



# Clinical Considerations for Integrating Ethical Principles of Beneficence in the Development of Evidence-Based Interventions: The case of Pediatric Misophonia

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## Abstract

Misophonia is a condition involving decreased tolerance and intense responses to specific sounds, often those that are human-generated and repetitive in nature. Misophonia frequently onsets during childhood and is associated with significant distress, impairment, and diminished quality of life. While misophonia research remains nascent and no definitive practice guidelines exist at present, extant studies offer several promising potential avenues in intervention development for adults with misophonia. However, such research is comparatively limited for youth. Before widespread adoption of promising treatments, it is important to consider the potential for harm or non-beneficence that may arise from the misinformed application of such treatments. In this article, we identify several potential pitfalls within intervention development for pediatric misophonia and provide recommendations to circumvent them. To that end, we focus on the following three topic areas: (a) challenges arising when psychological mechanisms are not considered in intervention development, (b) importation of a cognitive-behavior therapy (CBT) framework for obsessive-compulsive spectrum disorders without nuanced tailoring to misophonia, and (c) neglecting to include individuals with lived experience in the process of intervention development research. Considering these key areas within misophonia intervention development will be critical for upholding beneficence and minimizing harm in treatment of misophonia across the lifespan.

**Keywords** Misophonia · Youth · Harm · Exposure · Cognitive Behavioral Therapy (CBT) · Community-based Participatory research

Misophonia is a condition characterized by increased sensitivity to specific sounds (i.e., triggers)– or visual cues related to sounds– that elicits intense negative emotional, physiological, and/or behavioral responses (Swedo et al.,

2022). Trigger sounds are typically human-generated and repetitive in nature (e.g., chewing, breathing, pen clicking). Emotions arising in response to triggers can include anger, anxiety, and disgust, and are often accompanied by physiological reactions such as muscle tension, increased heart rate, and other forms of sympathetic nervous system activation (Rosenthal et al., 2022). For many individuals, misophonia often results in significant impairment in functioning, including difficulties managing arousal from triggers (e.g., life-narrowing avoidance and/or escape from situations in which triggers are present; Jager et al., 2020). Individuals with misophonia often report experiences of helplessness in response to the intensity of physical and emotional responses (Dozier & Morrison, 2017), experience diminished quality of life (Möllmann et al., 2023), and report challenges within familial and social relationships (Remmert et al., 2022). While most research on misophonia has occurred in adult populations, misophonia frequently

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onsets in childhood and/or adolescence (Claiborn et al., 2020; Guzick et al., 2023). Given the importance of early intervention for altering the trajectory of symptoms across the lifespan (e.g., Tourette Syndrome; Espil et al., 2022), research focusing on misophonia in youth is clearly an important priority.

As conceptualization, assessment, and intervention efforts within youth misophonia remain nascent, researchers and clinicians face unique opportunities with regard to shaping evidence-based practices in this area (Rosenthal et al., 2023). Within psychological science, such opportunities inevitably come with the important responsibility to uphold the highest ethical standards with regard to understanding and minimizing harm and maximizing beneficence for those we serve (American Psychological Association [APA], 2002; Dimidjian & Hollon, 2010). Accordingly, it is critical to balance consideration of intervention efficacy (e.g., symptom reduction) with recognition of potential for non-beneficence and harm when developing and refining interventions (Lilienfeld, 2007). In order to balance the *scope* (i.e., applicability) of clinical considerations for integrating ethical principles in the development of evidence-based interventions with *depth* (i.e., nuanced application to a specific condition), in the present article we consider the case of pediatric misophonia. To that end, in this article, we: (a) provide a brief overview of misophonia and available interventions, and (b) identify several potential pitfalls within intervention development for pediatric misophonia and provide recommendations for circumventing them.

## Misophonia: An Overview

Several emerging studies have evaluated the prevalence of misophonia but most focus on adults and employ retrospective recall for ascertaining onset, which makes it challenging to obtain a precise understanding of prevalence in youth. For example, studies of undergraduates ( $N=483$ ; Wu et al., 2014) and medical students ( $N=336$ ; Naylor et al., 2021) found that the prevalence of mild and moderate misophonia symptoms ranged from between 12 and 37%. As another example, the estimated prevalence within a representative adult sample from the United Kingdom ( $N=396$ ) was 18% (Vitoratou et al., 2023). However, a larger study of German adults ( $N=2,519$ ) found a prevalence of 5.9% (Jakubovski et al., 2022). More recently, a nationally representative sample of 4,000 U.S. adults yielded a 4.6% prevalence rate of clinically significant misophonia (Dixon et al., 2024). However, the lack of diagnostic consensus across academic disciplines and differences in methodological practices across studies make it challenging to accurately capture prevalence.

In youth, misophonia has historically been linked to obsessive-compulsive spectrum conditions, including obsessive-compulsive disorder (OCD; Reid et al., 2016) and tic disorders (Robinson et al., 2018), as well as other mental health conditions (e.g., anxiety and/or mood disorders; Guzick et al., 2023). However, emerging evidence suggests that misophonia likely represents a discrete condition marked by psychological processes that distinguish it from other concerns (e.g., the presence of anger/disgust rather than obsessive-compulsive patterns characteristic of OCD; McKay et al., 2018). In further support of a psychological conceptualization of misophonia, several studies have found that significant percentages of well-characterized samples of youth with misophonia have co-occurring mental health concerns, with mood and anxiety disorders among the most common (Guzick et al.; Siepsiak et al., 2022). Notably, in these studies, OCD is not among the most frequent comorbidities. Similar findings have emerged in a recent study of adults with misophonia, which revealed that anxiety and mood disorders (with social and generalized anxiety in particular)—and not OCD—were among the most frequent comorbid conditions (Rosenthal et al., 2022). Audiological research also suggests that misophonia is a distinct condition, albeit with similarities to other audiological conditions such as tinnitus and hyperacusis (Jastreboff, 2011; Jastreboff & Jastreboff, 2002). Lastly, from a neurobiological perspective, recent evidence suggests that misophonia symptoms may result from overconnected and/or reactive affective and attentional neural networks (Neacsiu et al., 2022). Overall, research across disciplines suggests that misophonia is a distinct condition from other co-occurring mental health conditions (McKay & Acevedo, 2020; Taylor, 2017). However, more work is needed to refine conceptualization, assessment, and treatment of misophonia—particularly in youth.

## Emerging Interventions for Misophonia

The bulk of the misophonia treatment literature highlights psychosocial approaches as the primary intervention modality (Mattson et al., 2023; Rosenthal et al., 2023). A large portion of this work has focused on adult populations, with relatively less intervention development efforts focused specifically on youth. For adults, one large ( $N=90$ ) non-randomized clinical trial found cognitive behavior therapy (CBT) to be generally efficacious for reducing misophonia severity (Schröder et al., 2017). A randomized controlled trial (RCT) ( $N=71$ ) found improvements from weekly group CBT as compared to a waitlist condition ( $d=1.97$ ; Jager et al., 2021). Lastly, a recent pilot trial of Barlow's Unified Protocol (Barlow et al., 2018) adapted for misophonia demonstrated preliminary evidence of acceptability and efficacy (McMahon et al., 2023). Aside from these trials,

there have also been a range of case studies describing treatments for misophonia in adults with variable response rates, including CBT with and without exposure, counter-conditioning therapy, tinnitus retraining therapy, eye movement desensitization and reprocessing (EMDR), and medication (see Mattson et al. for a review).

Despite misophonia reportedly emerging in childhood and/or adolescence, there is a dearth of research articulating treatment for youth with misophonia. Extant case studies have primarily employed variants of traditional and “third wave” CBT approaches (e.g., acceptance and commitment therapy [ACT], dialectical behavior therapy [DBT]). Within case studies of CBT, adolescent patients reported improvements ranging from 33 to 58% on misophonia rating scales (e.g., McGuire et al., 2015; Reid et al., 2016), alongside improvements in sound tolerance and life interference (e.g., Muller et al., 2018). Case studies examining ACT and/or DBT have yielded similar findings, with patients reporting over 50% reduction in misophonia symptoms and significant improvements in valued living (e.g., Kamody & Del Conte, 2017; Petersen & Twohig, 2023; Schneider & Arch, 2017). Additional treatment models include family-focused CBT-based approaches (Dover & McGuire, 2023) and adaptations to Barlow’s Unified Protocol for youth with misophonia (Lewin et al., 2021), with both approaches demonstrating preliminary efficacy. At present, to our knowledge, no published RCTs in youth with misophonia have been completed; however, several are in progress (see Lewin et al., 2021; Rappoldt et al., 2023 for descriptions of the protocols for ongoing RCTs).

Moving forward, rigorous RCTs with representative samples are needed to further elucidate efficacious treatments for youth with misophonia. Additionally, marked differences in considerations for youth-focused interventions compared to adults (e.g., involvement of families and/or teachers) will necessarily require careful adaptations in light of developmental factors. Previous efforts in developmentally nuanced downward adaptation of evidence-based intervention packages for adults—such as Barlow’s Unified Protocol (Barlow et al., 2018)—to youth (Ehrenreich-May et al., 2018) may also serve as a guide for the development of interventions for pediatric misophonia (see Lewin et al., 2021 for a promising example of this).

### **Importance of Addressing Potential for Harm & Upholding Beneficence**

Given the burgeoning nature of youth misophonia research, it is important to understand and address the potential for harm that may unintentionally occur when not fully appreciating the unique nature of the condition. Despite general efforts in the field to promote ethical practice (APA, 2002),

preventing harm and/or non-beneficence in psychological treatments for children is often not explicitly taken into consideration. Furthermore, when the prevention of harm and non-beneficence has been discussed and researched, it has historically occurred within the realm of adult psychotherapy (e.g., McKay & Jensen-Doss, 2021), yet remains relatively understudied within psychosocial interventions for youth. Such disparities are especially important for emerging conditions such as misophonia that necessarily possess a smaller evidence base and current absence of definitive practice guidelines (Ferrer-Torres & Giménez-Llort, 2022; Rosenthal et al., 2023). For example, a well-intentioned clinician providing treatment to a child with misophonia may employ cognitive-based techniques initially developed for adults without nuanced developmental tailoring, which may result in needless continued suffering. Some additional potentially harmful consequences could involve symptom worsening, opportunity costs, and unwarranted reductions in positive treatment outcome expectancies (Dimidjian & Hollon, 2010). Thus, it seems worthwhile to examine misophonia intervention development efforts from the perspective of understanding and addressing the potential for harm from inappropriately applied interventions.

Fortunately, researchers have an opportunity to approach this work with thoughtful attention to the perspectives and needs of those with lived experience, in combination with the best available scientific evidence. Informed by existing frameworks of evidence-based practice (e.g., Kazdin, 2007; Lilienfeld, 2019; Spring, 2007), it will be critical to ensure that interventions are being thoughtfully developed and implemented to protect youth with misophonia from harm and/or non-beneficence. Said another way, in order to achieve the important goal of developing equitable, compassionate, and efficacious interventions for youth with misophonia, a careful understanding of the potential for harm and non-beneficence is necessary (Dimidjian & Hollon, 2010; Lilienfeld, 2007).

Towards this goal, we have identified several potential pitfalls—and ways to address them—within misophonia intervention development research. Specifically, we identify (a) challenges arising when psychological mechanisms are not considered in intervention development, (b) importation of a cognitive-behavior therapy (CBT) framework for obsessive-compulsive spectrum disorders without nuanced tailoring to misophonia, and (c) neglecting to include individuals with lived experience in the process of intervention development research, as critical areas to consider for upholding beneficence and minimizing harm in treatment of misophonia across the lifespan.

When discussing these potential pitfalls and ways to address them, we want to emphasize our guiding framework of intellectual humility, equipoise, and appreciation

of diverse scientific and lived experience perspectives (Washburn et al., 2022). As scientists and clinicians who have dedicated significant time and energy to helping individuals with misophonia and their families, we believe that psychological science has something to offer for alleviating suffering in afflicted individuals. However, as discussed throughout this article, we contend that it is also essential to thoughtfully consider the perspectives of a wide range of individuals (and their loved ones) who have lived experience with misophonia, as well as work to foster inclusivity and community partnership throughout the research process (Wallerstein et al., 2020). Our hope is that such partnerships— and with them reciprocal, open communication from both sides— will foster the development of efficacious and acceptable interventions for youth with misophonia and their families.

### **Pitfall #1: Challenges Arising when Psychological Mechanisms are not Maximized in Treatment Development**

The biopsychosocial model of neurobiological, psychological, and environmental factors offers a potentially useful explanatory framework for conceptualizing the underlying mechanisms of misophonia (Rosenthal et al., 2023). Concerning the former, a robust line of research has implicated a range of neurobiological and neurophysiological correlates of misophonia (e.g., Hansen et al., 2022; Kumar et al., 2017, 2021; Schröder et al., 2019; see Neacsu et al., 2022 for a recent review). While research on neurobiological mechanisms of misophonia has potential to increase our understanding of the condition, such biologically based mechanisms may be relatively less malleable via intervention compared to psychological ones.

With regard to psychological mechanisms underlying misophonia, a range of attentional/perceptual, cognitive, affective, and behavioral processes have been elucidated to date, including generalized sensory sensitivity (Andermane et al., 2023), emotion regulation difficulties (Guetta et al., 2022), context-dependent perceptual processes (Samermitt et al., 2022), cognitive/social judgments (Hansen et al., 2024), and perceived stress (Guetta et al., 2024), to name but a few. While research investigating psychological mechanisms of misophonia is growing, more rigorous work in this area is needed to further our understanding of these processes. Some examples of future directions in this area include use of larger, more racially and ethnically diverse samples; strategic use of control/comparator conditions; and prospective studies using ecological momentary assessment. Additionally, linking basic research on psychological mechanisms to specific intervention principles that can precisely target them is paramount to further develop and

refine interventions for misophonia. Receipt of sub-optimal or benign interventions due to the failure to consider key mechanisms in their development may result in opportunity cost, wasted resources, and sustained suffering of patients and their families (Dimidjian & Hollon, 2010; McKay et al., 2021).

Below, in an attempt to link salient psychological mechanisms of misophonia to intervention development efforts, we provide a brief, non-exhaustive overview of several candidate mechanisms within the broad categories of cognitive and behavioral processes. While it is likely that cognitive, behavioral, and neurobiological processes dynamically interact and are not mutually exclusive of one another (Brout et al., 2018), the use of a cognitive-behavioral framework seems especially useful, as this conceptual model has demonstrated promise in nascent misophonia intervention development efforts (Lewin et al., 2021; Schröder et al., 2017). Such an approach may further the goal of more precisely linking evidence-based intervention principles to relevant psychological mechanisms underpinning misophonia.

### **Cognitive Mechanisms**

Affective experiences common to misophonia may shed light on cognitive mechanisms underpinning the condition. More specifically, the emotions of anger and disgust often elicited by triggers are predicated on an interplay of attentional biases, cognitive interpretations, and subjective experiences of affect (Savard et al., 2022). Antecedents for experiences of anger or moral disgust in misophonia likely involve a complex interaction between attentional biases to potential misophonia trigger situations (e.g., hypervigilance toward dinnertime noises) and cognitive interpretation of the extent to which the trigger sound represents a social norm violation (e.g., sibling chewing with her mouth open) or is within the volitional control of the person generating the sound (e.g., “she’s chewing extra loud in purpose to annoy me”). Thus, it is plausible that antecedent attentional biases and cognitive interpretations influence the magnitude of the affective response (Brout et al., 2018; McKay & Acevedo, 2020).

Additional cognitive factors that could perpetuate misophonia symptomology include the perceived uncontrollability of triggering events or low self-efficacy for adaptive coping with trigger situations (Frank & McKay, 2019). Relatedly, recent experimental work has demonstrated that interpretation of noise source plays a role in influencing emotional response to misophonia triggers (Heller & Smith, 2022; Samermitt et al., 2022). It is also worth noting that such cognitive processes identified here have been predominantly studied in adult populations, which means that caution is needed when generalizing these findings to youth.

Such caution is especially important in light of developmental considerations with regard to verbal articulation of misophonia-related thoughts and emotions. One additional caveat bearing mention is the notably heterogeneous range of cognitive processes described here, which span the gamut of attentional, perceptual, and higher-order cognitions. While we use the overarching term ‘cognitive’ for the sake of parsimony, more work is needed to unpack the potential differential implications of the variety of aforementioned processes.

In light of these promising candidate mechanisms of misophonia, several therapeutic skills/strategies have been developed to target such processes. For example, behavioral experiments have been designed to foster expectancy violations regarding low self-efficacy in one’s ability to cope with triggers and cognitive restructuring; defusion principles may address antecedent automatic thoughts or unhelpful interpretations concerning trigger situations (Lewin et al., 2021; Petersen & Twohig, 2023). However, these techniques often exist within larger multicomponent treatment packages (e.g., Lewin et al.). Thus, their specific dose/frequency can be difficult to quantify, making elucidation of the differential efficacy of specific components challenging. As such, in future investigations of these techniques, it will be important to accurately measure cognitive mechanisms using psychometrically sound rating scales and behavioral tasks. This could also be accomplished through developing and testing brief, focused interventions or via use of temporally dense measurement strategies precisely linked to use of such cognitive techniques.

### Behavioral Mechanisms

Within behavioral conceptualizations of misophonia, one foundational mechanism is reinforcement learning (a specific type of associative learning) that involves pairing a particular behavior with a positive outcome (i.e., a reward or the removal of an aversive experience). In particular, youth with misophonia may seek to avoid or escape anticipated or actual trigger situations to receive momentary relief from negative affective states or sensory experiences (i.e., experiential avoidance; Cowan et al., 2022). This removal of the aversive experience (i.e., negative reinforcement learning) serves to self-amplify the salience of triggers and sensitize the individual to more intense reactions to similar situations in the future. Such avoidance also has the effect of diminishing flexible behavioral responding in valued life domains and reducing quality of life (Frank & McKay, 2019). Essentially, the individual’s life can become (unintentionally) disproportionately structured around avoiding trigger situations rather than pursuit of what matters to them.

For youth with misophonia, this process of negatively reinforced avoidance behavior can sometimes manifest within the context of family accommodation, which is defined as (typically well-intentioned) behavior on the part of parents and loved ones to excessively arrange family structure/activities in service of facilitating repertoire-narrowing avoidance of trigger situations for the afflicted youth (Storch et al., 2023). However, much of the research on family accommodation to date has been conducted with youth fear and anxiety-related conditions (Shimshoni et al., 2019), and the extent to which family accommodation applies to misophonia remains an open empirical question. Another point bearing mention is that the term family accommodation might confuse maladaptive with *adaptive* accommodation, and thus a critical revision of the term as it applies to misophonia may be warranted.

Despite the promise of experiential avoidance as a key behavioral mechanism underlying misophonia, a note of caution is called for with regard to potentially over-pathologizing adaptive avoidance or skillful accommodation. To that end, it is critical to emphasize the distinction between maladaptive experiential avoidance that results in reduced contact with values-based goals (Hayes et al., 1996), and skillful advocacy behaviors on the part of an individual with misophonia to improve quality of life through structuring their environment to reduce trigger exposure (Gregory, 2023). Blanket application of the former as a mechanism underpinning misophonia runs the risk of invalidating the laudable– values-based– self-advocacy efforts inherent in the latter. Instead, returning to the original conceptualization of experiential avoidance (Hayes et al., 1996), which emphasizes the unique functional and contextual factors influencing an individual’s behavior in a given moment, may guide researchers and clinicians toward obtaining a more accurate understanding of the behavioral mechanisms underpinning misophonia. From an ACT perspective (Hayes et al., 2012), workability– or the extent to which a given behavior helps an individual move toward what matters to them in life– could be a useful guide for discerning the specific situations when avoidance of misophonia triggers may be adaptive/skillful versus detrimental/unhelpful (Spencer et al., in press).

### Path Forward #1: Promoting Evidence-based Practice and Attenuating Pseudoscience

With an eye toward dissemination and implementation efforts, it will be important not to overprioritize basic mechanistic studies at the expense of advancing applied intervention research. This is especially critical given the lack of definitive practice guidelines for youth misophonia at present. On the one hand, jumping into a treatment modality

before research support has accumulated can be detrimental. However, on the other hand, it can also be considered non-beneficial to wait too long or be too reticent to engage in treatment research or proffer intervention recommendations (Dimidjian & Hollon, 2010). Relatedly, the significant amount of suffering present for individuals with misophonia and their families, coupled with the lack of first-line interventions, can lead to the adoption of non-evidence based and pseudoscientific approaches (vs. approaches that merely have limited evidence). For example, similar to challenges within treatment for posttraumatic stress disorder (PTSD; Cox & Codd III, 2023), we have anecdotally observed recent proliferation of non-evidenced based approaches for misophonia, including emotional freedom techniques (i.e., tapping), brainspotting, untested apps, and full-length books on particular approaches without evidence beyond anecdotal support.

Once these approaches exist in the public, and particularly if there is a paucity of (or not well-disseminated) science-informed treatment options, these dubious interventions can gain traction and become entrenched, similar to what Cox and Codd III (2023) describe within PTSD. It can then be difficult to change public opinion later on when alternative interventions with scientific backing are developed. In fact, proliferation and adoption of psychosocial interventions lacking in empirical support and/or with dubious rationales constitutes a form of harm to patients and their families in terms of opportunity costs and untreated mental health concerns (McKay & Coreil, 2024). Thus, it is important to strike a balance between reciprocally informed basic science/mechanistic and applied intervention research, rather than a disproportionate emphasis on one or the other. As discussed earlier, a more nuanced understanding of cognitive and behavioral mechanisms of misophonia— and intervention techniques that can precisely target them— may be one promising avenue to further such a balance.

### **Pitfall #2: Importation of a CBT Framework for Obsessive-Compulsive Spectrum Disorders without Nuanced Tailoring to Misophonia**

As discussed above, recent research has demonstrated that misophonia likely represents a distinct condition (McKay et al., 2018; Neacsu et al., 2022), although its current classification status remains an open question (Swedo et al., 2022; Taylor, 2017). As such, efficacious interventions for misophonia will necessarily possess some nuanced differences from treatment packages designed for existing conditions (e.g., DSM-defined psychiatric disorders). As researchers continue to develop and test candidate interventions, it will be important to keep this in mind so as not to fall into the

trap of rote importation of CBT treatment packages without proper tailoring to the nuances of misophonia.

### **Dubious Support for Classifying Misophonia as an OCD**

While it has been argued that the circumscribed stimulus-response phenomenology of misophonia shares some overlap with OCRDs (Schröder et al., 2013), emerging research has suggested that misophonia is a condition notably distinct from OCD (McKay et al., 2018; Spencer et al., 2023). Unfortunately, this initial conceptualization of misophonia within the OC spectrum led to the inadvertent mistaken assumption that an off-the-shelf administration of OCD-focused treatment would be efficacious for misophonia. Although several case studies have demonstrated preliminary support for exposure therapy from an OCD framework for misophonia (e.g., McGuire et al., 2015), there is a growing consensus that exposure-based treatment delivered in the classic, habituation-focused format often used in treatment of OCD is relatively less applicable to misophonia (Frank & McKay, 2019; Rosenthal et al., 2023).

Several consequences have resulted from this initial conceptualization and push to treat misophonia as if it were a subtype of OCD. First, given the large research-to-practice gap (Balas & Boren, 2000; Williams & Beidas, 2019), there is a risk that clinicians may continue to approach misophonia treatment with this mindset for some time, similar to the challenges regarding dissemination of evidence-based approaches for PTSD described earlier (Codd III & Cox, 2023). Second, as a result of treating misophonia similarly to OCD, anecdotal evidence indicates that there has been somewhat of a backlash within the misophonia community against anything linked to OCD (and by extension, exposure principles). That is, those in the misophonia community are (understandably) especially sensitive to suggestions that misophonia might be similar to OCD and/or that it might benefit from exposure predicated on a habituation-based model. Such a response may be especially valid given the significant frustration associated with the lived experience of a discrepancy between therapeutic instruction emphasizing habituation via exposure and the actual lived experience of a failure to habituate. As a result, many misophonia advocates reject all aspects of OCD treatment and conceptualizations (Allergic to Sound, 2019; Smith et al., 2022). This makes it increasingly difficult to engage in the research needed to examine whether *certain* elements of OCD treatment, including nuanced adaptations of exposure principles, might be efficacious for misophonia (Frank & McKay, 2019).

## Challenges in Rote Importation of Existing Therapeutic Strategies for Misophonia

In order to inform intervention development efforts and adequately uphold beneficence in clinical practice, it is important to continuously cultivate a bi-directional link between science and clinical practice. To that end, CBT principles have demonstrated success for alleviating suffering due to a range of mental health issues (Fordham et al., 2021), and therefore represent an excellent starting point in misophonia intervention development work. However, as discussed earlier in *Pitfall #1*, when developing and testing interventions for an emerging condition such as misophonia, forming a cohesive underlying theory and linking proposed intervention strategies to candidate mechanisms are essential (Kazdin, 2007). Further research is needed to critically evaluate what aspects of a given intervention package (e.g., ACT, Barlow's unified protocol) are most relevant and efficacious for misophonia, rather than importing principles from such packages atheoretically without any (or minimal) tailoring.

For example, as described earlier, initial misophonia intervention development efforts examined classic exposure approaches, often implemented similarly to how one would do so for anxiety disorders and OCD (e.g., McGuire et al., 2015; Reid et al., 2016). However, there are key differences between misophonia and anxiety disorders (Guzick et al., 2023), including the primary emotions elicited by triggers, that have important implications for treatment (Schneider & Arch, 2015). If one looks more closely at these differences and maps them onto the underlying mechanisms targeted in treatment, it makes sense that anxiety disorders and misophonia might demand slightly different treatment approaches. In a similar vein, exposure principles for misophonia will likely require nuanced adaptation compared to fear-based conditions. This can include emphasizing inhibitory learning principles, or flexible “approach behaviors” consistent with goals and values, rather than a singular focus on habituation (Frank & McKay, 2019; McGuire & Storch, 2019). Said another way, shifting from an emphasis on habituation toward reduction of unhelpful avoidance behavior and bolstering self-efficacy in distress tolerance may help individuals with misophonia lead fulfilling lives (Rabasco & McKay, 2021).

Moving forward, it will be important to take the time to develop and test the underlying theory and mechanisms prior to diving into applied intervention testing too deeply, and to have the intellectual humility to adjust accordingly (Washburn et al., 2022). Relatedly, if an intervention kernel does not perform in an expected way, willingness to consider other options, while simultaneously trying to identify why— or what aspects of— the approach do not work, will be essential for building a progressive clinical science of

misophonia. This will enable continuous refinement of conceptualization and treatments, while avoiding “throwing the baby out with the bathwater” when unexpected findings emerge.

## Path Forward #2: Upholding Beneficence and Minimizing Harm in Exposure for Youth Misophonia

In situations where clinicians are faced with providing treatment in areas such as misophonia where the evidence base remains limited, it is important to have a strong case conceptualization/theoretical model, as well as collaboratively engage the patient and their family in the process of treatment planning. This ultimately creates a reciprocal dialogue and shared vision for treatment success and sustained recovery. Such an approach aligns with the ethical imperative to minimize harm and maximize beneficence (APA, 2002).

Unfortunately, if a clinician unintentionally assumes the role of expert with treatment being delivered in a unilateral manner, this can lead to unintended consequences. For example, without providing a nuanced and thoughtful rationale for exposure tailored to misophonia, youth may be likely to engage in subtle avoidance or safety behaviors throughout the exposure (e.g., covering their ears, looking away, or white-knuckling-it through exposure). They may also develop more negative attributions about their triggers (e.g., “this is never going to get better”), or could react impulsively (e.g., leaving the room, throwing a pen off the desk). A child engaging with exposure in this manner is *unlikely* to have a salutary expectancy-violating experience (e.g., “this was just as bad as I thought it would be,” “I knew I couldn't handle it”) and may feel hopeless about their prognosis. In contrast, if a child (and family) are engaged throughout the conceptualization and treatment planning process, they can build trust with a therapist to implement exposures alongside other effective coping strategies in the context of the treatment plan. Indeed, exposure may be helpful for reducing the detrimental impact of misophonia, as has been reported in numerous case studies and pilot trials described earlier.

## Pitfall #3: Neglecting to Include Individuals with Lived Experience in the Process of Intervention Development Research

As misophonia treatment research is at its infancy, there is a tremendous opportunity to partner alongside youth with misophonia and their families to guide intervention development research. Such efforts will undoubtedly improve intervention acceptability, relevance, and outcomes. Collaborating with youth suffering from misophonia and their family members through every step of the scientific process

stands in contrast with traditional top-down, researcher-driven method of intervention development (Collins et al., 2018). Although the latter method has led to the development of many evidence-based psychotherapeutic approaches (Fordham et al., 2021), the potential drawbacks of this approach have been increasingly recognized. Interventions developed in tightly controlled academic settings are often not easily implemented in community contexts, widening health disparities among marginalized and underserved communities (Collins et al.; Masuda et al., 2024). Further, failure to engage individuals with lived experiences has resulted in interventions that the affected community may consider ineffective, irrelevant, or—in some cases—even harmful (Anderson, 2023; Leaf et al., 2022). Thus, including youth with misophonia and their families on the *front-end* of clinical research, and incorporating their voices at every stage of the scientific process, can minimize the potential for harm. This will help us move toward the ultimate goal of establishing equitable, relevant, compassionate, and efficacious practices for youth with misophonia.

### Applied Behavior Analysis for Autistic Youth: A Case Study of a Field Improving with Lived Experience Perspectives

The field of applied behavior analysis (ABA) for autistic children provides a useful example of how a top-down clinician-centered framework can inadvertently lead to potentially harmful treatment. ABA has demonstrated efficacy for reducing challenging behaviors that are common among autistic youth, including self-harm or aggression, as well as bolstering development of adaptive behaviors such as those involving self-care or verbal communication (Anderson & Carr, 2021). That said, recent years have witnessed a severe backlash against ABA from many self-advocates in the autism community (Leaf et al., 2022). Many autistic adults who were treated with ABA as youth remember their experiences as emotionally painful, humiliating, or punishing, with the harms far outweighing the benefits (Anderson, 2023). Adults recall being forced to hide or “mask” autism symptoms and internalize emotional distress during ABA, which they believe in many cases led to mental health difficulties and poorer academic performance long-term (Anderson). Many ABA interventions that had been accepted in the professional community are now being challenged, leading to new recommendations that center client preferences alongside scientific evidence (Anderson & Carr). This example nicely illustrates how meaningful intervention development efforts may not solely be predicated on directly reaching a specific destination (e.g., reducing challenging behaviors). Rather, for successful intervention development in the long-term, it is important to engage those people who are on the journey toward recovery in determining which paths we

take to get there, as sometimes the most direct ones may have unintended consequences.

### What Constitutes a Harmful Treatment in Misophonia?

It is possible that we could end up in a similar place in the misophonia community. As discussed throughout this article, exposure therapy has become a controversial psychological intervention in the misophonia community, with some self-advocates adamantly opposing this approach (e.g., Allergic to Sound, 2019). Online misophonia support groups are filled with anecdotes of symptom exacerbation following exposure therapy, and in a survey of hundreds of parents of youth with misophonia, exposure therapy was rated as the least acceptable treatment option (Smith et al., 2022). Thus, from a community-centered perspective, we might consider the possibility of abandoning research into exposure therapy entirely, as it is *clearly* true that many youth are sensitized to triggers after participating in exposure. Conversely, there are *clearly* many youth with misophonia who have benefitted from exposure therapy, as this is among the most common techniques described in the emerging clinical literature, which has predominantly consisted of successful case studies (Lewin et al., 2021; Mattson et al., 2023). In fact, in one recent pilot study with adults (McMahon et al., 2023), exposure was included as part of a multicomponent CBT treatment protocol. In qualitative feedback solicited by McMahon et al., participants found the therapy to be acceptable, including the inhibitory learning-based exposure module, as it enabled them to “practice their skills in situations that feel challenging or bring up intense emotions,” (p. 15), essentially experientially demonstrating the capacity to handle situations once deemed intolerable.

This leaves this field in a difficult place. To that end, many self-advocates view exposure as a harmful treatment for misophonia. However, based on the scientific literature (e.g., Frank & McKay, 2019; Rosenthal et al., 2023) and the clinical experience of many psychologists (including ourselves), exposure appears to be among the most promising and clinically intuitive intervention kernels for this condition. Given this disparity, one might be worried that psychotherapy for misophonia is headed in a similar direction as ABA was for autistic youth decades ago. One way to potentially address this issue and bridge the gap between differing perspectives could be through qualitative research investigating the perspectives of individuals with misophonia who have had both positive and negative experiences with exposure-based treatments.

Within the field of clinical science writ large, several existing misconceptions may hinder the uptake of exposure for pediatric conditions where it is indicated (Reid et al., 2018). That is, the term “exposure therapy” often evokes



thoughts of immediate prolonged exposure to the most extreme triggers (i.e., flooding), which is unpopular among clinicians as well as patients (Becker-Haimes et al., 2023). Of course, a well-intentioned therapist would not conduct exposure this way, especially for youth, who often benefit from self-efficacy building experiences with exposure to situations where they are likely to be successful. Thus, finding new terms for exposure that more accurately describe what is done during therapy might be an important initial step for improving literacy. To that end, Becker-Haimes et al. have proposed the term *supported approach of feared experiences (SAFE)* and found that such terminology was rated favorably by clinicians for the purposes of communicating with patients and their families. More work is needed to ascertain the extent to which this terminology may be useful within misophonia.

As highlighted in *Pitfall #2*, many clinician-researchers have contrasted habituation-based exposure, which emphasizes continuous exposure to a situation until habituation is achieved, with inhibitory learning-based exposure, which includes elements of exposure that are likely to maximize inhibitory learning, or the strengthening of associative learning between trigger noises and tolerability, safety, or other non-aversive outcomes. This, in turn, *inhibits* aversive associations (e.g., trigger and negative affect) (Frank & McKay, 2019; McGuire & Storch, 2019). Inhibitory learning-based exposures may be more likely to be successful for youth with misophonia and anxiety disorders alike—as they do not set the expectation for physiological habituation to occur for the therapeutic exercise to be successful. Indeed, it seems possible that many anecdotes from individuals with misophonia concerning negative experiences with exposure are based on experiences with traditional habituation-focused exposures.

### **Path Forward #3: Community-Based Participatory Research as One Solution**

Although both re-branding and updating the theoretical rationale for exposure hold promise, these are inherently researcher-driven solutions to the issues we describe. Some self-advocates may instead believe the best solution would be to abandon exposure entirely. Another path to resolving questions related to treatment approaches like exposure is for clinicians and scientists to partner with youth with misophonia, their parents/caregivers, as well as affected adults. This approach would help ensure treatment development and routine clinical practice have the highest likelihood of maximizing benefit and avoiding harm.

Leveraging existing established frameworks delineated in community-based participatory research (CBPR) may prove useful in these efforts (see Collins et al., 2018;

Wallerstein et al., 2020 for extensive explication of CBPR approaches). This methodology explicitly involves affected communities in each step in the research process. An example of CBPR can be drawn from the qualitative work of Masuda et al. (2024), who integrated perspectives of Native Hawaiians (NH) with depression, NH cultural leaders, and clinicians serving NH patients with existing evidence-based clinical practice. These efforts were put forth in service of developing a culturally safe therapist training program to improve NH patient health and well-being. Qualitative methodologies, inclusion of stakeholder perspectives throughout the research process, and culturally humble self-reflection, as outlined in Masuda et al., may represent useful starting points for extending CBPR approaches to pediatric misophonia.

Ongoing partnerships between researchers and individuals with misophonia can facilitate processes that ensure their priorities, cultural knowledge, and perspective are well-represented. Individuals with lived experience may contribute to funding priorities, questions being asked in research, the methods used to answer those questions, and how scientific findings are interpreted and presented to both scientific and lay communities (Wallerstein et al., 2020). This process will help ensure research is mutually beneficial to clinicians and individuals and families who have lived experience with misophonia. In the spirit of this approach, we have sought and incorporated feedback on this paper from a layperson with lived experience of family members (including a child) with misophonia (J.P.S.). Such feedback proved invaluable to us as we worked to thoughtfully develop, articulate, and refine the ideas presented in this article.

### **Summary & Future Directions**

While still in its infancy, the burgeoning misophonia literature is promising for both its scientific rigor and decided focus on developing interventions to alleviate suffering in youth with misophonia and their families. In the present article, we reaped the benefits of this work by considering both *internal* (i.e., mechanisms of misophonia, specific intervention techniques) and *external* (i.e., dissemination and implementation efforts, community-based participatory research methods) validity of the emerging misophonia intervention development enterprise. Furthermore, framing our discussion of ways to advance misophonia intervention development through the lens of considering the potential for harm and upholding beneficence allowed us to highlight several areas of challenge (i.e., pitfalls) and recommendations (i.e., paths forward) for addressing these issues.

Before proceeding with summative recommendations for future misophonia research, we note some considerations regarding the applicability of the framework used in the

present article for integrating ethical principles in the development of evidence-based interventions, broadly considered. While we chose to focus on pediatric misophonia, the topics addressed here are germane to a range of interventions and populations. Indeed, several of the seminal works in this area (e.g., Dimidjian & Hollon, 2010; Lilienfeld, 2007; McKay & Jensen-Doss, 2021) provide conceptual accounts concerning the potential for harm in psychological treatments writ large. That being said, we believe that depth and specificity are also important vis-à-vis the application of said principles to specific conditions, such as pediatric misophonia. Essentially, focus on a specific condition permits a more concrete illustration of abstract conceptual principles, and allows for specific recommendations to promote ethical practice in the development of evidence-based interventions for that condition (Lilienfeld, 2019; Spring, 2007). In terms of future directions for upholding ethical principles across a range of conditions, it seems important to balance both specific application (i.e., precision, depth) with scope (i.e., broad applicability).

Several caveats also bear mention with regard to the framework used in the present article for integrating ethical principles in the development of evidence-based interventions for misophonia. While the three pitfalls and paths forward discussed herein are grounded in previous work on identifying and addressing potential for harm in psychological treatments (Dimidjian & Hollon, 2010; Lilienfeld, 2007), the choice of topics here were guided by our collective clinical and research expertise in misophonia. As such, these topics are not considered to be exhaustive, and a range of other considerations for intervention development in misophonia may be worthy of future investigation. Some examples of these include: (a) the extent to which candidate mechanisms underlying misophonia could be treated outside the scope of psychological practice (e.g., the role of sound tolerance in tinnitus retraining therapy; Jastreboff, 2011); (b) the importance of idiographic assessment and intervention for misophonia in light of significant variability in cooccurring mental health conditions and generalized sensory sensitivity; and (c) the need for research that includes diverse representation of all people, rather than a disproportionate focus on those who identify as White and female. Relatedly, it is important to highlight that the pitfalls and paths forward discussed in the present article may not inherently be both necessary and sufficient for treatment development. Therefore, equipoise and open-mindedness to alternative perspectives and ethical considerations will be critical for growing a generative clinical science of misophonia (Washburn et al., 2022).

In terms of moving the field forward toward eventual coalescence on practice guidelines for gold-standard interventions for pediatric misophonia, we offer the following

take-home messages. First, it will be important to consider cognitive and behavioral mechanisms underlying misophonia— and the extent to which specific treatment techniques can precisely and powerfully engage these mechanisms— within the development of comprehensive intervention packages. Correspondingly, it will be critical to tailor intervention strategies in a developmentally appropriate way for maximal impact. Second, a nuanced understanding of historical challenges in conceptualizing misophonia as an OCD may aid our ability to skillfully tailor exposure principles in a way that aligns with the basic science of misophonia. This approach will also be more likely to respect the perspectives of a diverse range of individuals with lived experiences. Relatedly, a deeper understanding of behavioral learning principles within misophonia could shed light on the critical distinction between unhelpful avoidance behavior and skillful accommodation. This may allow for maximal impact of values-based and inhibitory learning-informed exposure approaches. Finally, including the voices of those with lived experiences with misophonia throughout the research process will be important for developing, implementing, and disseminating efficacious and acceptable interventions for youth with misophonia. We hope that consideration of the complexities and potential pitfall areas described in this paper will facilitate upholding beneficence and minimizing harm in treatment of misophonia across the lifespan.

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## Compliance with Ethical Standard

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**Informed Consent** Since this article was a conceptual/theoretical review, informed consent was not applicable, as no data were collected from participants.

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