# A Large-Scale Study of Misophonia

Romke Rouw 101 and Mercede Erfanian2

Objective: We aim to elucidate misophonia, a condition in which particular sounds elicit disproportionally strong aversive reactions. Method: A large online study extensively surveyed personal, developmental, and clinical characteristics of over 300 misophonics. Results: Most participants indicated that their symptoms started in childhood or early teenage years. Severity of misophonic responses increases over time. One third of participants reported having family members with similar symptoms. Half of our participants reported no comorbid clinical conditions, and the other half reported a variety of conditions. Only posttraumatic stress disorder (PTSD) was related to the severity of the misophonic symptoms. Remarkably, half of the participants reported experiencing euphoric, relaxing, and tingling sensations with particular sounds or sights, a relatively unfamiliar phenomenon called autonomous sensory meridian response (ASMR). Conclusion: It is unlikely that another "real" underlying clinical, psychiatric, or psychological disorder can explain away the misophonia. The possible relationship with PTSD and ASMR warrants further investigation. © 2017 Wiley Periodicals, Inc. J. Clin. Psychol. 0:1–27, 2017.

Keywords: misophonia; ASMR; disorder; sound; synesthesia

#### Introduction

At the start of the new millennium, Jastreboff and Jastreboff (2001) coined the term *misophonia* in a review paper on auditory disorders. These authors define misophonia as a condition in which individuals react negatively to specific patterns of sound and/or to sounds that occur in specific situations or settings, whereas they tolerate other sounds that are frequently much louder (Jastreboff & Jastreboff, 2014). The small number of empirical studies that have been conducted on misophonia showed common properties of the misophonic condition (Edelstein, Brang, Rouw, & Ramachandran, 2013; Kumar, Hancock et al., 2014; Schröder, Vulink, & Denys, 2013; Wu, Lewin, Murphy, & Storch, 2014). Common misophonic triggers are human-generated sounds such as chewing and sniffing. However, each misophonic will have his or her own unique set of triggers, which may also include different types of sounds or even particular visual stimuli, such as leg swinging (Edelstein et al., 2013; Schröder et al., 2013; Johnson et al., 2013b).

Critical aspects of the condition are disproportional aversive responses to the trigger, awareness that this response is disproportionate, and no clear physical feature (such as the loudness of the sound) to explain the response (Jastreboff & Jastreboff, 2014). Instead, it seems that the meaning, social context, or interpretation of the trigger influences the response to these noises (Bruxner, 2015; Schröder et al., 2013). This definition distinguishes misophonia from other auditory-related conditions (Møller, 2011; Jastreboff & Jastreboff, 2015), such as tinnitus (hearing an often ringing sound when no sound is present), hyperacusis (a generally increased sensitivity to sound), and phonophobia (fear of a specific sound). Current treatments for

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Please address correspondence to: Romke Rouw, Brain and Cognition, Department of Psychology, University of Amsterdam, Amsterdam, The Netherlands, Postbus 15915, 1001 NK. E-mail: R.Rouw@uva.nl

<sup>&</sup>lt;sup>1</sup>University of Amsterdam

<sup>&</sup>lt;sup>2</sup>Maastricht University

misophonia include cognitive behavioral therapy (Bernstein, Angell, & Dehle, 2013; McGuire, Wu, & Storch, 2015; Schröder, Vulink, van Loon, & Denys, 2017), tinnitus retraining therapy (Jastreboff & Jastreboff, 2014), and counter conditioning (Dozier, 2015a). Although beneficial effects have been reported, there is a general consensus that further evaluations and specific quantitative studies are needed to examine the results and effectiveness of treatments (Jastreboff & Jastreboff, 2014; Cavanna & Seri, 2015; Cavanna, 2014; Johnson et al., 2013b). Furthermore, a better understanding of the condition and its behavioral and neurophysiological characteristics are needed to improve effective treatment and management strategies.

On Web of Science, there are currently 37 publications on the topic of misophonia. Of these publications, only nine are before 2013. In 2013, misophonia received an increased amount of attention from both inside and outside the scientific community (see www.huffingtonpost.com; metro.co.uk; www.nytimes.com; www.washingtonpost.com). As described above, scientific efforts have succeeded in outlining the types of associations and responses that define misophonia.

Furthermore, findings that cannot be exaggerated or "faked" have helped in establishing credibility of the condition. In particular, misophonia comprises a clear and distinct set of characteristics and complaints (Schröder et al., 2013; Edelstein et al., 2013; Wu et al., 2014). The reported disproportional aversive experience has been validated by finding an increased autonomic response (as measured with GSR¹) to trigger sounds, but not to corresponding visual stimuli, in misophonic participants compared with nonmisophonic participants (Edelstein et al., 2013). Furthermore, the reported sensory sensitivity has been corroborated with an altered early physiological signal (auditory N100) measured in an oddball paradigm with electroencephalogram (Schröder et al., 2014).

Despite these recent scientific advances, we know little about the causes and underlying mechanisms of misophonia. At the theoretical level, different models have been proposed (see Cavanna & Seri, 2015). However, very few experimental (neuroimaging, experimental psychology, psychophysiology, large-scale behavioral) studies have been conducted. One neuroimaging study came out very recently, relating the misophonic response to hyperactivity of the anterior insula and abnormal functional connectivity of this region with medial frontal, medial parietal, and temporal regions. Furthermore, it showed altered interoception in misophonics. These authors concluded that abnormal salience attributed to certain sounds, combined with atypical perception of internal body states underlies misophonia (Kumar et al., 2017; see also the Discussion section). Despite this important step forward, the limited number of (neuroimaging) studies does not yet allow drawing firm conclusions on the explanatory power of the different theoretical models. Although there are different viewpoints on misophonia, three fundamental questions need to be answered when unraveling the mechanisms involved in it.

One question is whether misophonia could be induced in any person, perhaps following the development of conditioned responses (Ferreira, Harrison, & Fontenelle, 2013; Jastreboff & Jastreboff, 2002). Alternatively, there may be certain characteristics (e.g., genetic predisposition or a neurological or psychological anomaly (Cavanna & Seri, 2015; Ferreira et al., 2013) that make a person more receptive or even predisposed to misophonia. Because not all misophonics report the same severity of symptoms, a related issue is whether certain individual characteristics or other clinical, psychiatric or psychological conditions affect the severity of the misophonic symptoms.

This brings us to the second question: What is the relationship of misophonia to other clinical, psychological, or psychiatric conditions (see Cavanna & Seri, 2015)? Is misophonia an idiopathic condition? Or is it related to (an)other condition(s)? Or is misophonia even perhaps only a symptomatic manifestation of another underlying "real" disorder? Although comorbidity with other conditions has been obtained (e.g., Ferreira et al., 2013; Kluckow, Telfer, & Abraham, 2014; Schröder et al., 2013), it is not yet clear if these co-occurrences are coincidental or not.

The third question pertains to the specificity of misophonia. Do misophonic complaints relate to a general cognitive and/or emotional divergence, for example, diverging processes in the

<sup>&</sup>lt;sup>1</sup>Galvanic skin response.

auditory domain or abnormal emotional processes? A mechanism proposed to underlie misophonia is increased functional connectivity between the auditory and the limbic system (Jastreboff & Hazel, 2004; Johnson et al., 2013b). In the Jastreboff model, misophonia involves not only conscious but also subconscious pathways, the latter governed by the principle of conditioned reflexes and playing a role in overactivating the limbic and autonomic nervous systems (Jastreboff & Jastreboff, 2014). This could imply that a general mechanism is involved in several types of conditions including tinnitus (Jastreboff, & Jastreboff, 2002) or obsessive-compulsive disorder (OCD) and Tourette syndrome (Webber, Johnson, & Storch, 2014). However, explanations could also be on a more specific level, for example, if there are only highly specific trigger-to-response associations without a more general underlying cognitive/emotional divergence (that could relate misophonia to other conditions).

This latter characteristic reflects a similarity between misophonia and the autonomous sensory meridian response (ASMR) and synesthesia conditions. The types of trigger (inducer) and response (concurrent) differ between these conditions; they all share the characteristic of highly specific and individually tailored trigger-to-response associations. ASMR is a phenomenon in which particular audio and visual stimuli will evoke pleasant, relaxing, and euphoric experiences, typically accompanied by tingling sensations on the scalp, neck, and spine.

As far as we know only one scientific study has investigated ASMR (Barratt & Davis, 2015). It reports that common triggers in ASMR are whispering, personal attention, crisp sounds, and slow movements, and that ASMR may provide temporary relief from pain or stress. Furthermore, a high prevalence of synesthesia was observed in subjects in the ASMR group. These authors suggest a possible link between ASMR, misophonia, and synesthesia. In synesthesia, a particular sensory stimulus (known as an inducer) evokes another seemingly unrelated sensation (known as a concurrent; Ramachandran & Hubbard, 2001; Rouw & Scholte, 2007). A common type of synesthesia is grapheme-color synesthesia, in which a particular letter or number evokes a particular color. The synesthetic experience is specific, consistent, and automatic (in the sense that it does not take effort to evoke the experience), and people report to have had it for as long as they can remember. There are clear parallels between these conditions because they all involve strong sensations, which moreover tend to be experienced as pleasant or unpleasant, being evoked by particular stimuli. Remarkably, the evoked additional sensations cannot be easily explained by the stimulus properties alone. Moreover, the conditions all tend to be explained in terms of increased cross-connections. Currently, the relationship between the three conditions is not vet clarified.

In this study, we will explore characteristics of the misophonic condition. Using an online study, we surveyed a large number of participants with misophonic complaints. This approach allowed us to identify the factors or characteristics most clearly related to the presence or the severity of the condition. The current study combined different approaches: it examined numerical data and open-answer questions and used hypotheses testing and exploratory (hypothesisgenerating) analyses. Data collection methods were always structured; questionnaires were fixed and evaluated in exactly the same way for each participant. Furthermore, the multiple choice questions allowed for easy numerical comparison. In contrast, the open-ended questions allowed for exploring the problems, sensations, and experiences of misophonia. Thus, the study combines hypotheses testing and quantitative data collection, with exploratory research to develop new ideas and hypotheses. Furthermore, the current approach is *not* based on, or dependent on, clinical diagnoses for each individual. Instead, we aimed to find patterns between the misophonic complaints and other personal and psychological characteristics. We therefore recruited based on reported complaints and did not draw conclusions on clinical implications.

First, we measured the severity of the misophonic symptoms. The large group of participants allows for examining the distribution and overall range of misophonic complaints. Wu et al. (2014) found that 20% of their entire sample of undergraduate students reported that misophonia caused significant interference in their lives. In contrast, clinical studies such as Veale (2006) and Schröder et al. (2013) stress that the severity and pattern of symptoms justify misophonia to be considered a subgroup, or even a separate clinical (as defined in the *Diagnostic and Statistical Manual of Mental Disorders*; 5<sup>th</sup> ed.; *DSM-V*; American Psychiatric Association [APA], 2013) category. We included questionnaires about emotional and physical responses and the effect

misophonia has on their life so that we can also examine if these different aspects of misophonia correlate.

Next, we explored the etiology of misophonia by asking participants about the onset of their symptoms and examining the relationship between misophonia and other environmental, developmental, and familial traits. We explored how often misophonia is reported to run in families. While currently there is little literature on the condition, we were able to formulate hypotheses based on previous empirical findings or theoretical suggestions. This included the age at which the first symptoms appeared. The specific hypotheses regarding onset of symptoms in middle childhood was derived from a previous study (157 participants filled-in a questionnaire), in which subjects reported a mean age of onset at 12 years (Kumar et al., 2014), and a study in which subjects reported a mean age of onset at 13 years (Schröder et al., 2013).

Another hypothesis was that the participants would report symptoms as getting worse over time (Edelstein et al., 2013; Kluckow et al., 2014; Bernstein et al., 2013), supposedly caused by the negative reinforcement provided by the reactions to the trigger (Jastreboff & Jastreboff, 2014). We also tested hypotheses related to environmental influences, in particular substance abuse. Alcohol has been reported to alleviate the intensity (Edelstein et al., 2013), whereas caffeine might have the reverse effect. This was found with a small group of subjects, but our current study allows for testing these hypotheses in a larger misophonic population (Cavanna & Seri, 2015).

Finally, we examined comorbidity with other clinical, psychological, or psychiatric conditions. There have been reports of misophonics experiencing altered processing at the auditory/sensory level (Wu et al., 2014; Schröder et al., 2014; Edelstein et al., 2013) and comorbidity with other hearing-related conditions (Cavanna & Seri, 2015; Møller, 2011). On the other hand, misophonia has been defined as a separate condition, and standard hearing tests show normal hearing in misophonic individuals (Schröder et al., 2013).

We also explored the relationship between misophonia and psychological, clinical or neurological conditions. Edelstein et al. (2013) found through interviews that some subjects described symptoms related to OCD, attention deficit disorder (ADD), or posttraumatic stress disorder (PTSD). A similarity between misophonic behavior and compulsive spectrum characteristics has been noted by several authors (Johnson et al., 2013b; Ferreira et al., 2013; Schröder et al., 2013; Webber et al., 2014). Schröder et al. (2013) reported that half of their subjects met the criteria for OCPD, a condition we inquire about in our questionnaire.

We also included questions about eating disorders. Kluckow et al. (2014) reported cases of individuals with a combination of misophonia and eating disorders, and they suggested testing the prevalence of this combination. This is particularly interesting given that the most common misophonic triggers are eating sounds. We test if reports on current or previous eating disorders are present in misophonics, and if the presence or absence of eating conditions seems to interact with misophonic mechanisms (as measured in severity of the misophonic symptoms). Although this relationship is an interesting and important question, the large differences reported so far in symptoms, proposed etiology, and theoretical explanations caused us to predict that eating disorders do not provide an explanation for, and are not related to, the misophonic condition. A connection between misophonia and tinnitus has been suggested (Neal & Cavanna, 2013), given the phenomenological similarity between misophonia and the sensory phenomenon of unpleasant sensations (Crossley & Cavanna, 2013), which provide involuntary urges to tic in patients with tinnitus. In our questionnaire, we explore the relationship between misophonia and hearing conditions.

Wu et al. (2014) studied a large group of undergraduate students and found an association between misophonia and general conditions such as depression, OCD, and anxiety. Ferreira et al. (2013) suggested that misophonia is better described as a symptom of OCD, generalized anxiety disorder, or schizotypal personality disorder. While we can rely only on self-report, we do ask participants about comorbidity with other conditions. The rationale is that if there is indeed a condition or disease with a particularly strong relationship to misophonia, it should reveal itself in this large participant group. It should show a stronger association with misophonia than the other comorbid diseases (which are present only by coincidence). These relationships are examined in our exploratory analyses.

Finally, we include explanations and questions about ASMR and synesthesia. In this study, we will test whether participants with misophonic complaints also experience these other conditions, in which a particular stimulus evokes an unusual or disproportional response. Little is known about misophonia, ASMR and synesthesia, yet a relationship between these conditions has been predicted in literature (Edelstein et al, 2013; Barratt & Davis, 2015) and the shared characteristics of the conditions invites further exploration.

#### Method

Participants received a link to an online test. The test was performed through a secure administration (Qualtrics software) and took between 20 and 30 minutes to complete. The study was approved by the ethical committee of the University of Amsterdam.

After clicking the link, participants first received information about the aim of the study, its procedures, confidentiality of research data, and on how to contact the experimenter or a member of the ethical committee. An informed consent document was given to participants, who declared to have read and understood the general information, take part voluntarily, and have understood the fact that they can stop their participation and withdraw their consent, anytime, and without any consequences. The experiment started if the participant gave his or her consent.

The online experiment comprised 55 items, including yes/no questions, multiple answer questions, and open-ended questions. Participants answered by clicking on the corresponding answer with their mouse or typing in their answer (in the case of open-ended-answer questions). Participants were asked about a variety of categories: demographic characteristics; the age of onset of their misophonic responses; if (and when) the participant had received a misophonia diagnosis; auditory triggers; possible changes, over time, of their misophonic responses; their family history in misophonia and other conditions or disorders; coping strategies; effects of substances on misophonic responses; emotional and physical properties of their misophonic responses; visual triggers; possible presence of synesthesia; possible diagnoses with another condition or disorder; possible presence of ASMR; the nature of their misophonic triggers; provoked thoughts during a misophonic response; the effects misophonia had on their life; and possible additional information they would like to share about their misophonia (an open-ended question).

At the end of our test, we presented previously published misophonia tests: Misophonia Activation Scale (MAS-1; Fitzmaurice, 2010, Kluckow et al., 2014, Dozier, 2015a), Misophonia Physical Sensation Scale (MPRS; Bauman, 2015), and Amsterdam Misophonia Scale (A-MISO-S; Schröder et al., 2013; 1. time, 2. interfere, 3. distress). In our test, the same types of questions do not always succeed each other, to counter automatic answering or answer biases. At the end of the experiment, participants had the opportunity to write down any additional questions or remarks, and we thanked them for their participation. Participants could leave their e-mail address to receive more information about the research project and a general report on the results of this study. The results of the experiment are presented below in four subsections: Participants, Severity of Symptoms, Developmental and Familial Traits, Prevalence and Comorbidity.

#### **Participants**

A total of 385 participants were recruited, 84 of whom did not complete the questionnaires and were thus excluded from further analyses. Participants were recruited online on various websites and forums. We recruited participants from the "Selective Sound Sensitivity" Yahoo group (see https://groups.yahoo.com/neo/groups/Soundsensitivity/info), which comprised patients from the Oregon Tinnitus and Hyperacusis Treatment Clinic. Recruiting this group enabled us to reach out to a large group of misophonics, including those with a clinical diagnosis.

There were few online groups when we first set up this study; however, since then there has been a huge upswing in attention toward misophonia. We also recruited participants from two

international Facebook misophonia support groups; one of the earliest and largest Facebook group for people with misophonic complaints, and a group dedicated to ongoing interaction between patients and clinicians or researchers. (https://www.facebook.com/groups/misophoniasupport/, https://www.facebook.com/groups/misophoniatreatment/).

Because these online locations bring people together based on those very specific types of complaints that we wished to examine, the websites and forums allowed us to recruit a very large group of participants. Although this approach is necessary to recruit a large number of this particular type of participants, it does imply that there is no random sample of participants, and that all measurements are based on self-report. These limitations needed to be taken into account in all our conclusions (see also the Limitations section).

Note that unbiased selection is extremely difficult for any study that aims to test a very large (international) group. To be able to include over 300 subjects in our study, we had to recruit specifically at a designated place that would allow us to get as many potential misophonics as possible. Recruiting in a general (nontargeted) population would have meant testing several thousands of individuals to find a sufficient number of people with misophonic complaints. The current participant group furthermore already had an interest in the topic and their decision to participate was based solely on their own motivation to contribute to misophonia studies. Thus, our approach discouraged the participation of less motivated and less serious participants.

The recruitment procedure led to a large and international group of participants. Participants were not paid and participation was completely voluntary. There is no complete consensus yet on the exact diagnosis of misophonia, and no clear and agreed-upon clinical definitions (or *DSM-V* criteria) exist. However, in this study, we are interested in the relationships with misophonic complaints rather than setting a sharp cutoff (clinical) diagnosis. Therefore, we examined all participants who self-report on suffering from misophonic complaints, and the range of severity of complaints was a factor in our analyses.

## Severity of Symptoms: Emotional, Physical responses, and Effect on Life

In this section, we describe the questionnaires that were used to measure the severity of misophonic complaints. All these materials were designed by other researchers and have been reported in previous studies. Relatively few studies have appeared on misophonia and much is still unknown about the condition. Accordingly, it is not yet fully determined which questions or items best predict or describe the misophonic condition. Questionnaires cannot lean on a tradition of methodological research, and the validity and reliability of the questionnaires need to be further studied. The current study is a step in this direction, which was set up to further our understanding of the misophonic condition and advance the development of misophonic measurement methods. We examined the misophonic measurements by including several questionnaires, from different studies and different authors. We also measured different aspects of the misophonic complaints. To further our understanding of the misophonic condition, we tested a large subject group and added wide-ranging additional questions. This approach allowed us to retrieve a broad perspective on the condition and further the development of misophonia measurement methods.

Misophonic complaints: Emotional. The MAS-1 (Fitzmaurice, 2010; Kluckow et al., 2014; Dozier, 2015a), retrieved from misophonia-UK.org, measures the severity of responses to misophonic triggers, focusing on emotional responses. Participants are presented with 11 levels of responses to misophonia, with higher levels reflecting increasingly severe effects. Participants indicate which is the highest level they still recognize as their own responses. The last level, 12, is the "other" category, created so that participants have the flexibility to put any alternative choices or remarks here. Participants need to provide one answer only; the minimum score is 1 (for level 0) and the maximum score is 11 (for level 10), with other scored as missing (see the Results section for further explanation).

Misophonic complaints: Physical. On the MPRS (Bauman, 2015), participants indicated physical sensations relating to their misophonia. The question of "PHYSICAL sensation to your

misophonia (emotional response to certain sounds)" was followed by 11 scales, increasing in reported intensity of the experiences (see the Results section for exact phrasing of scales). Participants were allowed to indicate multiple answers because we felt these physical sensations might be multifaceted. The 12<sup>th</sup> option was an open-ended question: "Please use space below if you'd like to add any extra information about your misophonia."

To avoid confusing a 0 score with a missing value, the lowest level (level 0) was scored with 1 point and the highest level (level 10) was scored with 11 points. A 12 indicated that the participant had chosen "Other" (see the Results section). Using multiple answers allowed us to compare relative frequency of certain physical sensations. If further analyses required a score (see the Results section) that measured individual differences in physical intensity, then we took the highest scale recognized by the participant as his or her score.

Misophonic complaints: Effect on life. The A-MISO-S (Schröder et al., 2013) is based on the Yale–Brown Obsessive-Compulsive Scale (Y-BOCS; Goodman et al., 1989). Participants indicated the severity of their symptoms by choosing one of five levels, with higher scores reflecting more severe effects (0 = none to 4 = extreme). We presented three of the A-MISO-S subscales

The first subscale asks: "How much of your time is occupied by misophonic sounds? (How frequently do the [thoughts about the] misophonic sounds occur?)." The second subscale asks: "How much do these misophonic sounds interfere with your social or work (role) functioning? (Is there anything that you don't do because of them? If currently not working, determine how much performance would be affected if patient were employed)." The third subscale asks: "How much distress do the misophonic sounds cause you? (In most cases, distress is equated with irritation, anger, or disgust. Only rate the emotion that seems triggered by misophonic sounds, not generalized irritation or irritation associated with other conditions)."

On each scale, the minimum score is 0 and the maximum score is 4. For further analyses, the mean score of the three subscales is calculated per person.

# Developmental and Familial Traits

We present participants with the following question: "How old were you since you started experiencing the misophonic symptoms?" Participants could not only choose an answer from one of five categories (as long as I can remember, childhood, 8–10 years old, early teenage years, 17) but also describe more specifically when the misophonia started (other, please explain). The open-ended answers allowed participants to report answers that do not fit with any of the categories, as well as providing information in addition to indicating one of the predefined categories. As for further studies, it is useful to work with particular age categories; answers that did clearly indicate a certain time in life were rated as belonging to a certain age category. Based on the predefined categories and the 42 provided answers, five answer categories were created (the boundaries that defined categories for answers to the open-ended questions are displayed in italics).

- 1. as long as I can remember (and answers referring to 2, 3, or 4 years of age).
- 2. childhood

(with age limits between 5 and 12)

- 3. early teenage years, 17 (with age limits between 13 and 17)
- 4. Adult

(18 years of age or older)

5. Don't know/other

We furthermore presented the following question: "Do you think the results have worsened over time?" Participants indicated yes, no, or stay the same. There was also an opportunity to provide a written answer (other, please explain). The development or change over time of

misophonic complaints was furthermore examined by analyzing the relationship between age of the subject and the severity of misophonic symptoms.

Based on previous reports (Cavanna & Seri, 2015), we devised questions to examine if misophonia runs in the family. Unfortunately, we could inquire about misophonia running in the family only to the best of the participants knowledge. We asked: "Do any family member(s) have similar symptoms?" Participants indicated no, unknown, or yes. If a participant answered affirmably, he or she was asked to elaborate and indicate exactly which family members.

# Prevalence and Comorbidity

Other conditions. The question "Have you been diagnosed with any other psychiatric conditions?" was followed by 10 different types of clinical items. Eight items, as well as no or other (please explain), were chosen based on the misophonia literature at the moment of setting up this study. The different items were as follows: tinnitus; obsessive compulsive personality disorder (OCPD); hyperacusis; auditory processing disorder; ADD; posttraumatic stress disorder (PTSD); exploding head syndrome (EHS); phonophobia. We asked: "Have you ever experienced or been diagnosed with any eating disorders?" Participants chose among four answers: yes - anorexia nervosa; yes - bulimia nervosa; other (please explain); no.

Another question probing comorbidity was "Have you ever experienced or been diagnosed with selective mutism? (an anxiety disorder in which a person who is capable of speech does not speak in specific situations or to specific people. Children with selective mutism stay silent even when the consequences of their silence include shame or even punishment.)" Participants chose either yes or no, followed by "Please use space below to provide additional explanation."

*Synesthesia*. We asked four questions on synesthesia and participants responded either yes or no. Each question was followed by an open-ended question: "If you do recognize this, please explain and give a few examples."

- Have you ever experienced "Hearing color Synesthesia"? (in which sounds induce colors, or visual images)
- Have you ever experienced colors with letters, numbers, days of the week?
- Have you ever experienced that letters, numbers, days of the week to you seem to have shape, spatial location, or "mental map" that seems to appear when you think of them?
- Do you have other types of synesthesia: Do certain experiences (seeing or hearing a letter, musical tone, name, person) trigger an additional sensation (color, personality, visual patterns, tactile sensations)?

ASMR. We asked the question "Do you ever experience pleasurable tingling sensation in the head, scalp, back, or peripheral regions of the body in respond to visual, auditory, tactile, olfactory, or cognitive stimuli? (e.g., experiencing tingling strong desirable sensation when someone is whispering in your ear or rubbing fingers on a rough surface)." Participants chose either no or yes, followed by the open-ended question "Please explain your experiences."

In our contacts with misophonics while setting up this test, anecdotal reports had suggested that some misophonics have another type of compulsion to listen to sound; therefore, we also included this as a question: "Do you feel a compulsion to listen to some specific sounds on regular basis which makes you feel better and help you to calm down? (e.g., calling random numbers and listening to people on the phone)." Again, participants chose either no or yes and the latter was followed by the open-ended question "Please explain your experiences."

Family. The question "Do any family members (as far as you know) have other neurological, psychological or psychiatric conditions, in particular OCD (obsessive-compulsive disorder), eating disorders, synesthesia, ADD, ADHD, PTSD (post-traumatic stress disorder)" was followed by 12 answer alternatives: tinnitus; obsessive compulsive personality disorder (OCPD); hyperacusis; auditory processing disorder; attention deficit disorder (ADD); post-traumatic stress disorder (PTSD); exploding head syndrome (EHS); phonophobia; eating disorder;

Table 1
Nationalities of Participants (Ordered by Continent)

Belgian	3	American (USA)	93
Danish	1	Canadian	12
Dutch	9	Jamaican	1
English	38	Mexican	6
Finnish	2	Bolivian	1
French	2	Columbian	1
German	19	Afghan	1
Greek	10	Armenian	1
Hungarian	1	Chinese	2
Irish	1	Iranian	1
Italian	2	Korean	1
Moldovan	2	Malaysian	1
Polish	1	Australian	8
Romanian	1	Indian	3
Russian	1	New Zealander	3
Scottish	1	Moroccan	1
Spanish	4	South African	2
Swedish	2	Mixed	63
<u>Turkish</u>	1		

synesthesia (letters always have colors/numbers have a spatial location/music tones have colors); other (please explain); no. This question was followed by the open-ended question "Additional space to describe conditions running in the family." We furthermore asked: "Do any family members have other types of perceptual dysfunctions? (in particular hearing issues or conditions that evoke emotions in response to sounds)."

#### Results

## **Participants**

The setup and procedures of this study allowed testing a large and diverse group of participants. In this section, we display their characteristics, including both participant demographics and characteristics and severity of their misophonic complaints as indicated by self-report questionnaires. A total of 301 (250 females) participants were included in the analyses (mean age 37 years; standard deviation [SD] = 14). Participants were of diverse backgrounds including 36 different nationalities (see Table 1).

## Severity of Symptoms

Misophonic complaints: Emotional. The emotional responses were measured with the MAS-1 (Fitzmaurice, 2010; see also Kluckow et al., 2014; Dozier, 2015a). Responses ranged from level 0 "Person with misophonia hears a known trigger sound but feels no discomfort" to level 10 "Actual use of physical violence on a person or animal (i.e., a household pet). Violence may be inflicted on self (self-harming)." Subjects indicate what is the highest level in this scale that fits with their misophonic complaints.

We included an "other" option, which provided participants the opportunity to give further descriptions of their complaints in case they felt the scales did not fit with their misophonic complaints. A total of 43 participants used this opportunity to further explain their condition, 24 of whom clearly indicated what level (scale) their (severest) complaints belonged. Participants were scored accordingly. If participants were not certain about their answer or if their answer was not clear or did not clearly indicate which scale described their worst experiences, then the response was categorized as other. For these 19 subjects, the MAS-1 scores were excluded from further analyses, leaving a total of 282 participants included in the analyses.

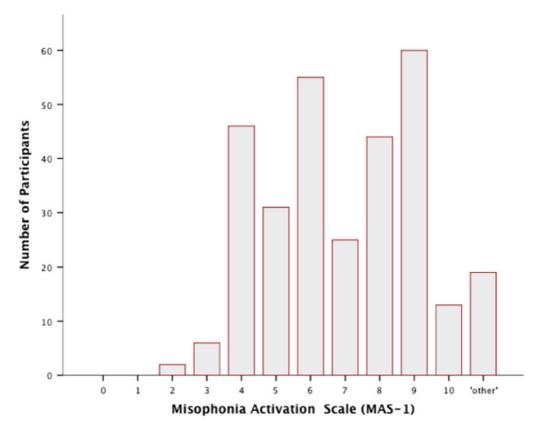


Figure 1. Severity of misophonic complaints, as measured with the Misophonia Activation Scale (MAS-1).

The answers to open-ended questions also allowed further insight in the kind of negative personal experiences some of these participants have. An example of this is a comment made in the MAS-1: "I have become a 'hermit' for the most part and only go out for groceries or to the library to get books (not easy since people aren't quiet in the library anymore)."

In our sample of 301 participants, the responses ranged from level 2 to level 10 (see Figure 1). The most common level of emotional responses (see Table 2) was level 9: "Panic/rage reaction in full swing. Conscious decision **not** to use violence on trigger person. Actual flight from vicinity of noise and/or use of physical violence on an inanimate object. Panic, anger or severe irritation may be manifest in sufferer's demeanor."

In addition to the MAS-1, we explored what types of emotional responses are common in misophonia and which are less common in our participant sample. Subjects are allowed to provide several answers and add their own answer in the other category. This showed that almost all subjects recognized the feelings: "extreme annoyance/irritation," "anger/rage," but also "stress/anxiety" (see Table 3). In the other category, the emotions reported (by more than one participant) are guilt (5), frustration (4), rage (3), depression (3), sadness (3), cannot focus (3), anger (2), want to die (2), feel trapped (2), overwhelmed (2), fear (of my own reactions) (2), shame (2).

Misophonic complaints: Physical. On the MPRS, participants indicated their physical sensations relating to their misophonia. There are 11 scales, increasing in reported intensity of the experiences. Participants could indicate multiple answers. The chosen answers ranged from level 0 to level 10, and several answers were recognized by at least one sixth of the participants. The most common answer was level 8: "I feel physical sensation which can be best described as emotional pain." Using multiple answers allowed us to compare relative frequency of certain physical sensations (see Table 4). If further analyses (see next results sections) required individual differences in physical intensity, then we took the highest scale recognized by the participant as his or her score.

Table 2
Severity of Emotional Responses To Misophonic Triggers, As Measured With the Misophonia Activation Scale (MAS-1)

MAS-1	No.	%
Level 0		
Person with misophonia hears a known trigger sound but feels no discomfort Level 1	0	0.0
Person with misophonia is aware of the presence of a known trigger person but feels no, or minimal, anticipatory anxiety  Level 2	0	0.0
Known trigger sound elicits minimal psychic discomfort, irritation or annoyance. No symptoms of panic or fight or flight response Level 3	2	0.7
Person with misophonia feels increasing levels of psychic discomfort but does not engage in any physical response. Sufferer may be hyper-vigilant to audio-visual stimuli  Level 4	6	2.0
Person with misophonia engages in a minimal physical response - non-confrontational coping behaviours, such as asking the trigger person to stop making the noise, discreetly covering one ear, or by calmly moving away from the noise. No panic or fight or flight symptoms exhibited	46	15.3
Level 5 Person with misophonia adopts more confrontational coping mechanisms, such as overtly covering their ears, mimicking the trigger person, engaging in other echolalias, or displaying overt irritation	31	10.3
Level 6 Person with misophonia experiences substantial psychic discomfort. Symptoms of panic, and a fight or flight response, begin to engage Level 7	55	18.3
Person with misophonia experiences substantial psychic discomfort.  Increasing use (louder, more frequent) use of confrontational coping mechanisms. There may be unwanted sexual arousal. Sufferer may reimagine the trigger sound and visual cues over and over again, sometimes for weeks, months or even years after the event	25	8.3
Level 8 Person with misophonia experiences substantial psychic discomfort. Some violence ideation	44	14.6
Level 9 Panic/rage reaction in full swing. Conscious decision not to use violence on trigger person. Actual flight from vicinity of noise and/or use of physical violence on an inanimate object. Panic, anger or severe irritation may be manifest in sufferer's demeanor	60	19.9
Level 10 Actual use of physical violence on a person or animal (i.e., a household pet).	13	4.3
Violence may be inflicted on self (self-harming)  Other	19	6.3

To further explored how common or how uncommon particular physical responses are in our participant group, we asked participants to indicate which physical responses from a list were recognizable. See Table 5 for relative occurrences of reported physical discomfort. Results reveal that a very common physical sensation in relation to their misophonia was increased muscle tension.

In the "other" section, participants reported a wide variety of sensations, from "no physical effect" to "sexual arousal" to "nausea." Effects that were mentioned by at least three participants were rage (8), pain/hurt (of which pain in ears 6), headache (5), anxiety (6), crying (7), panic (3), and anger (3).

Table 3
What Are the Feelings and Emotions Associated With the Trigger Sounds? (Multiple Answers Possible)

Feelings and Emotions	No.	%
Extreme annoyance/Irritation	284	94.4
Anger/Rage	272	90.4
Stress/ Anxiety	269	89.4
Invasive, intrusive, insulting, violating, offensive, disgusting, rude	242	80.4
Aggravation	235	78.1
Feeling trapped	233	77.4
Impatience	221	73.4
Panic	168	55.8
Other (Please explain)	32	10.6

Table 4
Misophonia Physical Sensation Scale (MPRS)

Physical sensations, measured with the MPRS	No.	%
Level 0		
I feel no physical sensation	23	7.6
Level 1		
I feel minimal physical sensation and can ignore it	12	4.0
Level 2		
I feel some physical sensation but can often/always ignore it	39	13.0
Level 3	61	20.2
I feel some physical sensation but have difficulty or cannot ignore it	61	20.3
Level 4  I feel elevated physical consetion and variable connection are it.	43	14.3
I feel elevated physical sensation and usually cannot ignore it Level 5	43	14.3
I feel elevated physical sensation, definitely cannot ignore it	61	20.3
Level 6	01	20.5
I feel elevated physical sensation, cannot ignore it and each incidence	57	18.9
has an impact on my life		
Level 7		
I feel physical sensation as described above and cannot cope with it	46	15.3
Level 8		
I feel physical sensation which can be best described as emotional pain	99	32.9
Level 9		
I feel physical sensation which can be best described as physical pain	32	10.6
Level 10		
I feel physical sensation which is overpowering and is causing physical	23	7.6
pain		

*Misophonic complaints: Effect on life.* On A-MISO-S (Schröder et al., 2013), participants indicated the severity of their symptoms from one of 5 levels, with higher levels reflecting more severe effects.

We presented three A-MISO-S subscales. The first asks, "How much of your time is occupied by Misophonic sounds? (How frequently do the [thoughts about the] misophonic sounds occur?)." Answers ranged from none to "extreme, greater than 8 hrs/day or near constant (thoughts about) sounds." Two participants indicated none and other answers ranged from mild to extreme. The most common answer in our participant group was "moderate, 1 to 3 hrs/day, or frequent (thoughts about) sounds (more than 8 times a day, most of the hours are unaffected)."

Table 5
Reported Physical Discomfort

What is the physical discomfort? (multiple answers possible)	No.	%	
Clenched/tightened/tense muscles	271	90.0	
Increase in body temperature, blood pressure, or heart rate	180	59.8	
Pressure in chest, arms, head or whole body	122	40.5	
Sweaty palms	63	20.9	
Hard to breathe	58	19.3	
Pained by trigger sounds	39	13.0	
Other (Please explain)	69	22.9	

Table 6
Answers to Subscale 1–3 of the Amsterdam Misophonia Scale

How much time		Interfere social	Interfere social or work life		How much distress	
None	2	None	7	None	0	
Mild	65	Mild	59	Mild	13	
Moderate	114	Moderate	148	Moderate	125	
Severe	87	Severe	73	Severe	125	
Extreme	33	Extreme	14	Extreme	38	

The second subscale asks: "How much do these misophonic sounds interfere with your social or work (role) functioning? (Is there anything that you don't do because of them? If currently not working determine how much performance would be affected if patient were employed)." Answers ranged from none to extreme. The most commonly chosen answer was "moderate, definite interference with social or occupational performance, but still manageable."

The third subscale asks: "How much distress do the misophonic sounds cause you? (In most cases, distress is equated with irritation, anger or disgust. Only rate the emotion that seems triggered by misophonic sounds, not generalized irritation or irritation associated with other conditions)." Answers ranged from mild to extreme. No participants indicated none; most commonly chosen answers were "moderate, disturbing irritation/anger/disgust, but still manageable" and "severe, very disturbing irritation/anger/disgust."

We explored what are common or uncommon effects of misophonia on the participant's life, by providing a list of complaints. Participants could indicate what complaints or effects they recognized (multiple answers were possible) and could add their own answer in the "other" category (see Table 7).

One fifth of the participants indicated that "thoughts of suicide" is one of the effects that misophonia has on their life. The answers to the open-ended question also showed the severity of feelings for a subgroup of the participants. Participants reported about misophonia interfering with their work life to the degree of having to change/quit jobs, deteriorating relationships and social life, interfering with normal daily life when triggers cause a lack of focus, and avoidance or aggressive (e.g., self-harm) behavior. Other people not knowing or not believing the severity of the misophonic complaints were felt to enhance their daily problems. Examples of answers to the question "How do the trigger sounds effect on your life" are as follows:

- "Depression, sadness, failure and wanting to die and commit suicide."
- "Fear of uncontrolled verbal and physical REACTIONS."
- "I feel hatred towards the person making the sound sometimes. I say something to my family when I can't stand it, but my friends have no idea I have this problem. I'm embarrassed and ashamed of being this way, but I don't know how to stop."
- "Suicidal thoughts I just long to die and escape the unbearable torture."

How do trigger sounds affect your life?	No.	%
Tried not to be around people if they make trigger sounds	267	88.7
Can't pay attention at a movie or in class when people are making trigger sounds	262	87.0
Realizes they are hyper focused on noises that should be in the background and are unable to ignore them	224	74.4
Triggers are worse when tired	182	60.5
Can be triggered by sounds from television or video	176	58.5
Feels better when can locate source of sound	134	44.5
Stays away from certain foods/avoids making certain sounds	122	40.5
Thoughts of suicide	66	21.9
Other (Please explain)	63	20.9

Table 7
Reported Effects of Misophonia on Participant's Life (Multiple Answers Possible)

At the end of the experiment, participants were provided with the opportunity to write any general remark about the research. Examples are as follows:

- "I have no understanding of why I am like this, it's very distressing when it happens & I get very embarrassed at my reaction & I find it really hard to explain to others."
- "I need to get help about this."
- "Please help."

Misophonic complaints: Covariates. In this section, we discuss characteristics of the environment or of the misophonic individuals that may influence severity of the symptoms. We examined influence of substance abuse as reported by male versus female participants. Furthermore, we examined how severity of symptoms are distributed and if different measurements of symptom severity correlate.

Three questions probed effects of pharmacological agents on misophonia, including alcohol, caffeine, and nicotine. The fourth question was "Do any other chemicals affect the symptoms?" We included marijuana, ecstasy, and mushrooms as examples. Participants chose one of four answer categories: "lessened symptoms," "aggravated symptoms," "no change," or no use of that particular substance.

Results are presented in Table 8. A relatively large percentage (36%) of the group mentioned alcohol as lessening the symptoms. Some participants reported to have used alcohol with the purpose of reducing the misophonic symptoms. Most misophonics indicated that caffeine does not seem to affect the symptoms, and most misophonics do not use nicotine or other chemicals. Of the participants indicating lessened symptoms with other chemicals, most (N=24) mentioned marijuana/cannabis. Within this group, many participants indicated that they have used it only rarely, and not anymore (e.g., by fear of losing their job).

We also contrasted the severity of complaints as reported by male versus female participants. From each participant, we took (a) the score on MAS-1, (b) the highest indicated score on the MPRS, and (c) the mean score on the three subscales on the A-MISO-S. Mean and standard deviation are reported in Table 9. The reported severity of symptoms is somewhat increased in females, compared with males.

A Kruskal-Wallis test evaluated the differences between two gender categories. The tests showed no effect for MAS-1, a marginally significant effect for MPRS,  $X_2(1, N=301) = 2.78$ , p = .095, and increased median for A-MISO-S,  $X_2(1, N=301) = 6.11$ , p = .013. The increased severity reported by females, compared with males, might be a gender bias in (reported) severity of symptoms; however, please note that with Bonferroni correction for multiple comparisons (p < 0.0167), only the effect measured with A-MISO-S is significant. Furthermore, the different sizes of the groups (51 males vs. 250 females) might influence the severity differences.

Table 8 Effects of Different Chemicals on Misophonic Complaints

	No.	%
1. How are symptoms affected by alcohol?		
Lessened	107	36%
Aggravated	6	2 %
No change	61	20%
No alcohol use	128	43%
2. How are symptoms affected by caffeine?		
Lessened	9	3 %
Aggravated	53	18%
No change	184	61%
No caffeine use	56	19%
3. How are symptoms affected by nicotine?		
Lessened	19	6 %
Aggravated	3	1 %
No change	57	19%
No nicotine use	223	74%

Yes- Lessened symptom	39	13%
Yes- Aggravated symptoms	11	4%
No	51	17 %
Unknown	201	67 %

Table 9 Reported Severity of Misophonic Complaints by Female Versus Male Participants

	Female Mean (SD)	Male Mean (SD)	p-value
MAS-1	7.77 (1.94)	7.34 (2.22)	n.s.
MPRS	6.57 (2.97)	5.78 (3.15)	.088
A-MISO-S	3.38 (0.71)	3.09 (0.71)	.008

Note. SD = standard deviation; MAS-1 = Misophonia Activation Scale; MPRS = Misophonia Physical Sensation Scale; A-MISO-S = Amsterdam Misophonia Scale.

Summary and the distribution of severity of symptoms. In summary, the measurements show that our participants differ in nature and severity of misophonic complaints, with a relatively high incidence of participants indicating their complaints as "moderate" on the misophonia assessment scales. For another substantial group of participants, however, the misophonic responses to sounds were experienced as extreme, severely disturbing, and even had a devastating effect on their life.

None of the questionnaires were normally distributed (Shapiro-Wilk > .93; (N=282) p <.001). As can be seen in Figure 1, the MAS-1 showed that the responses are diverse. Rather than a normal distribution, the distribution includes a large group of subjects with relatively mild complaints and another large group of subjects with severe complaints. Such distribution does not seem to be in line with the notion that everybody has misophonia, but on a gradually increasing scale of intensity. Perhaps more than one group of misophonics is represented here, with more than one (causal) mechanism. It could also be related with our particularly large group of participants, thereby including many different types of people reporting misophonic complaints. Because the questionnaires were all non-normally distributed, in further analyses nonparametric methods are chosen.

The three measures show moderate to strong correlations, between MAS1 and A-MISO-S,  $r_s$  (282) = .67 p < .001, MAS-1 with MPRS,  $r_s$  (282) = .53, p < .001, and MPRS with A-MISO-S,  $r_s$  (301) = .47, p < .001.

# Developmental and Familial Traits

Do the misophonic symptoms worsen over time? More than three quarter of the participants indicated that their symptoms had worsened over time (N=232, 77%), against a much smaller number of participants indicating that it did not get worse (N=11, 4%) or stayed the same (N=31, 10%). A total of 27 (9%) participants indicated "other," a category that comprised very diverse answers. Participants indicated that they have developed coping strategies/life changes that make it easier to deal with their misophonia. Others indicated that the misophonic responses have stayed the same but that the number of triggers has increased. A few participants chose the "other" category to indicate that their misophonia got "a lot" worse.

Onset of symptoms. Participants provided diverse responses to the question "How old were you since you started experiencing the misophonic symptoms?" Answers ranged from "as long as I can remember" to "started around 2013, aged 57." Yet a clear pattern emerged from the results, with most of the participants indicating that the problems started in childhood (N=136, 45%). Another large group indicated they had problems since teenage years (N=91, 30%); 44 (15%) participants answered "As long as I can remember." It was also less common to experience misophonia since adulthood (N=27, 9%), and three answers were in the "other" category (1%).

As explained in the Method section, the participants used open-ended question for many different purposes, and 39 participants in total provided a written answer. Most answers could unambiguously be categorized in one of these age categories (only three participants did not clearly indicate one of the four age categories). Several participants indicated that there were early complaints and that only later in life these complaints increased in severity to become real problems. For example, one participant indicated that as a child she probably had a weaker type of misophonia, but that this problem became apparent only in adulthood. These reports are in line with the notion that the severity of misophonic complaints increases over time. This latter notion was examined by contrasting severity of misophonic symptoms across age groups. The categories did not differ in terms of current age of the participants. Thus, someone answering "all my life" has had misophonic complaints for a longer period of time than someone answering "since adulthood." As in the previous section, severity of symptoms is measured by (a) the score on the MAS-1, (b) the highest indicated score on the MPRS, and (c) the mean score on the three subscales on the A-MISO-S.

A Kruskal-Wallis test evaluated the differences among the four age of onset categories (always, childhood, teenager, adult) on median change of symptom severity. Even without Bonferroni correction, the tests showed only a marginally significant or no significant effect, for MAS-1,  $X_2(3, N=282) = 7.63$ , p = .054; MPRIS,  $X_2(3, N=301) = 3.10$ , p = .376; A-MISO-S,  $X_2(3, N=301) = 4.70$ , (3), p = .196.

An overview of severity of symptoms split out by age of onset (Table 10) revealed that the indicated symptoms seem lowest for the group in which misophonia started in adulthood. We therefore performed an exploratory analysis with Kruskal-Wallis split between all participants answering that their symptoms started before adulthood, versus all participants answering that their symptoms started as adults. It showed a difference on median change of symptom severity in MAS-1,  $X_2(1, N=282) = 6.70$ , p = .01, a trend with A-MISO-S,  $X_2(1, N=301) = 3.40$ , p = .065, and no significant effect with MPRIS,  $X_2(1, N=301) = 2.24$ , p = .135; therefore, with Bonferroni correction (p < 0.0167), there was only a significant effect on the MAS-1 but not on the other measures.

Overall, these analyses did *not* show an overall effect between age of onset and severity of symptoms in adulthood. There is, however, a small effect of less severe symptoms for participants reporting that their symptoms started in adulthood.

Table 10
Each of Five Answer Categories to the Question "How Old Were You Since You Started Experiencing the Misophonic Symptoms?"

	No.	%	MAS-1	MPRS	A-MISO-S
1. "As long as I can remember" (2–4 years)	44	15%	7.63 (1.90)	6.86 (2.69)	3.36 (0.61)
2. "Childhood" (5–12 years)	136	45%	7.90 (2.02)	6.54 (3.10)	3.39 (0.70)
3. "Early teenage years" "17" (13–17 years)	91	30%	7.73 (1.89)	6.30 (2.97)	3.30 (0.73)
4. Adult (18 years or older)	27	9%	6.61 (2.13)	5.59 (3.27)	3.10 (0.86)
5. Don't know/other	3	1%	, ,	. ,	,

*Note.* Number and percentage of participants in each of the five answer categories, followed by mean and standard deviation of the three measurements of severity of misophonic complaints. SD = standard deviation; MAS-1 = Misophonia Activation Scale; MPRS = Misophonia Physical Sensation Scale; A-MISO-S = Amsterdam Misophonia Scale.

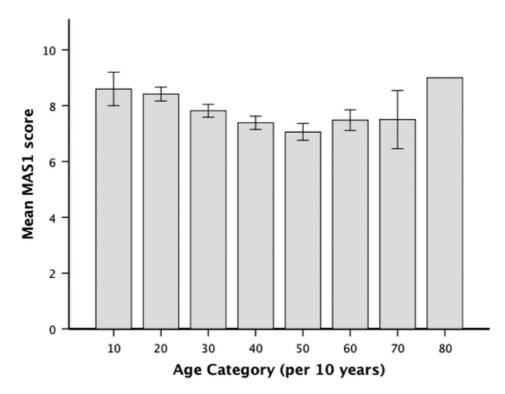


Figure 2. Severity of misophonic symptoms as measured with MAS-1, per participant age category. Note. Age categories are per 10 years of age. The last two categories hold N=4 and N=1 participant(s), respectively.

Current age and strength of symptoms?. Three subjects did not provide their age. There is a significant small-sized negative correlation between age and strength of symptoms, obtained with the MAS-1,  $r_s(280) = -.212$ , p < .001, and the A-MISO-S (mean subscales 1 to 3),  $r_s(299) = -.15$ , p = .012; with Bonferroni correction, these effects are significant, p < .0167.

Figure 2 shows (in line with the negative correlations reported above) that the experienced severity does not in general increase with age. Instead, reported severity is lowest for the middle-aged participants. Although the reported severity increased in subsequent age categories, this should be evaluated with care because there are only a few elderly participants (eight participants are older than 65 years of age).

Running in the family. We asked the question, "Do any family member(s) have similar symptoms?" Responses were as follows: 67 (22%) indicated that they did know family members

with similar symptoms, 100 (33%) indicated *no* family members with similar symptoms, and 134 (45%) indicated "unknown."

Contrasting the 100 participants reporting *no* family members with similar issues with the 67 participants who *do* know family members with similar issues shows a slightly increased reported severity of the misophonic complaints if the participant knows family members with similar symptoms (mean and *SD*), respectively: MAS-1 7.65 (1.9) versus 7.79 (2.0), MPRI 6.29 (3.1) versus 6.63(2.7), A-MISO-S 3.33(.65) versus 3.37(.74), but these effects are very small and nonsignificant (in the Kruskal Wallis test, all three questionnaires, .2 < chi-square, .27, p= .6).

Describing the affected family members, the misophonics reported more female family members than male family members with similar symptoms: more often mother (N=48) than father (N=19), more often sister (N=37) than brother (N=10), more often daughter (N=29) than son (N=17). Either misophonia is more common in females, or this particular participant group (mainly comprising females) was biased in their responses.

# Prevalence and Comorbidity

Other conditions. We asked participants if they had been diagnosed with other conditions, to explore patterns of comorbidity. We also inquired about the presence of neurological, psychological, or psychiatric conditions in their family members.

A total of 151 (50%) participants reported no other conditions or diagnoses. From the list of conditions, the most commonly reported items were tinnitus (12%), PTSD (12%), and ADD/ADHD (12%), followed by eating disorder (8%), OCPD (8%), selective mutism (6%), and hyperacusis (4%). In the "other" category, most mentioned conditions were anxiety disorders (anxiety/panic/phobic conditions) (N=41, 13%) and depression/depressive disorders (N=40, 13%).

The mixed nationalities in our group, and particularly the fact that the data are based on self-report, makes it difficult to contrast these prevalence rates with the prevalence rates as reported in literature. We will therefore not perform such prevalence analyses. We instead aim to assess if conditions are somehow related to misophonia or rather co-occur coincidentally. Our rationale is that if conditions are related, then their mechanisms are not independent, and thus it is likely that the presence of one condition will affect the nature and severity of the symptoms of the other condition. However, if we find that the presence (vs. absence) of a condition shows no effect on the severity of misophonic symptoms, then it indicates that these two conditions are likely to coincide without reasons to assume interactions or shared mechanisms between the conditions.

The relationship between the co-occurring conditions and misophonia was examined by comparing severity of misophonic symptoms in participants with, versus participants without, that other condition. For this analysis, we used the severity of misophonic symptoms in overall effects on life (A-MISO-S). We excluded conditions reported by very few (less than N=15, or 5%) participants: These conditions were not related to misophonia for the great majority of our participants, and the small subject number would make the analyses vulnerable for outliers. For all other reported conditions, we correlated presence/absence of the condition with one specific scale measuring severity of misophonic symptoms, the A-MISO-S scores.

There were nine tests in total (tinnitus, eating disorder, selective mutism, PTSD, OCSD, ADD/ADHD, anxiety-related conditions, depression and no condition). With Bonferroni correction for multiple comparisons ( $\alpha = .006$ ), only two correlations survived. First, subjects reporting no comorbid disorder at all had less severe misophonic complaints  $r_s(301) = -.16 p = .006$ . We found only one particular condition related to severity of misophonic symptoms measured with A-MISO-S; increased severity of misophonic symptoms was related to reported presence of PTSD,  $r_s(301) = .19 p = .001$ . Concerning the conditions reported in the "other" sections, presence of depressive (N=40) or anxiety-related (N=41) conditions did not matter for severity of misophonic symptoms (all Kruskal-Wallis tests nonsignificant, with chi-square smaller or equal to 1).

Further analyses showed that participants reporting PTSD indicate more severe misophonic symptoms on all the Misophonic questionnaires. Kruskal-Wallis showed a difference on median

change of symptom severity. These effects were significant after Bonferroni correction (p < .0167) in all of the three questionnaires; in MAS-1,  $X_2(1, N=282) = 6.04$ , p = .01; in MPRIS,  $X_2(1, N=301) = 7.18$ , p = .007; and in A-MISO-S,  $X_2(1, N=301) = 11.21$ , p = .001.

We examined if the presence of misophonia in the family and the presence or PTSD are related (e.g., are these two different sources for misophonic complaints). However, whether or not a participant reported family members with similar misophonic problems did not correlate with any of the other factors of interest (PTSD, synesthesia, eating disorders, ASMR). Similarly, whether or not a participant reported PTSD did not correlate to their reports on synesthesia, ASMR, or eating disorders.

Synesthesia. The questions on synesthesia showed 9% to 17% prevalence, which is much higher than the prevalence (2% to 4%) for these types of synesthesia as reported in the literature (Simner et al., 2006). However, again the prevalence numbers are affected by how (stringent) inclusion criteria are set (Simner et al., 2006; Johnson, Alison, & Baron-Cohen, 2013a), and in the current study self-report is sufficient for inclusion. The (in)dependence of the two conditions was therefore examined by analyzing the reported severity of misophonic complaints. For sequence-color synesthesia and sequence-shape synesthesia, the Kruskal-Wallis test did not show increased scores on the A-MISO-S (p > .1), and for hearing-color, there was a slight trend on the A-MISO-S,  $X_2(1, N=301) = 3.30, p = .07$ .

Participants indicating "other synesthesia types" had increased scores on A-MISO-S,  $X_2(1, N=301)=9.34$ , p=.002. A total of 49 participants chose this "other" category. Participants gave a description of their experiences, resulting in a wide range of their ("other") types of synesthesia, from people evoking colors, sounds evoking a particular taste, to particular emotions with touch (e.g., rough or smooth surfaces). We listed these inducers and concurrents and tested if any of the particular inducers (e.g., "sounds") or any of the particular concurrents (e.g., "colors" or "emotions") were related to the reported severity of misophonic complaints. No effects or relationships became apparent in these analyses; therefore, we currently have no explanation for the effect of "other" categories on the A-MISO-S.

In line with current knowledge on synesthesia (Barnett et al., 2008), the presence of one type of synesthesia correlated with the presence of other types of synesthesia. Participants reporting sequence-shape synesthesia (days or letters have a spatial shape) were more likely to report hearing-color synesthesia,  $r_s(300) = .307$ , p < .001, or sequence-color,  $r_s(299) = .318$ , p < .001. And hearing-color correlated with sequence-color,  $r_s(300) = .483$ , p < .001.

ASMR. A remarkable finding in our study was the high incidence of reports on particularly pleasant responses to listening to sounds. The question described ASMR, a relatively unknown condition in which particular sounds or sights elicit particular pleasant feelings, as euphoric, relaxing, and involving tingling sensations on the skin. So far, only one scientific publication has studied this phenomenon (Barrat & Davis, 2015). Despite this being an unknown condition, almost half (49%) of the participants reported recognizing these phenomena. This shows that for half of the participants, experiencing emotions in response to particular sounds extends beyond their misophonia. This was also suggested by the finding that 30% of the participants reported "compulsive listening to specific sounds."

To further study these phenomena, we examined severity of misophonic symptoms for participants with versus without ASMR symptoms. This showed no significant relationship for MAS-1 and A-MISO-S and only a weak and nonsignificant relationship with MPRIS,  $X_2(1, N=301)=3.08$ , p=.079. Note that these questionnaires asked the severity of emotional responses in only one direction—how negative or disturbing the symptoms are. It seems that ASMR adds positive emotions to the scale of sound-induced emotions but does not significantly decrease the negative effects of misophonia.

The conditions of ASMR, misophonia, and the "other" (sound) types of synesthesia might be related to each other, as indicated by the high presence of ASMR and "other" (sound) types of synesthesia in this group of misophonics. Furthermore, the presence of ASMR also correlates with reporting "other" synesthesia,  $r_s(301) = -.232$ , p < .001. Note, however, that given the relative unfamiliarity of the conditions this needs to be further studied. Furthermore, the use of

only one question to probe ASMR makes it more vulnerable for possible false positives or false negatives in its measurement.

As a final note, all nonparametric tests were also performed as one-way analyses of variance to see if this would change any of the conclusions. It did not change reported significance for any of the results.

#### Discussion

Currently, much is still unknown about the features and underlying mechanisms of misophonia. In the current project, we examined which patterns emerge when we examine the characteristics of misophonic individuals and misophonic complaints in a large group of participants. We examined the (severity of) misophonic symptoms and the reported comorbidity with other clinical, psychological, or psychiatric conditions, and we also explored the relationship between misophonia and other cognitive, auditory, or emotional characteristics.

Our participants differed in the nature and severity of their misophonic complaints, ranging from minimal discomfort and no fight or flight response to full panic/rage response and violent behavior toward others or self (self-harming). A large portion of the participants rated, on the severity assessment scales, the level of their complaints as "moderate." For a substantial group of participants, however, the misophonic responses to sounds are experienced as extreme and severely disturbing. These participants exemplify the significance (and thereby the relevance) of understanding this condition. They reported misophonic responses that have a devastating effect on their life. Our results thus showed a large range in misophonic complaints.

Furthermore, the reported severity of the complaints was not normally distributed. A study of a large group of undergraduate students by Wu et al. (2014) showed that 20% of the students had at least "moderate sound sensitivities" that cause "significant interference" (minimally 7 on a scale from 1 to 15). The group reported by Schröder et al. (2013) had an average score of "severe" (15 out of 24). Jastreboff and Jastreboff (2014) note that Schröder et al. (2013) studied a population of psychiatric patients who happened to have misophonia as well, and they noted that, in their own clinical work, it was very rare to find misophonic patients that exhibit psychiatric problems. In our results, there is no normal distribution of the misophonic complaints. Therefore, in terms of severity of symptoms our results show that misophonics are not necessarily a unitary or homogeneous group.

Furthermore (see below), misophonics differed in terms of comorbidity with other conditions. This suggests that there might be heterogeneity in the nature and in the mechanisms involved in misophonia. Our study is particularly fit to find these individual differences within the group, as we recruited a large and diverse group of participants (including different nationalities and different age groups), because a large group of participants with different backgrounds were recruited.

Much is still unknown about the developmental pattern, cause, and pathogenesis of misophonia. We have learned, however, that there are patterns in the reported onset of misophonic problems (similar findings were obtained in different groups of misophonics). The majority of our participants, reported that the onset of their misophonic problems was in childhood or in early teenage years. This is in accordance reports of misophonics found in a large group of undergraduate students (mean age of onset 12: Kumar et al., 2014) and in a group of misophonics recruited in a psychiatric setting (mean age of onset 13: Schröder et al., 2013). While the results rely on self-report and are an estimation rather than a precise indication, a consistent pattern of results is obtained.

The misophonic reports also show a contrast with the condition synesthesia, where subjects normally report that they have had their unusual (synesthetic) experiences for as long as they can remember (Sagiv, Simner, Collins, Butterworth, & Ward, 2006; Dixon, Smilek, Cudahy, & Merikle, 2000). In our study, a very large number of subjects have memories of misophonic episodes in childhood, suggesting that misophonia typically is already present in childhood. Participants often shared lively memories of misophonic episodes in childhood. This may suggest that the characteristics of their family setting may be important in understanding the development of misophonia (Johnson et al., 2013b).

Future studies can inform us about misophonia "running in the family." We found that one third of the participants in our study knew of family members with similar symptoms. This might suggest a genetic predisposition for misophonia; but given our dependence on self-report, this needs to be further studied. A search for genetic links would be interesting and could also include an examination of the gender bias obtained in this study. The gender bias might, however, also merely reflect a gender difference in self-referral, as has previously been observed in synesthesia (Simner et al., 2006; Rouw et al., 2016). Another question is why females, compared with males, reported more severe misophonic symptoms.

Most (more than three-quarters) of the participants indicated that their misophonic symptoms have worsened over time. Some participants indicate that their symptoms have worsened *a lot*. Our findings are in line with the misophonic case studies, reporting a worsening of symptoms over time (Kluckow et al., 2014). We did not test children, and therefore, cannot examine if this implies that the symptoms are worse in adults than in children or if older children have worse symptoms than younger children. It does indicate, however, that our participants do not have a general effect of habituation to their trigger sounds.

Dozier (2015b) provides a theoretical framework for these reports of progressive worsening, by pointing out that angry feelings typically increase tension in skeletal muscles. Such increased tension would in turn enhance the physical response to the trigger stimulus. This way, prolonged or repeated exposure to the trigger sounds would create a self-strengthening situation rather than extinction of the misophonic response. It would be informative to examine the development of misophonic symptoms in a longitudinal study. Furthermore, an interesting link is suggested with a physical stress response; we will return to the relationship between misophonic complaints and physical (stress) response below.

## Comorbidity with other conditions

Participants were asked about comorbidity with clinical, psychological, psychiatric, neurological, or hearing conditions. The relationship can tell us something about the mechanisms involved in misophonia: Is it an independent condition, completely unrelated to another disease or condition? Is it associated with other conditions but only in a way of sharing symptoms? Is it associated in terms of interactions in underlying pathology? Or can we find evidence for a more extreme interpretation of comorbidity, stating that misophonia is actually only the symptomatic manifestation of another, "real" disorder?

To start with the last of these viewpoints, our results do not support the presence of another condition or disorder as the "real" underlying cause of the misophonic symptoms. No other condition was sufficiently present in our group of misophonic participants to explain away the misophonia. Half of the participant group did not report any of the inquired conditions, reporting instead to have no additional condition at all. The other half of the participant group did report other conditions, but they did not report one condition or disorder in particular; instead, these misophonics were highly heterogeneous in their responses.

We examined if there is a relationship between (previous or current) eating disorder and misophonia (Kluckow et al., 2014) because eating (slurping, smacking) noises are the most common misophonic triggers (Wu et al., 2014; Schröder et al., 2013; Edelstein et al., 2013). Only a small number of misophonics reported to have (had) eating disorders, and the presence of an eating disorder (bulimia, anorexia nervosa or another eating disorder) did not significantly increase the severity of misophonic complaints. Although eating disorders for some participants might be a factor interacting with their misophonia, our results do not suggest that eating disorder is a general underlying principle explaining the condition.

Is misophonia related to any other clinical, psychological, or psychiatric conditions? Because it is difficult to make very precise calculations on prevalence in this study (see the Limitations section), we did not base our conclusions on prevalence. Instead, as a first step we simply examined if a condition was, or was not, present in this group of misophonic participants. The possible relationship with misophonia was then further explored by examining if a condition showed a relationship to the *severity* of misophonic complaints. This analysis gave two results.

First, participants without other conditions report less severe misophonic complaints. This indicates that comorbidity with other conditions or diseases is related to an increase in the severity of misophonic complaints. This finding is in line with previous studies noting shared pathology between misophonia and other diseases, such as anorexia nervosa and OCD (Kluckow et al., 2014); general sensory sensitivities, obsessive-compulsive symptoms, anxiety, and depressive symptoms (Wu et al., 2014); or OCPD (Schröder et al., 2013). These findings of comorbidity are however not necessarily pertaining specifically to the misophonic condition. Shared pathology and comorbidity is often observed in medical conditions, but unfortunately it is still poorly understood (Cramer, Waldorp, van der Maas, & Borsboom, 2010; Kessler 1994; Krueger & Markon, 2006; Friborg, Martinussen, Kaiser, Øvergård, & Rosenvinge, 2013). Second, we found a relationship between severity of the misophonic symptoms, and PTSD.

Relationship with PTSD. Participants with PTSD showed increased severity of misophonic symptoms, on all misophonia measurement scales. This was not merely a general response bias (subjects reporting one condition are also likely to report increased strength of another condition) because the severity of misophonic symptoms was not found related to any other relevant condition, such as depression, anxiety-related disorders, OCPD, or selective mutism. A relationship between PTSD and misophonia has been described in a case study by Dozier (2014), presenting a man with misophonia who was diagnosed with PTSD. He developed misophonia while serving in the Marines in Afghanistan. The misophonic triggers did not elicit PTSD responses, but instead the reverse was proposed (a causal relationship between PTSD and the development of misophonia).

One of the diagnostic criteria of PTSD is alterations in arousal and reactivity (DSM-V). This arousal characteristic of PTSD has similarities with the physical aspect of misophonia, as misophonic sufferers often report physical tension as part of their misophonic response. In our study, 90% of the participants recognized a physical response of "clenched/tightened/tense muscles" as characteristic for their misophonia. In a previous skin conductance response study (Edelstein et al., 2013), misophonic stimuli were found to be physiologically arousing. These findings suggest that in order to understand misophonia, it is important to understand the role of the physical stress response (as well as the emotional response; Dozier, 2015b).

The findings do not address the origin of this physical response, in particular whether or not it is a conditioned response (Dozier, 2015a). Similarly, note that we do not suggest that PTSD as a condition explains the existence of misophonic complaints. The great majority of our participants do not report PTSD (in line with Schröder et al. 2013, who used clinical diagnostic criteria). The results are, however, in line with the possible role of self-strengthening of the misophonic response through increased physical (muscle) tension. We found reports of increase in the severity of misophonic complaints in combination with PTSD as well as reports by almost all misophonics of a physical (muscle) response as part of their misophonia. This is an important topic for follow-up research.

### Relationship with ASMR

Our findings are in line with the hypothesized relationship between misophonia and ASMR. A remarkably large subgroup of misophonic participants recognized the description of ASMR (Barratt & Davis, 2015). Currently, there are no clear "diagnostic" criteria, and very little is known about the condition of ASMR. Still, half of our participants recognized the description of pleasurable, tingling sensations, indicating that for them, unusual emotional responses to particular (sound) sensations extends beyond their misophonia. An important question for follow-up studies is whether the mechanisms involved in the abnormal negative emotional responses with particular trigger sounds (the fight-or-flight response typical for misophonia) also make misophonics more susceptible to abnormal positive emotional responses to sounds (the relaxing and tingling sensations typical for ASMR).

This suggestion is particularly interesting in light of the recent findings by Kumar et al. (2017). This study showed that the abnormal salience attributed to particular sounds is related

to abnormal activation and functional connectivity patterns of the anterior insula cortex (AIC). The hyperactivation of this brain region was moreover found to mediate the autonomic responses in misophonia. Furthermore, questionnaire scores showed higher interoceptive sensibility in misophonics than in controls, consistent with abnormal functioning of the AIC. Overall, these obtained mechanisms could help explain the abnormal interactions between sensory processes (abnormal salience attributed to particular sounds) and emotional processes.

The unusual responses to particular stimuli as obtained in ASMR and misophonia is akin to synesthesia. In all of these conditions, a certain stimulus will evoke a particular and additional response that cannot clearly be traced back to the stimulus properties. While the relationships between these conditions are still elusive, the similarity in symptoms allows to generate hypotheses about the misophonic condition. A decade of research has provided knowledge on the mechanisms involved in the unusual cross-sensations in synesthesia as well as its underlying functional and structural brain properties (Rouw, Scholte, & Colizoli, 2011). This knowledge can be used in formulating hypotheses about the neurological mechanisms involved in misophonia.

In particular, can increased structural connectivity be obtained between inducer and concurrent structures (in the case of misophonia, particular limbic and sensory structures), as has been previously obtained in synesthetes (Rouw & Scholte, 2007)? Second, in synesthesia, a role of "higher" brain areas, in particular the parietal cortex, is crucially involved in synesthesia. The explanation is that parietal mechanisms underlie the general tendency to "bind" the different sensations together. Just as new models of synesthesia integrate these two main findings into "two-stage" models (Hubbard, Brang, & Ramachandran, 2011), a model on misophonia needs to integrate both the specific sensory characteristics of the ("triggers"-to-response) associations, and the general or "higher order" processes underlying the tendency for unusual "binding" between different sensory and emotional modalities. The latter higher order processes are furthermore relevant in explaining how the interpretation and context of trigger sounds will influence the misophonic responses.

Finally, we did not find that the obtained influences and relevant characteristics of misophonia themselves correlate. For example, we did not find a correlation indicating that in one group of participants the misophonia might have been caused by trauma (as indicated by the presence of PTSD), while another group has misophonia "running in the family." Similarly, the presence of ASMR is independent on the participant's reports on PTSD. This divergence of influencing factors is in line with the findings of Wu et al. (2014). Moderate relationships led these authors to conclude that misophonia may be related to multiple forms of psychopathology, through either direct or associative relationships. Webber and Storch (2015) point to the relevance of understanding such heterogeneity for the treatment of misophonia because variation (e.g., in symptom presentation) suggests that there may not be a "one size fits all" treatment.

Limitations. While the online test has succeeded in recruiting a large sample of misophonic participants, the approach does entail limitations. The most important is that the data rely on self-report. Subjects were recruited online, and they participated based on their own interest in helping out in a study on this topic. Self-report is not a reliable diagnostic measure, and none of our results should be interpreted or perceived as clinical reports. In particular, asking about comorbidity will likely lead to overrepresentation of conditions if participants are asked which diagnosis they have received, compared with diagnosing the participants during the experiment and in a clinical setting. In our method, the diagnostic criteria are less strict, plus diagnoses from the past will also be reported in the self-report. Perhaps (but this seems less likely in a group that voluntarily came forward to talk about their misophonic disease) there is also a tendency to not report diseases. For these reasons, we treat the current study as an examination of associations, but not as a prevalence study.

Rather than analyzing absolute measures of prevalence, we looked at the reported symptoms, characteristics, and conditions as they compared with each other within this group. The rationale is that it is not likely that the participants would selectively remain completely silent on one condition while reporting on other conditions. Furthermore, even if participants tend to underreport a particular condition, only a small number of subjects reporting a condition is sufficient to include in our analyses. Next, we performed a separate analysis that is independent of this

issue, namely, correlating the comorbid condition to the reported severity of misophonic conditions. Further investigations on prevalence numbers would be an interesting topic for future studies, but preferably these should take place in a clinical setting. Furthermore, any prevalence study still needs a large number of participants.

The use of self-report is also a limitation for all other collected responses. It is likely that not all answers are complete or sufficiently specific, and perhaps some answers are simply not true. This means that in our study, any single answer cannot be given a lot of weight. Instead, the large number of participants should balance these types of effects out, as "noise" in the measurements. This method of dealing with incorrect or imprecise responses does not hold, however, when there is a particular direction or bias in the responses. Whenever we thought this could influence the results, the effects were presented and the implications were discussed. An important example is the possibility that female overrepresentation is in fact a female bias in self-report. Female overrepresentation may disappear in studies avoiding self-report bias, as has been previously found in synesthesia research (Simner & Carmichael, 2015; Rouw & Scholte, 2016).

Currently, little is known about mechanisms involved in misophonia. This study has generated new hypotheses about the underlying mechanisms and explored patterns of influences on the condition. As in all psychological research, only replication in other studies will provide more definite answers. As a final note, this is not a developmental study or a longitudinal study. The results do not allow conclusions about causality. While it is possible to speculate about underlying mechanisms in the discussion, the results themselves are presented as "associations" and thus without any causal connotation.

#### Conclusion

We started this article with three fundamental questions about the mechanisms of misophonia: Can everybody develop misophonia or are there particular vulnerabilities or predispositions? How is misophonia related to other diseases or conditions (is misophonia a separate and independent disorder)? And, third, how specific are the mechanisms involved in misophonia; are misophonics different only in their trigger-to-response reactions, or do misophonics diverge in general (e.g., cognitive or emotional) mechanisms as well? First, our results suggest that certain personal and environmental characteristics can influence the susceptibility to misophonia as well as the severity of the misophonic response. These characteristics include current age, gender, family characteristics during development, and the capacity to avoid the misophonia getting worse over time (e.g., avoid repeated exposure to the trigger sounds). Most misophonics reported knowing family members with similar complaints. This suggestion that misophonia might be "running in the family" warrants further investigation.

As for the second fundamental question, current findings support the view that misophonia is a separate and independent condition. While we found less severe misophonic complaints in the absence of any other psychiatric, clinical or psychological condition, the pattern of co-occurrences with other diseases or conditions showed that not one of the psychological, clinical, or psychiatric conditions could serve as an alternative explanation for the misophonic complaints. Furthermore, the reported presence or absence of another condition did not affect the (severity of) misophonic symptoms. There was only one exception to this rule, as the severity of the misophonic symptoms was found related to PTSD. Misophonics also tend to indicate abnormal physical stress responses in relation to their misophonia. These findings provide interesting suggestions for future research; in particular, how an anomaly in the physical stress response system could be related to (the severity of) misophonic complaints.

In terms of the third question, the misophonia is specific in that no *general* cognitive or emotional effects were found to underlie or explain the condition. Yet the mechanisms at play in misophonia are larger than just the specific trigger-to-response associations. A recently published neuroimaging study explains misophonia as an abnormal salience attributed to sounds coupled with atypical perception of internal body states (Kumar et al., 2017). Interestingly, we found that half of our misophonics recognize a description of ASMR, in which particular stimuli (often man-made sounds such as whispering) evoke disproportionately pleasant, relaxing, or tingling

sensations. This raises an interesting question on the proposed misophonic mechanisms: Does the abnormal salience to stimuli and altered perception of body states also allow strongly enhanced *positive* emotional and physical responses to particular sounds?

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