding the literature on misokinesia, a less common symptom of misophonia in which the trigger is the sight of seeing someone’s repetitive motions. When noted in the scientific literature, misokinesia is often mentioned briefly as a symptom of misophonia and remains understudied [4]. Participant’s emphasis on the importance of misokinesia to understanding the phenomenology of misophonia suggests that investigators may consider misokinesia when conceiving of future research.

In consideration of the potentially debilitating ways misophonia can affect a person’s daily activities, participants requested more research on the daily impact of misophonia, including research on how misophonia affects family dynamics. Storch et al. [40] found that many parents were unaware of how best to support their child with misophonia and suggested that maximizing adaptive accommodations and supportive communication while reducing more maladaptive accommodations could be one avenue. Parent participation has been linked to positive outcomes in therapy for other conditions and may serve as an important intervention for misophonia given the large role of the family in youths’ lives [41]. Parental noises are often the primary trigger in youth with misophonia, further highlighting the need to involve the family. Studies investigating the role of the family in therapy for misophonia could help establish the family as an important facilitator of successful misophonia therapy.

Also on participants’ list of research priorities was more understanding about the connection between misophonia and other conditions such as anxiety or other decreased sound tolerance syndromes such as hyperacusis, a topic also frequently debated within misophonia literature. Some studies note associations between misophonia and other conditions, while others argue that misophonia is a unique

condition that may be present with another condition, yet not associated [4,6,8,42–44]. Alternatively, investigators have suggested emotion regulation difficulties as the link between misophonia and other conditions such as depression and anxiety [45,46]. Regardless, given the high prevalence of mental health conditions in the general youth population [47] and possibility of transdiagnostic therapy as described above, screening for other conditions when a patient presents with misophonia is warranted. Therapies such as the Unified Protocols for Transdiagnostic Treatment of Emotional Disorders in Children and Adolescents may be particularly suited for youth with misophonia and co-occurring emotional disorders [22] although additional study is necessary. It must also be considered that youth with misophonia may experience anxiety or depression secondary to their functional impairment from misophonia, as people with misophonia have been shown to be at risk for a lower quality of life [9,48]. This experience has been articulated on factor analyses of misophonia questionnaires such as the “pessimism” factor on the Misophonia Assessment Questionnaire (MAQ) and the “internalizing” factor found on the S-Five [11,49].

Lastly, participants were frequently interested in understanding the prognosis and natural history of misophonia for a youth. Although many reports have identified the onset of misophonia in childhood or adolescence, the natural history of misophonia is not known due to a scarcity of longitudinal or prospective studies [1]. In consideration of the impact of misophonia on quality of life and its impact on the family unit, studies investigating the natural history of misophonia could help individuals and families anticipate and plan for future challenges.

This study has important limitations. First, the sample included self-selected, predominantly White, female youth and parents with high education levels. Future research could gather the perspectives of a sample more representative of the general population and expand the network of family members contributing to the interviews (e.g. siblings, fathers, grandparents). Furthermore, it's possible that answers given by participants about research direction is affected by knowledge of the current literature and the study they were participating in, so future research could also assess participants' knowledge to gauge this source of potential bias.

This study was the first qualitative analysis of youth with misophonia and their parents' perspective on advocacy, research, and treatment needs. Important directions for advocates, clinicians, and researchers arose throughout the interviews and highlighted the community's desire for awareness of the impact of misophonia on the patient, need for practical and accessible therapies, and interest in further characterizing the condition including etiology, symptoms, associated co-occurring conditions, daily impact, and natural history. Crucially, these findings underscore the importance of continued progress in the field of misophonia as patients and their families have here described how further advocacy, research, and treatment could meaningfully affect their experience living with misophonia.

Consent to participate

Informed consent was obtained from all parent participants and assent from all children participants.

Author contribution statement

All authors have made substantial contributions to the conception or design of the work; or acquisition, analysis, or interpretation of the data. Furthermore, all authors drafted or critically revised the work, approved the final draft for submission, and agree to be accountable for its accuracy and integrity. Specifically, **Katherine Abraham** contributed to formal analysis, writing – original draft, writing – review & editing. **Catherine Rast** contributed to methodology, investigation, data curation, and writing – review & editing. **Eric Storch** contributed to conceptualization, methodology, and writing – review & editing, and supervision. **Andrew Guzick** contributed to conceptualization,

methodology, investigation, formal analysis, writing – review & editing, and supervision.

Ethics approval

This study was approved by the Baylor College of Medicine Institutional review Board. The procedures used in this study adhere to the tenets of the Declaration of Helsinki

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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