

This book is aimed at all those who want to know about misophonia in a detail way or, having never heard of misophonia, wish to understand what it is about and to be aware of it. It is aimed both at people who are misophonic, whether young or adult, and at those who are not misophonic: parents and relatives of misophonic children and young people, schoolteachers and educators, sports tutors and entertainers of any kind of activity that may involve people with misophonia.

Discovering Misophonia provides an overview of the disorder in various aspects, from scientific basis to social consequences of misophonia at home, school, and work, illustrates the fundamentals related to the treatment of misophonia and the support of sufferers and offers an original proposal of diagnostic and investigative tools produced in the context of this research.

The present work originates from a European initiative involving ten organizations from eight different countries: Italy (leader), Austria, Slovenia, Cyprus, Iceland, Spain, Turkey, and Poland. Authors of the book are experts from the participating organizations with contributions from specialists associated with the partnership, including members of the Duke University's Center for Misophonia and Emotion Regulation (North Carolina) and the president of the Italian Misophonia Association AIMIF (www.misofonia.it), who edited the volume.



DISCOVERING MISOPHONIA

Edited by Mario Campanino

DISCOVERING MISOPHONIA

How to live fully
with misophonic awareness

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of the European Union



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This book is printed in font Helvetica Neue to make reading easier for people with dyslexia.

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Discovering Misophonia

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Editor's Note: Who is this Book for?

This book is aimed at all those who want to study misophonia in more detail or, having never heard of misophonia, wish to be aware of it and understand what it is about. It is aimed both at people who are misophonic, whether young or adult, and at those who are not misophonic: parents and relatives of misophonic children and young people, schoolteachers and educators, sports tutors and activity entertainers of any kind that may involve people with misophonia.

The purpose of this book is to be able to talk to everyone about misophonia, with a popularising intent but also to present more on a scientific level for those who wish to. Whoever decides to read it and get closer to the theme of misophonia will have made an important contribution to the greater well-being of people with misophonia. In fact, this disorder is currently still little known and the impossibility, for misophonic people, to share their discomfort socially, is one of the greatest wrongs it causes.

To all readers of this book goes the thanks of each person with misophonia.

Introduction

“Misophonia’ is still a relatively young term, barely over twenty years old. When it first came into use - in the United States, it was 2001 - its creators probably did not realise how wide-ranging its impact would be. This is because every misophonic person has difficulty in bringing out clearly the nature of his or her symptomatology before actually understanding what it is, and thus it remains submerged and hidden. Therefore, it may seem that misophonia is not very widespread, however an average of the results of many studies - albeit not systematic - on the prevalence of the disorder reveals that about 13% of the population has symptoms of misophonia. A very high percentage when compared to that of other, even better known disorders (worldwide, attention deficit hyperactivity disorder ADHD is present in about 5% of the population).

Nevertheless, despite how new the term is, important steps have been taken in the research on the causes and treatments of misophonia, especially thanks to the latest developments in neuroscience. In Europe, precisely these developments have brought about an initial approach to the subject, with the creation of organisations devoted to it (such as the Misophonia Association

of the Netherlands in 2015 and the Italian Misophonia Association AIMIF in 2018) and specific initiatives including the Misophonia@School project, of which this volume represents one of the main results, proving to be the first action on a European scale dedicated to the recognition of the disorder in education (the Misophonia@School project, for the inclusion of students with misophonia in European schools, is an Erasmus+ Strategic Partnership developed thanks to the co-funding of the European Commission - Italian Agency for the Erasmus+ Programme).¹

The purpose of these pages is to introduce the subject of misophonia in a concise and clear manner through a two-part exposition.

The first part provides an overview of the disorder in its various aspects:

- the one concerning the scientific basis of misophonia, explaining in an understandable as possible language the results of the current research on the disorder;
- the one concerning social (interpersonal) consequences of misophonia, at home, at work, and in extended social circles;
- the one concerning the difficulties that students with misophonia encounter at school and in other non-formal learning contexts, and strategies to overcome them.

1. See the full description of the project and its results in Chapter 8: 'The Misophonia@School Innovative Approach and Tools'.

Whereas, in the second part, the fundamentals related to the treatment of misophonia and the support of sufferers are set out:

- the presence and impact of the comorbidity of misophonia with other known disorders;
- the techniques and results of treating misophonia through cognitive-behavioural therapies;
- the diagnostic and investigative tools on misophonia, including those produced by the European initiative from which this work originates.

This book is available in nine European languages (Italian, English, German, Slovenian, Greek, Icelandic, Spanish, Turkish and Polish) and is available for download online in electronic format.²

In submitting it to European and worldwide audiences, we hope that this journey on the trail of misophonia, albeit a brief one, will be sufficient to open readers' eyes to a disorder that so greatly influences the lives of those who suffer from it, and to provide suggestions on strategies to deal with it and overcome it too.

The Authors

2 The publication can be downloaded from numerous European websites: among them, the Misophonia@School project website (www.misophonia-school.eu) and that of the Italian Misophonia Association AIMIF (www.misofonia.it) are worth mentioning.

FIRST PART

*KNOWING AND UNDERSTANDING
MISOPHONIA*

Chapter 1

What is Misophonia?

By Mario Campanino

Definitions and symptoms

Misophonia literally means ‘hatred of sounds’. The word comes from the Greek ‘miso’ (hatred) and ‘phonia’ (sounds).³

People suffering from misophonia are characterised by strong negative emotional response to specific sounds, also called ‘trigger sounds’. Typically, trigger sounds are sounds of eating, chewing, and breathing generated by other people. There are also some other less common trigger sounds, for example the sound of keyboard typing or rustling paper. When exposed to trigger sounds, people with misophonia react very harshly, e.g., trying to escape from the situation. If escape is not possible, they experience anger, anxiety, and di-

³ The author wishes to give due recognition to Prof. Sukhbinder Kumar for having generously provided many important suggestions, during several informal conversations, that contributed to the drafting of this chapter and the following one.

sgust. Sometimes, the anger is expressed by reacting violently to the person producing the trigger sound.

Effects of misophonia on sufferers are very noticeable. Indeed, misophonia can have devastating effects on the family, work, and social life of the sufferers. They will avoid having meals with other family members because they are triggered by the sounds of eating/chewing. They will avoid using public transport because the eating sounds are common there. At school, like at workplace, they will avoid social interactions with other students or colleagues. People with severe misophonia may drop out of work/education. Misophonia can cause strained family relationships: divorce or walking out of a relationship are known to happen because one partner does not like the sounds of the other. Trigger sounds sometimes evoke violent reactions (e.g., physically assaulting the producer of the trigger sound), particularly among young sufferers. Misophonia may cause social isolation which leads to depression. Cases of suicide/attempt to suicide by sufferers have been reported in the media.

Misophonia symptoms seem to start in a peculiar way. Initially, the reaction is triggered from the sounds of a particular person. For example, a daughter having meals with family members that starts feeling anger towards the sounds of eating made by her mother or father. Initially, sounds from other people do not evoke the negative emotional response. Several studies have now shown that the average age of onset of misophonia is around 12, but sufferers can be as young as 6/7 years of age.

Over the course of time, the trigger sounds become more general, that is, rather than by a particular person, people with misophonia are now triggered by more people. With age, the control over outburst of anger increases (that is, they are less likely to react with violence toward the trigger producing person).

Misophonia has not been formally recognised as a neurological/psychiatric disorder, and there is no 'official' definition of misophonia. There is still lot of confusion among researchers and clinicians about what misophonia is or is not, but, recently, several neuroscientists, psychologists, and psychiatrists dealing with misophonia came out with the following 'consensus' definition of Misophonia:

“Misophonia is a disorder of decreased tolerance to specific sounds or stimuli associated with such sounds. These stimuli, known as “triggers,” are experienced as unpleasant or distressing and tend to evoke strong negative emotional, physiological, and behavioural responses that are not seen in most other people” (Sweedo et al., 2022).

History and prevalence of misophonia

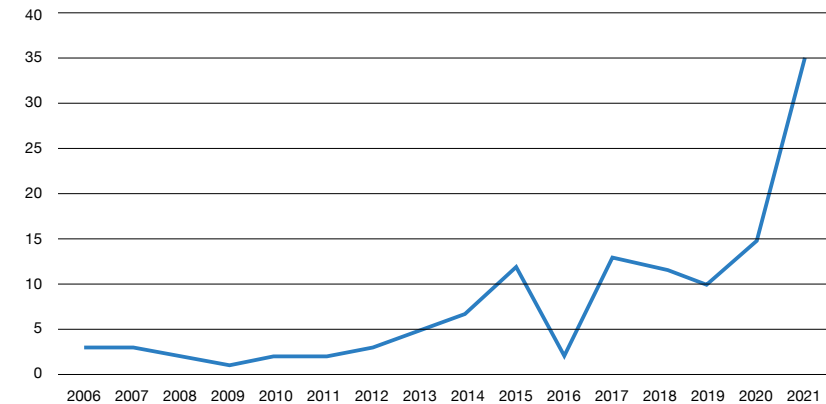
The word 'Misophonia' was coined by the audiologists Pawel Jastreboff and Margaret Jasterboff in 2001 while they were studying hyperacusis and phonophobia (fear of sounds), that have been known for a long time. In hyperacusis, sufferers experience 'normal' sounds to

be very loud, and the source of sound or the acoustic pattern of sound is not very important.

The Jastreboffs found that some people were irritated or felt very angry when they heard certain sounds. These sounds were repetitive in their acoustic pattern. For example, sounds of somebody eating, chewing and breathing: most importantly, the loudness of these sounds played no role, that is, the eating sound could be very soft, but it was still perceived negative by the sufferer. This 'new' disorder was, therefore, different from hyperacusis.

So, the Jastreboffs coined the term 'misophonia' to make a distinction from hyperacusis and, though the term does not capture the essence of misophonia (not all sounds are 'hated' by misophonia sufferers), it, however, has stuck (persisted) and is commonly used. There is no formal recognition of the term so far in any classification of medical disorders.

Interest of both researchers and clinicians has grown over the years. Following is the graph showing the number of publications on misophonia over the last years:



Initially, the cause of misophonia (as explained by the Jastreboffs) was thought to be due to problem in the sound processing (or auditory) and emotion processing parts of the brain. They didn't think misophonia was a psychiatric disorder. In hyperacusis, only the auditory part of the brain was considered problematic: now, new research on misophonia shows that the auditory part of the brain is 'normal'. More research work is underway to test it further.

The exact estimate on the prevalence of misophonia is not known as no comprehensive data has been collected. Few studies targeting limited populations (for example, students) have been done. A US based study (Wu et al, 2014) found 20% of undergraduate students in a university had symptoms of misophonia. A Chinese study (Zhou et al, 2017) found the prevalence in college

students to be 6%. In the UK, 12% medical students reported moderate symptoms of misophonia. A household sample from Turkey showed 12.8% of the population had misophonia symptoms.

As the numbers suggest, there is a large variance in estimates, but the numbers suggest that prevalence of misophonia is quite high. None of the studies reported so far have used a random sampling of the entire population, therefore, further work is needed to get a more accurate estimate of the prevalence.

Distinction from other sound sensitivity disorders

Before we understand how misophonia is distinct from other disorders, it is important to remember what misophonia is not:

- Misophonia is not just a 'normal' annoyance we may have for certain sounds.
- The emotional reaction in misophonia is very distinct from normal annoyance: sufferers feel anger/anxiety compared to normal annoyance.
- Sufferers feel as if the sounds are penetrating their body and personal space and feel a loss of control.
- Once sufferers listen to a trigger sound, their attention is automatically drawn to the sound, and they cannot do or attend to anything else in the presence of the sound.

To understand how misophonia differs from other disorders, let us start with its close 'relative', hyperacusis. In hyperacusis, sufferers experience quiet and normally comfortable sounds to be very loud. In misophonia, loudness is not an issue: both comfortable and loud sounds can cause distress. It is the pattern of sounds that matter in misophonia. Furthermore, in misophonia, the source of sound that triggers reaction is almost always another person. In hyperacusis, source of sound causing distress may not be a person (for example, the sound of a refrigerator).

The context in which sounds occur is important for misophonia but not for hyperacusis. For example, the same sound when identified as an eating/chewing sound causes more distress compared to when the source is identified as non-eating. For hyperacusis, context is not important: the same distress is caused irrespective of the context. In addition, hyperacusis and misophonia have different brain mechanisms: hyperacusis is associated with processes in the sound processing brain area (the auditory part of the brain), while misophonia relates to processing in the 'higher order' emotion processing parts of the brain and not to the auditory processing.

Chapter 2

Scientific Basis of Misophonia

By Mario Campanino

Misophonia has been 'discovered' very recently: furthermore, there is a lack of awareness about misophonia both among general population and clinicians. Very often, misophonia sufferers are not taken seriously:

- They are thought to be 'overreacting'.
- People with misophonia suffer silently to avoid being labelled 'crazy'.
- Clinicians like GP (general practitioners) also do not take the condition seriously enough.

Faced with this situation, the way out is to collect scientific evidence for misophonia. Indeed, it could convince both clinicians and general population about misophonia being a genuine disorder and it will help towards a formal recognition of misophonia, so that it can be listed in neurological/psychiatric diagnostic manuals such as DSM-5. Furthermore, scientific evidence will boost further research into misophonia which can

help finding a relief/cure for it. The kinds of scientific evidence to collect are various:

- Clinical case reports and self-report measures of misophonia.
- Measure of non-brain physiological activity such as heart rate and skin conductance in response to trigger and non-trigger sounds.
- Measure of brain activity.

Self-report as a measure of misophonia

In the self-report studies, subjects are typically given a pre-designed questionnaire (paper or online). Subjects then answer the questions based on personal experience of misophonia. In some cases, a clinician can conduct the interview with the misophonia sufferer: in this case, questions in the interview may be based on a questionnaire but may not be fixed a priori; sometimes more than one clinician is involved.

Before 2013, there were several clinical reports of misophonia published. These consisted of symptoms of either one or two patients reported by a clinician. Clinical case-reports are not suitable for a large sample. Questionnaire based studies, instead, work well for a large sample size, and one specific population may be targeted, for example students.

Schroeder et al (2013), reported 42 misophonia sufferers. These patients were seen in a clinic by a team of

trained psychiatrists. Most subjects (81%) had eating sounds as their triggers; the second most trigger sounds were nasal/breathing sounds (64%). The mean age of the onset of the discomfort was 13. About 52% had OCPD as comorbidity. About 29% reacted with verbal aggression and about 11% reacted with physical aggression.

Kumar et al (2014) used an online questionnaire. The data from 157 participants were analysed of which 93% had eating sounds as their triggers: the average age of the onset of symptoms was 12; 86% had anger as their dominant emotional response to sounds; most (84%) would leave the situation where the trigger sounds were being produced.

Wu et al (2014) collected data from 483 undergraduate students in a US university using a questionnaire. Nearly 20% of the sample had clinically symptoms of misophonia and in many cases symptoms of misophonia were correlated with obsessive-compulsive and anxiety symptoms.

Naylor et al (2021) used a questionnaire to collect data from 336 undergraduate students in the UK: clinically significant symptoms of misophonia were found in 49.1% of the sample, whereas moderate to severe symptoms were found in 12% of the sample.

Nowadays, we have many questionnaires available for self-report:

- Misophonia Amsterdam Questionnaire (Schroeder et al, 2013).
- Misophonia activation scale (Fitzmaurice, G., available online).

- Misophonia Questionnaire (Wu et al, 2014).
- S-Five (Silia et al, 2020).
- Duke Misophonia Questionnaire (Rosenthal et al, 2021).

Which questionnaire should be used? There is no standardised questionnaire available yet and questionnaires need to be validated for them to be clinically useful. Some attempts have been made: for example, the S-Five has adopted a validation procedure. Until a standard questionnaire exists, the recommendation is to use more than one questionnaire and, along with the misophonia questionnaire, use questionnaires to assess other symptoms of distress such as anxiety.

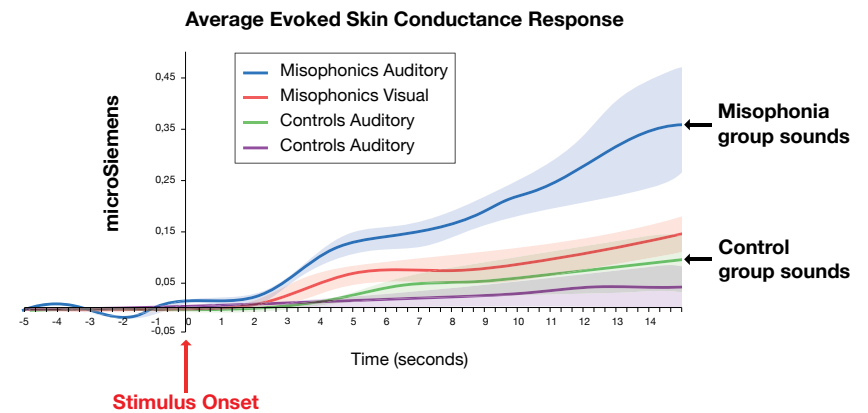
Non-brain based physiological measures

The central idea about non-brain based physiological measures is that the trigger sounds cause ‘arousal’ in the body. For example, the trigger sounds may increase the heart rate and change in heart rate can be measured using electrocardiograph (ECG). The arousal can also be measured using skin conductance response, also called as galvanic skin response (GSR). The idea is that arousal results in stronger activity of sweat glands: this causes you to sweat more (for example, palms become sweaty). Sweat makes skin more ‘conductive’, that is, it allows more current to pass through it. This conductivity can be measured by attaching two electrodes on two fingers.

The first study to use non-brain based physiologi-

cal measure was Edelstein et al (2013). In this study, a range of sounds like pen-clicking and chewing sounds were used. Sounds were presented to both misophonia group and controls, and visual stimuli were also used. Subjects were asked to rate the distress caused by the auditory and visual stimuli, while skin conductance response was measured in response to the stimuli.

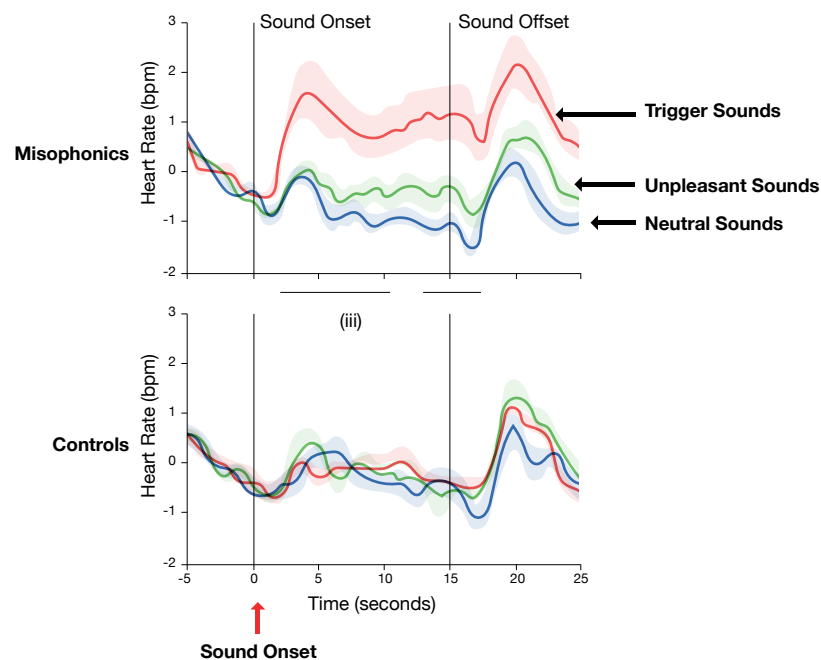
Misophonia sufferers rated the sounds to be more distressing than controls (bar chart on the right). They showed stronger skin conductance response to sounds when compared to controls.



Skin conductance response to auditory and visual stimuli.

Kumar et al (2017) measured heart rate and skin conductance. Three categories of sounds were used: (1) Trigger sounds; (2) Unpleasant sounds; (3) Neutral sounds. Trigger sounds are sounds of eating/chewing;

unpleasant sounds are annoying but do not cause a misophonic reaction (for example, a baby cry); neutral sounds are sounds such as sound of rain. Sounds were presented to misophonia sufferers and controls inside an MRI scanner and skin conductance and heart rate were measured in response to sounds.



As a first short conclusions, it is possible to affirm that trigger sounds cause increased heart rate and skin conductance response in misophonia sufferers. This is consistent with ‘fight/flight’ response described by misophonia sufferers. The increased physiological responses (skin conductance and heart rate) are consistent with the

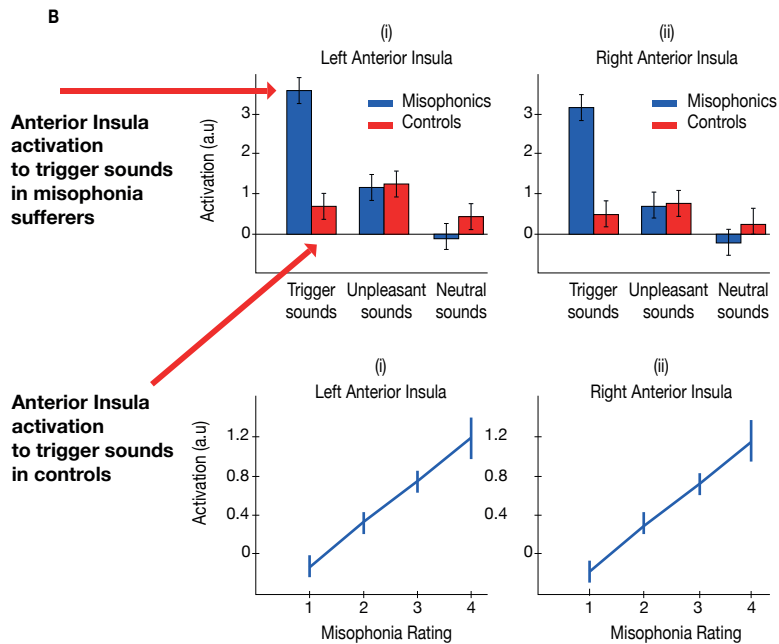
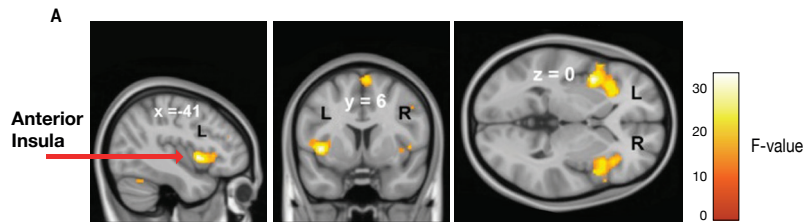
experienced distress in misophonia sufferers. Compared to controls, misophonia sufferers do not show increased physiological responses to non-trigger sounds.

Brain based physiological measures

What brain areas are involved in misophonia? The initial model of misophonia by Jastreboff and others suggested anomalous functioning of the sound processing part of the brain. Kumar et al (2017) at Newcastle University performed the first brain imaging study. The study was based on functional magnetic resonance imaging (fMRI). Three categories of sounds (as already described) were chosen: (1) trigger sounds, (2) unpleasant and (3) neutral. Brain activity was measured when subjects were listening to these sounds and two groups of subjects were involved: misophonia sufferers and controls. After every sound, subjects also gave a rating of distress experienced.

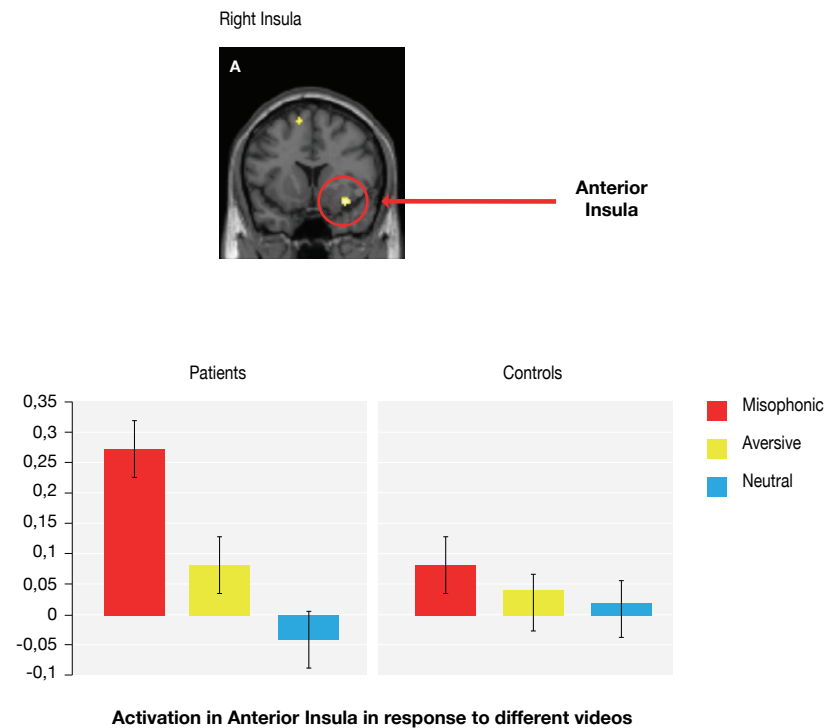
The analysis of data revealed that misophonia sufferers showed much stronger activation in a part of the brain called Anterior Insula when compared with controls (data shown in next figure). The stronger activation was in specific to trigger sounds. Unpleasant and neutral sounds showed equal responses in both misophonia sufferers and controls.

The sounds processing part of the brain did not show any different activation compared to controls. That is, the auditory part of the brain is showing ‘normal’ activation.



Another brain imaging study using fMRI was performed by Schroder et al (2019). The stimuli used were videos rather than sounds. Like the Kumar et al (2017) study, they used three categories of videos: (1) trigger, (2) unpleasant, and (3) neutral. Brain activity was measured when subjects were watching the videos, and two groups of subjects were involved: misophonia sufferers and controls.

The analysis of data revealed that misophonia sufferers showed stronger activation in Anterior Insula in response to trigger videos (data in the next figure). The study also measured heart rate and showed increased heart rate in misophonia sufferers when watching trigger videos. The sound or vision processing part of the brain did not show any different activation compared to controls. The study, therefore, replicated the findings of Kumar et al (2017).



Both the fMRI studies show Anterior Insula is activated by trigger sounds in misophonia. What is the role

of Anterior Insula? Anterior Insula is known to be involved in emotion processing and to control activity of our internal organs such heart/lungs. In misophonia, it seems that stronger activation of Anterior Insula is driving the physiological responses (heart rate and skin conductance). Why trigger sounds activate the anterior insula in misophonia sufferers is not clear. Further work is needed to understand the brain mechanism of misophonia.

Social basis of misophonia

So far, misophonia is considered as a disorder of sound processing. But the fact is that the trigger sound is always from another person. Could there then be a social component to misophonia?

In their more recent work (Kumar et al, 2021), the authors proposed that misophonia should be understood within a social framework. The brain areas involved in the processing of social stimuli (such as sound from other person) are very different compared to when sound comes from a non-person. The Anterior Insula is also known to be involved in the processing of social signals. The fact the sound processing part of the brain in misophonia responds normally and that the Anterior Insula is strongly activated suggest social basis of misophonia.

In processing social signals, mimicry is widely known to occur. Mimicry means 'automatic' and unconsciou-

sly copying the action of others. For example, if I watch you moving a cup from one place to another, then my brain areas which are involved in moving my muscles are activated as if I were moving the cup. That is, simply watching an action or hearing the sounds produced during an action is enough to activate the part of my brain which moves muscles.

Kumar et al (2021) showed that the auditory part of the brain and the brain part which moves muscles of the face are strongly connected. It may be that just watching or hearing the chewing sound of the trigger person activates the 'mouth moving' part of the brain. This part is also very strongly activated when the misophonia sufferers listen to trigger sounds. Some misophonia sufferers automatically start mimicking the action of the trigger person, and automatic mimicry of the trigger person points to a social basis of misophonia. The issue, however, needs further evidence. If the social basis of misophonia is the future evidence, then this will change the way we understand misophonia and what sort of treatment options should be considered.

Clinical diagnosis and treatment

Although arguments for misophonia as a psychiatric disorder have been made, it is not listed in any of neurological/psychiatric classification guide such as DSM-IV or ICD-11. Currently, there is no standard procedure for diagnosing misophonia. Research labs use interviews/

questionnaires to classify a subject as misophonic or not. For example, some questionnaires that are commonly used are:

- Amsterdam Misophonia Scale (Schroeder et al, 2013; Plos One)
- Amsterdam Misophonia Scale-Revised (Jagger et al, 2019; Plos One)
- Misophonia Questionnaire (Wu et al, 2014)

Treatments that are being considered for misophonia can be classified under three headings:

- 1) Sensory
- 2) Pharmacological
- 3) Psychological

In the sensory treatment, attention is paid to modify the auditory input. For example, the simplest method is to block the sounds by putting some sound obstructing device such as an ear defender or headphone. Another way is to not to block the sounds but modify the sounds by masking them with say 'white noise'. In another version, trigger sounds are presented in association with neutral/pleasant sounds so as to modify the emotional response.

The second treatment option is pharmacological. When a misophonia sufferer approaches a general practitioner for help, sometimes antidepressants or anxiolytics (anti-anxiety drugs) or beta-blockers are

prescribed. These drugs reduce anxiety and emotional responses to stressful situations, but they are not specific to misophonia, and there is no scientific evaluation of how effective the sensory or pharmacological based options are for misophonia.

The third option is psychological treatments. Cognitive Behavioural Therapy (CBT) has shown very encouraging results for misophonia: the idea behind CBT is to re-frame and re-think about the emotional response with the help of a trained psychiatrist.⁴

Other potential treatments which have not been tried and evaluated could be brain based. For example, stimulation of a particular brain area using transcranial magnetic stimulation (TMS). In this method, the stimulation is applied at the scalp to switch on or switch off a brain area to understand its role. In misophonia, for example, TMS could be targeted at Anterior Insula or related brain areas.

Another possibility is using biofeedback or neurofeedback. With this method, the subject is trained to control either body physiological response (such as heart rate: biofeedback) or brain activity (neurofeedback). Effectiveness of both these methods in misophonia treatments have not been evaluated so far.

4. See Chapter 6 of this book.

Chapter 3

How Misophonia Affects our Personal and Social Lives

*By Sonja Berko, Wolfgang Eisenreich,
Engin Eker and Hjörtur H. Jónsson*

The Importance of an Individual's Social Life

An individual's social life is incredibly important for his/her overall well-being and happiness. Humans are social creatures, and we have a natural desire to connect with others and form meaningful relationships. Here are a few reasons why an individual's social life is so important:

- *Emotional support:* Our social connections provide us with emotional support when we're going through difficult times. Having friends and family members who are there for us can help us feel less alone and more capable of handling life's challenges.
- *Improved mental health:* Studies have shown that having strong social connections can improve men-

tal health and help prevent conditions like depression and anxiety. When we feel connected to others, we're more likely to feel happy and fulfilled.

- *Increased resilience:* People with strong social connections tend to be more resilient in the face of adversity. They have a support system to rely on and can lean on their friends and family members during tough times.
- *Physical health benefits:* There is evidence to suggest that social connections can also have physical health benefits. For example, people with strong social ties are less likely to experience chronic diseases like heart disease and dementia.
- *Personal growth:* Being part of a social group can also help us grow as individuals. We learn from our interactions with others and are exposed to new ideas and perspectives that can broaden our horizons.

Social functioning refers to an individual's ability to interact effectively with others and to fulfill the roles and responsibilities of a member of a social group. It plays a vital role in our well-being and quality of life. Here are some reasons why social functioning is important:

- *Mental health:* Social functioning can have a significant impact on an individual's mental health. A lack of social support and meaningful relationships can lead to feelings of isolation, loneliness, and depression.
- *Physical health:* Social support and social networks have been linked to better physical health outco-

mes, such as lower rates of chronic diseases and mortality.

- *Career success:* The ability to work well with others and communicate effectively can lead to career success and advancement.
- *Personal growth:* Social interactions provide opportunities for personal growth and development, such as learning new perspectives and gaining new skills.
- *Community involvement:* Social functioning allows individuals to engage in their communities and contribute to social causes and movements.

Social functioning is therefore crucial for our overall well-being and success in various aspects of life. It enables us to form meaningful relationships, connect with others, and contribute to society.

The individual's social life provides emotional support, improves mental and physical health, increases resilience, and helps us grow as individuals. Therefore, it is essential to remember that misophonia is a genuine condition that can have a significant impact on an individual's personal, daily, and overall social life. Educating others about the condition and its effects can help reduce stigma and increase understanding, leading to more inclusive and supportive social environments.

Social Context in Misophonia

In a social context, the effects of misophonia are extremely significant. Relationships, friendships, parenthood, school, study, employment, and general health are subject to a great deal of strain. If a person is severely impacted by the disorder, it can be life-altering and have a significant influence on his/her everyday personal and social functioning. Individuals with misophonia are frequently misunderstood by their surroundings. This is due to unfamiliarity with the disease and others' inability to comprehend what it might be like for them to respond so strongly to an innocent sound. Hence, misophonic people frequently feel helpless and suffer in silence.

The effects of misophonia depend largely on the quantity, prevalence, and ability to avoid trigger stimuli. If a person is rarely exposed to trigger stimuli, misophonia has almost no effect on their life. Otherwise, it causes great distress and can reduce the quality of life. Individuals with misophonia report experiencing anxiety related states such as irritability, anger, restlessness, feeling of escape, intolerance, tension, and readiness to react. In addition, they report experiencing depressive states, namely hopelessness, pessimism, confusion, unhappiness. Also, disturbing bodily stimulations – sweating, increased heartrate, muscle contraction, stress, emotional outbursts - are reported. Such emotional states and physiological autonomic responses may cause individuals with misophonia to face problems in everyday life, especially in social contexts.

Building relationships and socializing with others are actions that individuals perform to express themselves. These acts are almost always driven by various emotions. In addition to emotional aspects, every experience has a cognitive code as well. Accordingly, it can be stated that such codes are not functioning in a proper way in individuals with misophonia. When they are triggered by disturbing stimuli, they cannot maintain the level of reactivity they would normally have. These triggers lead to a sensitive, vulnerable, and aroused mood which makes their mental balance exposed to deterioration. This leads to consequences such as alienation from social environment, quick temper, inability to focus on relational messages, and tolerate tension. Because they are not able to focus on relational messages, individuals with misophonia lose the contact with the other person and cannot focus on what the other person is saying. This leads to attitudes such as misunderstanding or overreacting because their dysfunctional cognitive patterns are activated. It is inevitable that such difficulties in emotion regulation cause problems in close and social relationships.

The avoidance of trigger noises is often what dictates the course of a misophonic person's life and typically results in limits in social functioning and occasionally even social isolation, and it has been found that living in seclusion is detrimental to one's health.

Social isolation, also known as social distancing or loneliness, can have various effects and causes. Particularly highlighted are:

- *Mental health problems:* Social isolation can lead to mental health issues such as anxiety, depression, and stress.
- *Physical health problems:* People who are socially isolated are more likely to suffer from physical health problems, such as heart disease, high blood pressure, and obesity.
- *Poor sleep:* Social isolation can disrupt sleep patterns, leading to insomnia or difficulty falling asleep.
- *Substance abuse:* Social isolation can increase the risk of substance abuse, such as alcohol or drug addiction.
- *Cognitive decline:* Social isolation has been linked to cognitive decline, including a higher risk of dementia.
- *Reduced quality of life:* Social isolation can lead to a reduced quality of life, with decreased satisfaction in relationships, work, and overall life experiences.

When behaviors of individuals with misophonia were examined in different environmental conditions, variations were reported. For instance, considerable deterioration of social connections was reported in work or school context and in social life. On the other hand, the impairment in the home environmental context remained smaller compared to work or school settings. This may be explained that, at home, individuals with misophonia may switch to their safety behaviors to avoid their distress without any serious consequence. How-

ver, within a social context, such as at work or school, it is usually not possible for individuals to escape from a situation involving distressing sounds.

Misophonic people tend to avoid social contacts, avoid crowded environments and try to be alone. But even if they are alone, because of the disturbing perception of environmental stimuli, they may lose their focus and have difficulty in tasks that require mental concentration such as studying, reading, and working.

Misophonia in Everyday Life

Living with misophonia can be challenging as it can affect everyday life in various ways. Both the sufferer and the immediate environment are victims. As a result of their misophonia, some people may become socially isolated. They may avoid social situations or interactions with others in order to minimize their exposure to trigger sounds. This can lead to feelings of loneliness, depression, and anxiety, as well as a sense of disconnection from others.

Let's see how misophonia affects an individual's inclusion and participation in various social spheres.

Health

The stress caused by misophonia can lead to physical symptoms such as headaches, elevated blood

pressure, and digestive problems. It can also exacerbate existing mental health conditions such as anxiety and depression. Of course, everybody with misophonia reacts differently physically to the sound of the trigger, which is responsible for an involuntary reaction or reflex.

Dealing with the stress created by triggers in social situations, people are more stressed with feelings such as hopelessness, anger, and helplessness, which again causes them to enter a more irritable mood. When they feel this way, in this vicious cycle they become even more sensitive to triggers. People with misophonia may feel intense anxiety, anger, or disgust when exposed to these sounds, and they may go to great lengths to avoid situations where they might encounter them.

As the anxiety level, the probability of activating these defensive reactions increases. People whose reactions are controlled by human functions such as eating or breathing, although they understand misophonic people, they are still disturbed by this restrictive situation and begin to withdraw from investing in their relationship with individuals with misophonia.

Therefore, misophonia can be associated with certain symptoms of mental disorders (depression, OCD, and bipolar affective disorders). Researchers have observed that subjects with depression and anxiety disorders, with a 60-70% overlap of these symptoms, have difficulty regulating the emotions that arise because of triggering. The latter is reinforced either by avoiding social situations or social triggers that push the person into social isolation.

In 2017, environmental and noise experts predicted that in twenty years noise would be the environmental issue with the greatest impact on public health if no action is taken. Noise pollution causes, among other things, sleep deprivation and stress, and people with misophonia frequently have a high stress level. In addition, the more stress they feel, the worse their triggers become.

Family

Living with misophonia can be challenging, but having a supportive family can be an essential factor in coping with this condition. Families can provide a safe and supportive environment for misophonic individuals. For example, family members can avoid making trigger sounds or help the person cope when they are exposed to these sounds. They can also offer emotional support and understanding, which can be crucial for managing the stress and anxiety that often accompany misophonia.

It is important, for family members, to educate themselves about misophonia to better understand what their loved one is going through. They can learn about the different trigger sounds and how they affect the person with misophonia, as well as ways to help them cope with their condition. Family members can work together to create a sound-friendly environment, such as using soundproofing materials or using white noise to drown out trigger sounds.

In some cases, family counseling may be beneficial for both the misophonic individual and their parents and other family members. These counseling sessions can provide a space to discuss the challenges of living with misophonia and develop strategies to manage the condition as a family.

Some useful hints can help parents with a misophonic child. If the child has misophonia, there are, indeed, several things parents can do to support them:

- It's important to validate the child's experiences and feelings. Listen to them when they express their frustration and help them feel heard and understood.
- Work together with the child to identify the specific sounds that trigger their misophonia. Once it is known what triggers their response, you can work together to find ways to minimize exposure to those sounds.
- Limit the child's exposure to trigger sounds as much as possible. For example, you may need to reduce the frequency of family meals or create a separate eating space for the child.
- Provide the child with a safe space where he/she can go to escape trigger sounds. This could be a quiet room or a pair of noise-cancelling headphones.
- Help your child to develop coping skills to cope with misophonia. This might include deep breathing exercises, relaxation techniques, meditation, or find a counselling support in cognitive-behavioral therapy.

- Educate family members, teachers, and friends about your child's misophonia. This can help them understand and be more supportive of your child's needs.

Remember that misophonia can be a challenging condition to live with, and it may take time to find strategies that work for your child. Be patient, supportive, and willing to work with your child to find solutions that help him/her manage the symptoms.

The School Environment

School is an environment where various kinds of stimuli come together. They can create very difficult situations for people with misophonic features. No matter how careful teachers are to fulfil the requirements of the educational environment, misophonic features prevent the emergence of the necessary attention, focus and creativity. When misophonic students' mental capacities are prevented to a certain extent, it becomes difficult to maintain academic success, which in turn will probably lead to lower grades at school.

The role of primary and secondary schools in the development of students' socialization skills is indisputable. Students with misophonia may begin to move away from the social environment and activities of the school, and therefore will probably be less successful and socially withdrawn from their peers. It is not possible for these students who do not benefit from these

educational and social opportunities and who cannot participate even if they want to, to achieve many organizational and protective mental and social gains which are the results of the education process.

Creating a socially aware school environment for misophonic people can help to mitigate the negative impact that certain sounds may have on their learning and wellbeing. By implementing the so-called socially supportive measures, a school can create a socially aware environment for misophonic pupils and students and promote a positive and inclusive learning experience for all of them. Here are some suggestions:

- *Provide a safe space:* Establish a designated quiet space or room where students can go to if they feel overwhelmed by certain sounds. This space should be a place where they can relax and take a break from the noise.
- *Educate students and staff:* Educate students and staff about misophonia and the potential triggers. This can help create awareness and understanding among the school community.
- *Implement sound-reducing measures:* Use sound-reducing materials in classrooms and common areas. This may include using carpets, curtains, and acoustic panels to absorb sound.
- *Avoid triggering sounds:* Avoid using triggers sounds such as chewing gum, clicking pens, tapping fingers, etc. in the classroom.

- *Modify classroom activities:* Modify classroom activities to reduce the potential for trigger sounds. For example, use headphones for videos or audio activities.
- *Create a supportive environment:* Foster a supportive environment by encouraging students to be mindful of each other's needs and to ask for help when needed.
- *Provide school counseling:* Provide access to counseling services for students who are struggling with misophonia. This can help them develop coping strategies and manage their emotions.

Working Environment

Misophonia can also affect a person's ability to concentrate at work, especially in an open-plan office where there are many people around making trigger sounds. This can impact productivity and professional success and may cause additional stress and anxiety. It can be very challenging for individuals with misophonia to cope with triggering sounds in a work setting. If the persons with misophonia are struggling to cope with the work environment, there are several strategies to try:

- *Use noise-cancelling headphones:* Wearing noise-cancelling headphones can help to reduce the impact of triggering sounds, particularly if you need to focus on a task that requires concentration.

- *Request reasonable accommodations:* Depending on the severity of your misophonia, you may be able to request reasonable accommodations from you as an employed person, such as a one-place office, a change in work hours, or a modified work schedule.
- *Practice self-care:* Managing stress is important for individuals with misophonia, as stress can exacerbate symptoms. You may want to consider incorporating stress-management techniques, such as mindfulness meditation or yoga, into your daily routine.
- *Educate your colleagues:* It can be helpful to educate your colleagues about your condition and explain how certain sounds can trigger intense emotional reactions. This can help to create a more supportive work environment where people are mindful of their behavior.
- *Seek professional help:* If your misophonia is significantly impacting your ability to work or affecting your mental health, it may be helpful to seek professional help from a therapist or counselor who specializes in treating this condition.

Managing misophonia at work will require a combination of strategies tailored to person's specific needs and circumstances. It may take some trial and error to find the most effective approach, but with persistence and support, it is possible to find ways to manage symptoms and succeed in the job-career.

Relationships

Misophonia can also put a strain on relationships with friends, especially if they are not aware of the condition. It may cause the person to avoid certain activities or social situations, which can lead to feelings of isolation and loneliness. As such, misophonia can have a significant impact on friendships, as it can make it difficult for someone with misophonia to spend time around friends who make triggering sounds which can lead to feelings of frustration, and even anger.

For example, if a friend has misophonia triggered by the sound of chewing, they may struggle to enjoy meals with their friends. They may find themselves avoiding social situations that involve eating or feel the need to leave abruptly when someone starts chewing loudly. This behavior can be perceived as rude or standoffish, causing tension and strain in the friendship.

Similarly, if a friend with misophonia is triggered by tapping or clicking sounds, they may have difficulty spending time around friends who fidget or use electronics with sound. This can make it challenging to engage in activities together, such as watching a movie or playing games.

Such situations can create barriers to socializing and bonding with friends. However, it's important to remember that it's not the misophonic person's fault, and they are not trying to be difficult or rude. By being understanding and accommodating, friends can help alleviate the negative impact of misophonia on their relationships.

For a Misophonia Socially Aware Environment

Despite the challenges that misophonic people may face in social environments, it is important to recognize their value and contributions to their communities. Like anyone else, misophonic individuals have unique talents, interests, and perspectives that enrich the social fabric of their environment. It is also important to acknowledge that misophonia is a real and valid condition, and to work towards creating more inclusive and accommodating social environments. This may involve raising awareness about misophonia and its impact, educating others on how to avoid trigger sounds or modify their behavior, and advocating for accommodations in public spaces such as schools, workplaces, and public transportation.

Social exclusion can have a significant impact on people with misophonia, as it can exacerbate their symptoms. It can trigger feelings of stress and anxiety in anyone, but it can be especially challenging for people with misophonia. Exposure to trigger sounds can lead to an intense physical and emotional response, which can be exacerbated by the stress of feeling excluded from social situations. Consequently, they may struggle to form and maintain close relationships because of their condition. This kind of social exclusion can lead to feelings of isolation and loneliness, which can be especially difficult for them. Misophonia can have a significant impact on a person's quality of life, and negative aspect of social exclusion can make it even worse.

The importance of misophonic people in their social environment lies in their humanity and their right to participate fully in society, free from unnecessary barriers and stigma. By embracing diversity and promoting inclusion, we can create a more vibrant and compassionate world for all.

It is for reason that we believe that a misophonia socially aware environment will no doubt in the coming future be directed towards a socially inclusive environment that can be friendly to people with misophonia. Creating it involves understanding their needs and accommodating them as much as possible. It requires a collaborative effort between those with the condition and those without. By working together and being mindful of each other's needs, it is possible to create a more inclusive and supportive environment for everyone.

Chapter 4

Coping with Misophonia in Education

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Misophonia is a challenging disorder when it comes to formal and non-formal educational contexts. Early years at school can be particularly hard, having to share spaces with others inside and outside. Discovering you have misophonia and trying to come to terms with it can be an alien and confusing experience for students, being that the disorder is still quite unknown.

This is a world which doesn't yet fully understand what misophonia is. Most people still don't know it exists or has a name. Being aware that there is such a disorder though, now means for teachers and parents to walk hand in hand and make life easier for students who are misophonic.

Guidelines are offered in this handbook not only about the disorder itself, but also how to identify misophonic students. Specialists in the handbook have provided the information about the disorder and through

observation and tests carried out by teachers in schools and universities, a list of easing adaptations for a friendly misophonic environment have been drawn up. This handbook is therefore a starting point for schools where inclusion is a must.

Formal educational contexts and misophonia

Every person with misophonia is different. Children with misophonia may have more severe or less severe responses to trigger sounds at different times of the day, and according to the different environments. This is reflected in their daily behavior in class and can negatively affect their interactions with their peers and teachers.

Considering what misophonic students' must struggle with at school and how important inclusion is for them and for all students, schools will most probably face these problems:

- teachers have to deal with an unknown disorder, so training and advice from specialists is a must;
- most students are not diagnosed, so his or her behavior could be misunderstood;
- lack of an environment which fosters cooperation with the rest of the educational community may make a teacher's job more difficult when encountering a misophonic student.

According to research, children encountering misophonic sounds can show the following symptoms:

- they may cover ears with hands;
- they may experience mood changes such as becoming angry, fearful, or overwhelmed in response to sounds that other children do not even notice;
- they may feel a desire to leave specific places;
- they may tend to avoid specific places where misophonic sounds are known to occur;
- they may have difficulty with self-regulation that seems atypical for the child's age;
- self-isolation may occur.

These symptoms can be misunderstood in schools, so it is very important for teachers to be aware that they could be related to misophonia.

Regarding self-isolation, we need to point out that misophonic students tend to isolate themselves to avoid what, for them, may well be stressful sounds. In this sense, lunch time, break periods where students gather to have a snack, play with a ball, or just sit to chat can be a very stressful time for a misophonic student. Nevertheless, sometimes common areas can strangely enough also be misophonic-friendly so to say. Common areas can also mask trigger sounds. Thus, when observing students who could well be misophonic, teachers and parents should consider the classroom the best environment to collect information, regarding behavior and attitudes which could recall the misophonic syndrome.

Misophonic student's behavior or what can be considered as misbehavior needs to be somewhat reinterpreted. Teachers and parents, observing a child with misophonia, may consider the child's attitude negatively at the beginning, but reconsidering what he/she does, being aware of what happens to a misophonic person in contact with trigger sounds, will surely reassure adults that what seems to be misbehavior is actually just a reaction trying to cope with what's going on in a misophonic brain and body. Recent research suggests that the misophonic brain misinterprets sounds as toxic or threatening and sets off our survival system, better known as the fight/flight response. Thus, students with misophonia may appear to have behavior problems; however, it could simply be their response to the anger that the misophonic sounds trigger.

So, we clearly understand that misophonia is not just a behavior or misbehavior, it's a syndrome and it can affect concentration and memory which may also affect the ability to focus on studies. Students may experience significant symptoms of fatigue due to the high state of arousal and fight/flight response. Triggers can provoke different responses depending on the individual and how well they are able to cope on that day. The student may physically react, for example by rocking, covering ears, hunching down in their seat, leaving the room abruptly. Students may even experience high levels of anxiety. Teachers and parents need to be aware of the fact that the classroom could, therefore, be a hostile environment to misophonic students as the silence required for the

lessons can enhance and trigger misophonic sounds for misophonic students. These students may well feel the need to leave the classroom and consequently they may ask to go out to reduce their anxiety. Needless to say, on exam day or when taking tests, students with misophonia may suffer and not perform at their very best. Failure may then cause an increase in anxiety.

Besides, taking part actively in extracurricular activities may become difficult for students suffering from misophonia. They will try to avoid activities which will make them come in contact with trigger sounds. So, school trips can also be considered a burden to them. They may not be comfortable in school buses, cinemas, theatres, etc. Misophonic students, like students with other disabilities and disorders, may also experience bullying. Analyzing students' behavior and bullies can help teachers become aware of the problem enabling him or her to observe and detect what, in fact, could be due to misophonia. Indeed, many misophonic students may end up not taking part in any extracurricular activity. School may become their closest enemy if teachers and parents don't collaborate together with specialists to make their school life easier. So, teachers and parents must start considering what can be done to make schools and universities a better place for misophonic students. Before doing so, some charts are provided in the following to help identify behaviors which could belong to misophonic students.

Observation charts to detect misophonic students

As we have previously mentioned, misophonia is an unknown disorder and the advice of a specialist is necessary. Besides the Misophonia@School mobile application,⁵ using the charts below may help teachers to be aware of a misophonic student in the classroom. Teachers can only observe whether any of the reactions present in the charts are frequent in their students. If so, following advice from an expert will then be required.

⁵ See Chapter 8.

Common reactions in misophonic people to trigger sounds

Trigger sounds	Mouth noises (chewing, slurping, crunching)	Leg rocking Waggling or jiggling feet	Joint cracking	Sniffing or nose rubbing	Tapping	Pen clicking
Reactions						
Mood disorder						
Attention deficit						
Sweating or quickened heartbeat						
Muscle tension or pressure throughout the body						
'Fight or flight' reaction (anxiety or panic)						
Physical or verbal violence						
Ear plugging						
Crying, screaming or making loud noises						

Less common reactions in misophonic people to trigger sounds

Trigger sounds	Rustling of papers or fabric	Clocks ticking	Nail clipping or filing	Glasses or cutlery clinking	Hair twirling	Animal sounds or humming sounds
Reactions						
Mood disorder						
Attention deficit						
Sweating or quickened heartbeat						
Muscle tension or pressure throughout the body						
'Fight or flight' reaction (anxiety or panic)						
Physical or verbal violence						
Ear plugging						
Crying, screaming or making loud noises						

Non-formal educational contexts: tips and advice

In non-formal education contexts, misophonic students (as mentioned before for extra-curricular activities) could avoid taking part. To this purpose, the following guidelines for parents and educators are to be considered useful to help misophonic children:

- Reactivity is often lower when walking or doing sports, so activities which involve walking and sports are to be considered.
- Avoiding specific places where triggers are known to occur.
- Misophonic children should be encouraged to do activities and hobbies outside of school if there are no school activities the misophonic child wants to engage in.
- Do not force the misophonic child to continue doing an activity if it is becoming too stressful; remember, the lower the child's overall stress, the easier it is to manage misophonia.
- Comfort the child if they feel left out and consider arranging something you can do together that day, such as visiting a zoo or whatever activity you feel is appropriate.

Educational Strategies for misophonic students

Considering misophonia as a condition characterized by an impulsive aversive physical reaction of irritation, anger, or disgust when confronted with specific, repetitive stimuli, teachers should be aware of such reactions and consider what may happen in class with a detected misophonic student. Thus, they should strategically rearrange classroom furniture or plan a misophonic-friendly activity (moving around the classroom with a group activity or peer to peer activity, even Total Physical Response activities for language learning) every lesson which could help avoid amplifying trigger sounds in the school environment to allow students to feel included.

So, teachers first observe students and then plan the right strategies to face and overcome the problems which have already occurred or may occur allowing the teaching/learning process to be successful. The charts in the above paragraph could help teachers to verify whether the behaviors or reactions of their students could be considered in the range of the misophonic disorder and with the help of a specialist and the student's family the teaching/learning process must be thoroughly planned to avoid misophonic students dropping out of school caused by constant anxiety and failure, which are a consequence of what happens to a misophonic student in time without being aware of the problem and overcoming it.

As mentioned above, students with misophonia may have problems such as impaired concentration while

studying or doing their work, isolation and alienation from certain environments, and limited ability to communicate with others. If the teacher has observed reactions such as chest tightness, muscle stiffness, increased heart rate, increased body temperature, and palm sweating or any of the reactions listed above, soothing the reaction is what teachers are called to do. Many studies have shown that there is a direct and significant relationship between misophonia and anxiety in students. So once teachers have observed students and they realize that their student may well be misophonic either for a physical reaction or psychological one, the next step is to adopt (as is mentioned above) the right strategies, techniques, manners, and behaviors which will enable the student to calm down and feel reassured.

Misophonia is a chronic condition, with onset most commonly described in childhood. So, teachers may well observe misophonic reactions in pupils at a very young age. There is uncertainty with regard to a possible hereditary component to misophonia, even though several sufferers identified the condition in at least another family member. However, these notions are derived from early studies whose interpretation requires caution, so teacher observation is fundamental and together with medical support strategies may well be drawn up.

The coping strategies adopted by students with this condition do not necessarily involve avoidance (removing self from certain situations) or other socially dysfunctional behaviors such as challenging other people in order to stop them making noises or mimicry to

'cancel out' the trigger sound. What's important is that misophonic students focus on positive feelings and on their own sounds, thus internal dialogues have all been reported as useful techniques to cope with misophonia symptoms as well as helping those students to do activities that will avoid amplifying trigger sounds. Nevertheless, parents and teachers should also concentrate on arising positive feelings.

But how can positive feelings arise? What may teachers do? Here are some tips for teachers to overcome misophonic reactions in students:

- Allow the children initially to leave the area where the trigger sound is taking place but without seeming avoidance. Give the student a colored card to show on their leave without giving any explanation. This should only occur for a short period so that leaving the classroom does not become a habit but a quick break to take a deep breath and focus on positivity. The school may have a furnished area for misophonic students with soft toys or certain colors to lower anxiety.
- Teachers and parents should convince children that trigger sounds last very little and ask them to focus on their breathing.
- If someone is producing the trigger sound, they could be kindly asked to stop by the teacher who should always observe misophonic students and be aware of their reactions.

- Children should be taught to divert their thoughts and distract themselves from the sound.
- Allow children to bring something that triggers a positive feeling (i.e., a toy, etc.).
- Allow students to listen to their favorite songs with earplugs, white-noise or sound generators or earphones while working.
- Testing and exams could be done in a separate room if necessary, according to how severe the disorder is.
- Adjust the environment at school or in the classroom to meet students' needs, for instance children with misophonia are very sensitive to certain colors, such as blue or green, which seem to be soothing for them.
- Do not force your student to stay in an activity if it is becoming too stressful.
- Avoid using a blackboard or chalks, better to use an interactive whiteboard.
- Try to use as much technology during the lesson as possible in order to avoid paper and pens.
- In school trips, if possible, arrange for alternative travel arrangements for the child (although this is not always possible, i.e., driving the child by parents and meeting up with the rest of the group).
- Often it is helpful for a child to see a school counsellor.

SECOND PART

SUPPORTING AND TREATING PEOPLE WITH MISOPHONIA

Chapter 5

Misophonia and Co-Occurring Disorders

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Many people ask whether misophonia is related to certain mental health problems. It is difficult to know, for sure, because the research addressing this question started less than 10 years ago. But there are some things that can be said based on the available studies that have been published. In this chapter, we provide a brief overview of the scientific findings on some of the most studied disorders and problems that may co-occur with misophonia. Although most of the research on this topic has been done by asking participants if they have been diagnosed with select symptoms or disorders, we focus mostly on studies that have used structured interviews and more rigorous methods.

Misophonia and anxiety disorders

Many studies have started to explore how anxiety symptoms are related to misophonia. A research group

based in Amsterdam found that 9% of adults with misophonia had a co-morbid anxiety disorder (Jager et al., 2020). In one of the studies that we did at Duke University, however, the problem that was most related to misophonia was anxiety. Similarly, in a study conducted at the University of Warsaw, panic disorder was the second most prevalent among misophonia sufferers (Siepsiak et al., 2022). Even though people with misophonia experience a range of emotions (e.g., anger, disgust, irritation), the feeling of anxiety is common. When encountering misophonic triggers, the body may go into a flight or fight reaction, producing anxious arousal that functions to mobilize escape or confrontational behaviors. When anticipating being triggered, individuals with misophonia are often on edge and hypervigilant, scanning their environment and ruminating about being triggered.

With this in mind, the prevalence of anxiety within this population seems to make sense. In Rosenthal et al. (2022), 57.7% of the study sample met full criteria for at least one anxiety disorder at the time of being interviewed. Two of the most diagnosed anxiety disorders were social anxiety disorder (SAD; 31%) and generalized anxiety disorder (GAD; 25%). However, statistical analyses suggested that neither of these disorders were significant predictors of misophonia severity after controlling for age and sex, so we need more research to determine the trajectory and relationship among misophonia and anxiety disorders.

Still, while anxiety disorders may be prevalent but

not predict misophonia severity, there is clear overlap descriptively between misophonia and anxiety disorders. In Rosenthal et al. (2022), with nearly 60% of the sample meeting criteria for at least one DSM-5 anxiety disorder, it is probable that those with misophonia are more likely to have co-morbid anxiety than those in the general population (estimates of anxiety disorders in the general population range from 4.8% to 10.9%; Stein et al., 2017). Future research is needed to better understand the development and trajectory of misophonia and anxiety (i.e., relationships and differences between anxiety developing before the onset of misophonia, and vice versa).

How is misophonia similar to anxiety disorders? Without getting into the details of every specific anxiety disorder, we can say this: anxiety disorders and misophonia both feature anxious arousal, attentiveness to unwanted specific cues, anticipatory cognitive processes, and escape or avoidance behaviors to reduce aversive emotional arousal. How are misophonia and anxiety disorders different? A primary difference is that anger is not a primary emotion in anxiety disorders, but is common (if not central) to misophonia.

Misophonia and mood disorders

Second to anxiety disorders, mood disorders were the next most prevalent type of disorder that had overlap with misophonia in Rosenthal et al., 2022. Indeed,

14.4% of the sample met full criteria for at least one mood disorder at the time of being interviewed. Within that group, 7.7% were diagnosed with persistent depressive disorder and 6.7% were diagnosed with major depressive disorder. Around half of the sample had major depressive disorder at some point in their lifetime. Jager et al. (2020) reported mood disorders were among the most common psychiatric disorders in their sample of adults seeking treatment for misophonia. And, clinically, individuals with misophonia often describe feelings of isolation, detachment, and being misunderstood, as well as decreased self-esteem and self-efficacy. These difficulties can spill over into other domains of life outside of misophonia.

One possibility is that misophonia is correlated with negative mood in general, and not major depression specifically. However, it should be expected that some people with misophonia will report high symptoms or meet full diagnostic criteria for depressive disorders.

Misophonia and trauma-related disorders

People with misophonia develop strong reactions toward particular sounds or related stimuli. Many people have asked, “Is misophonia related to trauma?” Researchers have started to investigate this question. In the study done by Rosenthal et al., (2022), most participants did not have trauma-related disorders, with 24% having a trauma-related disorder at some point in their

lifetime. Another study (Siepsiak et al., 2022) found that only 12% of participants with misophonia met the criteria for current post-traumatic stress disorder (PTSD). Because these studies used structured diagnostic interviews (the gold standard method) to assess trauma-related disorders, these data suggest misophonia may not be highly related to a history of traumatic stress.

PTSD is a mental health condition that is triggered by a terrifying event (e.g., death, threatened death, serious injury, or sexual violence)— either experiencing it or witnessing it. Symptoms may include flashbacks, nightmares and severe anxiety, as well as uncontrollable thoughts about the event. What are the similarities between misophonia and PTSD? In PTSD, acoustic stimuli related to trauma can cause intense aversive emotional arousal with subsequent avoidant behavior. PTSD-related stimuli can arouse a sudden recollection and/or re-experience of the trauma, or of the original reaction to it, and may even trigger dramatic, acute bursts of fear, panic or aggression. These symptoms could, for some people, appear similar to reactions to triggering contexts in misophonia.

What are the differences between misophonia and PTSD? In PTSD, a life-threatening traumatic event (e.g., death, threatened death, serious injury, or sexual violence) has been experienced and the primary emotion is fear, not anger. Additionally, PTSD patients usually have recurrent, unwanted distressing memories of the traumatic event and experience intense negative emotions and physical sensations when recalling the trau-

ma memory. In contrast, in misophonia, the majority of patients have not experienced a life-threatening traumatic event causing misophonia and fear does not appear to be a primary emotion. If the patient is literally fearful of a sound and avoids it, they might have what is called phonophobia, and this is a different disorder than misophonia and PTSD. In addition, there are no data to suggest that people with misophonia usually recall a traumatic memory when having intense emotions and physical sensations after hearing trigger sounds. The conclusion: misophonia does not appear to be caused by or specifically related to traumatic events.

Misophonia and obsessive-compulsive disorder

Obsessive-compulsive disorder (OCD) features a pattern of unwanted thoughts (obsessions) that usually lead patients to do repetitive behaviors (compulsions) which function to neutralize the intensity of the obsessions. Patients with OCD attempt to ignore or stop their obsessions, but that often increases their distress and anxiety. Ultimately, patients feel compelled to perform compulsive acts in order to relieve their obsessional thoughts. But troublesome thoughts or urges keep returning despite attempts to ignore them or get rid of them. This leads to more ritualistic behavior — the vicious cycle of OCD. These obsessions and compulsions cause significant distress and interfere with daily activities.

Some people find it confusing to distinguish between

misophonia and OCD. Many studies have shown a correlation between misophonia and OCD symptoms (e.g., Wu et al., 2014; Zhou et al., 2017). Rosenthal et al. (2022) found that 27% of individuals with misophonia met the criteria for OCD in the course of their lives in an American sample. Two European studies found even fewer cases of OCD among people with misophonia. Jager et al. (2020), found only 2.8%, and Siepsiak et al., (2022), found only 6% of individuals with misophonia met the criterion for current OCD. In addition, another study found that some parts of OCD are related to lower misophonia (McKay et al., 2018). Together, this all seems to suggest that OCD and misophonia are fundamentally different, but may, for some people, share some overlapping features.

What are the similarities between misophonia and OCD? In misophonia, there is a preoccupation with specific sounds, which could resemble obsessions in OCD. Both disorders and other anxiety disorders (as well as PTSD) have avoidance as a primary feature. What are the differences between misophonia and OCD? Generally, OCD patients perform compulsive acts in an attempt to change obsessional thoughts, and anger is not commonly reported. In contrast, patients with misophonia typically do not react to triggering cues in order to change obsessional thoughts, per se. Instead, reactions to avoid or escape from misophonic cues function to reduce unwanted physiological, emotional, and cognitive processes related to a range of emotions, such as irritation, disgust, anxiety, and anger.

Misophonia and personality disorders

People with personality disorders have longstanding rigid and unhealthy patterns of thinking, functioning, and behaving. A person with a personality disorder has difficulty perceiving and relating to situations and people. This causes significant problems and limitations in relationships, social activities, work and school.

The presence of concurrent personality disorders has been found in patients with misophonia, although it is less common than other mental health problems. A study reported a comorbidity rate of 5% (Jager et al., 2020), while another reported a comorbidity rate of 13% (Rosenthal et al., 2022).

The most prevalent personality disorder among misophonia patients is obsessive-compulsive personality disorder (OCPD; Jager et al., 2020; Rosenthal et al., 2022). In Jager et al. (2020), 26% of participants with misophonia had traits of OCPD. This disorder is characterized by a pervasive preoccupation with orderliness, perfectionism, and control (with little room for flexibility) that ultimately slows or interferes with completing a task. It is important to note that OCPD is not the same as OCD, as OCD is mostly characterized by efforts to neutralize obsessional thoughts with repetitive actions or other thoughts.

Borderline personality disorder (BPD) may be the second most common personality disorder among patients with misophonia (Jager et al., 2020; Rosenthal et al., 2022). BPD is a condition characterized by severe

emotional dysregulation, behavioral problems, and difficulties with interpersonal relationships. People with BPD are more likely to experience intense emotions over a long period of time, and it is harder for them to return to a stable baseline after being exposed to emotionally triggering events. This difficulty can lead to impulsivity, poor self-image, stormy relationships and intense emotional responses to stressors. Having difficulty with self-regulation can also result in dangerous behaviors such as self-harm. People with misophonia may have high levels of inflexibility, perfectionism, and emotion dysregulation (Guetta et al., 2022; Rinaldi et al., 2022). However, most do not meet the diagnostic criteria for BPD.

Misophonia and sensory processing disorder

Sensory Processing Disorder (SPD) is a term used to describe a range of difficulties responding to everyday sensory stimuli (Miller et al., 2009). As misophonia is also a problem related to sensory processing issues, one may question if these are the same conditions. However, although misophonia sufferers often report being triggered by visual cues, and they also can have other sensory issues, they are over-responsive to very specific sound stimuli. SPD is not characterized by over-responsivity to oral and facial repetitive cues, as is the case for misophonia. At present, there is little known about the link between misophonia and SPD. Because SPD is a broad

term and is not fully understood or defined (Harrison et al., 2019; McArthur, 2022), it makes it even more difficult to understand the relationship between SPD and misophonia. Nonetheless, some preliminary data showed that although misophonia sufferers have increased sensory responsiveness, these are two different disorders (Kaufmann et al., 2022).

Misophonia and autism spectrum disorder

Abnormal sensory processing is one of the main symptoms in autism spectrum disorder (ASD). Therefore, the associations between misophonia and ASD would also seem an obvious area to be explored. Surprisingly, again - it is still one of the least researched subjects. In a study in the Netherlands (Jager et al., 2020), autism was diagnosed in 3% of the misophonia participants. However, people with ASD primary diagnosis were excluded from this group, so this percentage cannot reflect actual proportions. A larger percentage (5.6%) of self-reported ASD was found in self-reported misophonia sufferers in an online English-speaking sample (Claiborn et al., 2020). In a Polish study, people with self-reported ASD had significantly higher severity of misophonia symptoms than those without such diagnosis (Siepsiak et al., 2020a), but their outcomes did not indicate impairing significance of misophonia symptoms, and were much lower than outcomes of assumed misophonia sufferers. In addition, researchers from En-

gland (Rinaldi et al., 2022) found increased ASD symptoms in children and adults with assumed misophonia. However, further studies should verify whether that was a link between misophonia and ASD, or rather between some broader type of decreased sound tolerance and ASD symptoms. Because atypical reactions to a variety of everyday sounds are common in autism, when it comes to exploring these two conditions, the way misophonia is defined can particularly impact the results.

Although we still cannot say a lot about the relationship between misophonia and ASD, we can be rather sure about two things. It is already known that autistic people can suffer from misophonia (but they are rather more likely to have other types of decreased sound tolerance, such as hyperacusis or phonophobia; Williams et al., 2021), and that people with misophonia can be on the autism spectrum, but most of them are not.

Misophonia and attention deficit and hyperactivity disorder

Attention deficit and hyperactivity disorder (ADHD) is another developmental disorder in which sensory sensitivities are often present (Lane et al., 2010). This may also lead to a question of whether misophonia is related to ADHD. What do we know about the relation between those two disorders? In Turkey, in a population prevalence study (Kılıç et al., 2021), ADHD diagnosis was significantly more frequently reported by misophonia sufferers (20%) than by non-misophonia participants

(7%). In a study of self-diagnosed participants with misophonia from a variety of countries all over the world (Rouw & Erfanian, 2018), 12% reported to be diagnosed with ADHD, but some statistical analysis showed that the symptoms of misophonia were not related to this diagnosis. In a recent American sample (Rosenthal et al. 2022), the small significant relationship with self-reported ADHD disappeared after statistical corrections. A similar percentage (13%) was found in self-reported misophonia participants in another American study (Claiborn et al., 2020), however, no data on relationship between these two disorders were presented.

In several studies in the Netherlands (Schroder et al., 2013; Schroder et al., 2014; Jager et al., 2020; Schroder et al., 2017), between 4.4% and 5.4% participants with misophonia were diagnosed with ADHD. In an American misophonia treatment study, 1 person out of 18 (6%) was diagnosed with ADHD (Frank & McKay, 2019). Are all these numbers high? It was estimated that cross-national prevalence of ADHD is around 5% (Polanczyk & Rohde, 2007), and a more recent study showed that around 9%-10% children and teenagers in the USA meet diagnostic criteria of ADHD (Bitsko et al., 2022). As such, the rate of ADHD in misophonia in these studies was roughly similar as in the general population, and not higher.

Consideration of subtypes or domains of ADHD (attentional difficulties, impulsivity, and hyperactivity) may help us better understand in which ways misophonia is or is not related to ADHD. In one study (Silva & Sanchez,

2019), participants with misophonia had worse outcomes in selective attention tasks, but only during exposure to chewing. No differences between misophonia, tinnitus, and healthy control groups in attentional tests were observed, when chewing was not applied. Similar effects were found in Daniels et al. (2020). They showed that the severity of misophonia symptoms in non-clinical participants is related to poorer outcomes in attentional tasks, but only when the trigger sounds are present. These data indicate that people with misophonia may not have attentional deficits, and their results worsen only when they are extremely stressed, which is natural and happens to other people too, when they are highly stressed. However, there are conflicting data as well. In a different study (Frank et al., 2019), participants with misophonia had worse attentional results, also when they were not exposed to triggers. This means we don't have the final answer about this topic, and more research is needed.

Regarding impulsivity, in a study in the Netherlands, participants with misophonia were as good in some research tasks as controls (Eijsker et al., 2019). They preferred to make the tasks better, but slower. Impulsivity was also either very weakly related or not related, depending on its types, to misophonia symptoms in inpatients with depression in Poland (Siepsiak et al., 2020b). Ultimately, studies are needed to clarify better whether impulsive behavior in people with misophonia may be limited to situations with trigger sounds or to more general stressful situations (Cassiello-Robbins et al., 2020).

Regarding hyperactivity, to date there are no data about this feature in misophonia. Finally, it is worth noting that when it comes to comparing neurological correlates of ADHD and misophonia, it seems that these two have little in common (Neacsiu et al., 2022).

Conclusions

What conclusions can we make about which mental health and sensory processing problems are related to misophonia? Because the research is still new, we cannot make definite conclusions about many things. However, here are three reasonable conclusions that can be made: (1) misophonia is not related to any one specific mental health problem; (2) symptoms of some mental health problems may overlap with misophonia, but that does not mean the two disorders are the same; and (3) the two most common kinds of co-occurring mental problems may be anxiety and mood disorders. Together, this all means that people suffering with misophonia should be evaluated by trained mental health professionals for co-occurring psychiatric disorders, and treatment plans may need to be made that are individualized and flexible based on the unique needs of each person.

Chapter 6

Using Cognitive Behavioral Therapies in the Treatment of Misophonia

By Jacqueline Trumbull, Ashley A. Moskovich and M. Zachary Rosenthal

People with misophonia experience a lot of emotional suffering. Unfortunately, there are no scientifically established treatments for this disorder. This is a problem that we will talk about in this chapter. One part of the problem is that misophonia is not recognized as a formal disorder by any medical discipline. It could be a disorder at the intersection of multiple medical specialties, including, for example, the clinical fields of audiology, occupational therapy, otolaryngology, neurology, psychiatry, and psychology. Most of the research to date has focused on connections between misophonia and mental health. But we must keep in mind that misophonia is not classified as a psychiatric disorder, and it may not even be best to think about it only as a mental health problem.

With that said, misophonia is characterized by a heightened sensitivity and reactivity to sound and/or

visual triggers, resulting in distressing bodily reactions, as well as upsetting thoughts and feelings. Many people also have other mental health conditions such as anxiety and depression (Swedo et al., 2022). Given this, psychological treatments that help individuals cope with emotional distress may be well matched for misophonia and improve quality of life. Research has begun to test whether this is the case, and results are early but promising.

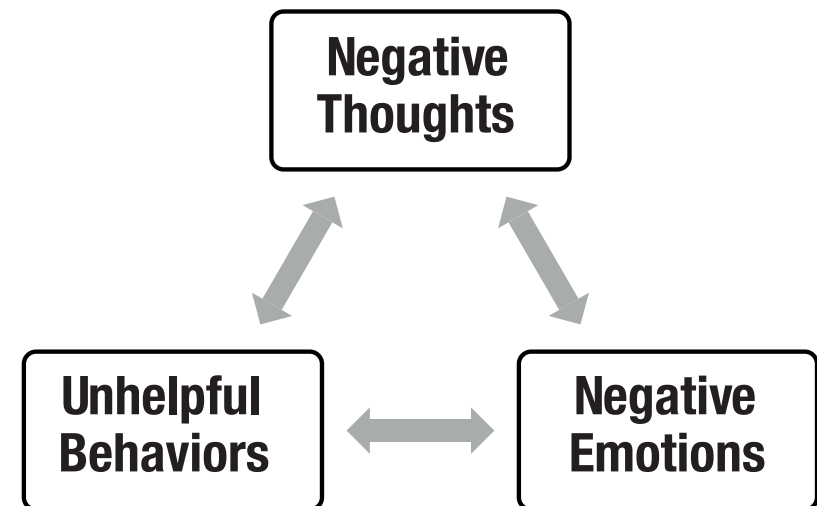
The goal of this chapter is to describe how a family of psychological treatments called Cognitive Behavioral Therapies (CBT) may be helpful as one part of a broader approach in helping people with misophonia. We first provide an overview of CBT and its application to misophonia. We then discuss findings from research studies that have begun the work of testing CBT as a treatment for misophonia. Lastly, we offer treatment recommendations in light of the current research.

Cognitive Behavioral Therapies (CBTs)

CBTs include a large group of psychotherapies that have been shown to be effective for a wide range of mental health concerns including things like depression, anxiety disorders, post-traumatic stress disorder (PTSD), substance use, and eating disorders. CBT do not refer to one specific treatment, but rather is an umbrella term for the numerous talk therapies that follow a similar approach. There are many differently labeled

brands of CBTs (e.g., cognitive therapy, behavioral activation, dialectical behavior therapy, the unified protocol, exposure and response prevention, and acceptance and commitment therapy). Despite uniquely branded names, many CBTs do similar things to help people. As such, CBT can be done in a way that is not branded by a specific manual, but instead uses common principles and approaches across CBTs, individually tailored for each patient.

Applying the CBT Model to Misophonia



Generally speaking, in a CBT model, psychological problems occur when negative or unhelpful thoughts, emotions and behaviors cause distress or problems in

one's life. Because thoughts, emotions and behaviors impact each other, one negative thought (or emotion or behavior) can set off a chain reaction that causes other emotions and behaviors, and so on and so forth. This can leave people feeling trapped in a problematic cycle of distress (see Figure 1).

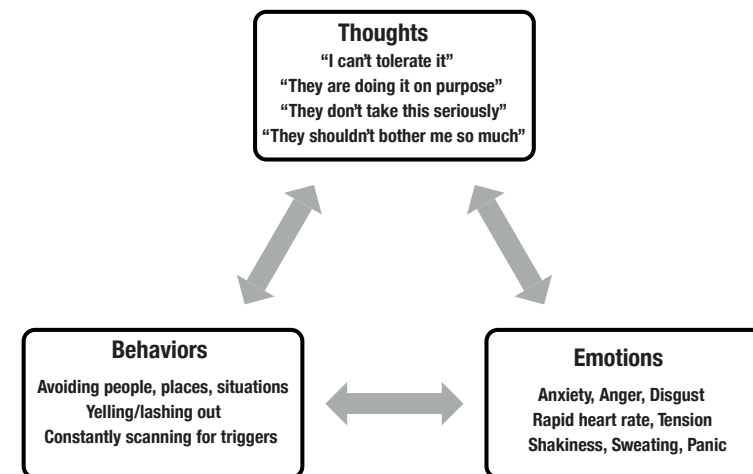
In line with a general CBT model, individuals struggling with misophonia find their triggers and situations that their triggers could occur in extremely distressing. They report thinking things like "I can't tolerate it" and then feeling extremely anxious or angry. They often report that this leads them to avoid situations because of how uncomfortable they feel or find themselves uncontrollably yelling at loved ones out of frustration. While these behaviors (e.g., avoiding situations, yelling) temporarily decrease distress, they also can lead to problems at school/work or in relationships, which in turn results in more distressing thoughts and feelings (e.g., thinking "I'm a failure", feeling guilty for lashing out). This often leaves people with misophonia feeling stuck and hopeless because the thoughts and feelings associated with their triggers feel intolerable, yet the ways they have learned to reduce their distress only cause more problems.

Using CBTs to Treat Misophonia

CBTs are usually somewhat or very structured and time-limited (e.g., 8-20 sessions). They can be delivered in an individual, group or family format. CBTs help people

with misophonia by the therapist and patient/client collaboratively working together to identify and change patterns that are learned but that are not always helpful. This includes figuring out and changing patterns of thinking, feeling, communicating, paying attention, managing bodily sensations, and reacting behaviorally in situations where they may be triggered by misophonic cues.

Put another way, CBTs help people learn new ways to cope with negative thoughts, physiological reactions, and feelings and learn more helpful ways to live in order to change patterns that are problematic. This decreases distress and improves quality of life by changing how they live their life at home, school, work, and social situations.



In CBTs, people with misophonia learn to identify unhelpful patterns and then learn to develop new patterns using what we can call evidence-based cognitive

behavioral skills. These are strategies for addressing problematic thoughts, feelings, sensations and behaviors that have been shown to be helpful when tested in scientific studies for other people. There are many CBT strategies found to be helpful across countless research studies over decades of scientific research for many different problems. Some CBT strategies target problematic thoughts, while others target problematic feelings or behaviors; however, targeting one impacts the others by disrupting the negative cycle (see Figure 2 for examples of common CBT treatment targets in the treatment of misophonia).

For example, people in CBTs may learn more helpful ways of thinking about triggers and the situations in which they occur (e.g., “They aren’t intentionally trying to upset me with that noise”), strategies for managing the distressing feelings and bodily sensations that happen when triggered (e.g., learn breathing techniques to decrease anxiety and reduce physical arousal), and practice more helpful ways to react when triggered that do not cause more problems (e.g., attending a social event with a plan to take brief breaks to calm down if triggers feel overwhelming so that they do not lash out at others). “Homework” is often given to help people practice and develop mastery over the coping skills they learn between therapy sessions. The overarching goal is to empower people by giving them the tools they need to cope with misophonic triggers.

Types of CBTs

As described above, there are many different types of CBTs. These branded CBTs all follow the CBT model but combine specific cognitive and/or behavioral strategies into a packaged treatment. For example, behavioral activation (Lejuez, Hopko, Acierno, Daughters & Pagoto, 2011) focuses on the use of behavioral strategies whereas acceptance and commitment therapy (Hayes, Strosahl, & Wilson, 1999) combines a specific set of strategies called acceptance and mindfulness skills into treatment. Branded CBTs are often manualized and specify treatment duration and format (e.g., group, individual), outline session content with guidelines on what CBT strategies to use when, and provide specific homework assignments.

Some branded CBTs tailor the content of treatment to the needs of a specific population. For example, CBT for Insomnia (CBT-I; Taylor & Pruiksma, 2014) combines CBT strategies known to help with the thoughts, feelings and behaviors that interfere with sleep (e.g., addressing anxious thoughts that make it difficult to fall asleep, practicing relaxation strategies before bed, establishing a sleep routine). Others are transdiagnostic; that is, the same treatment can be used with a range of clinical presentations. These transdiagnostic CBTs use interventions that target common problems thought to contribute to various mental health conditions. The same treatment can then be used for any number of clinical presentations that share this common problem.

Dialectical behavior therapy, for example, focuses on helping individuals regulate challenging emotions and has been shown to be an effective treatment for many mental health concerns that share this problem, including personality disorders, mood disorders and eating disorders (Bedics, 2020).

A new transdiagnostic framework for CBTs that may be useful for misophonia is a process-based approach, or PB-CBT (Hayes & Hofmann, 2018). PB-CBT is a flexible way to tailor treatment to the person's presenting problem(s), values, and goals. The client and therapist work together to identify patterns of problematic thoughts, feelings and behaviors as is done in other CBTs. However, they do not follow a manualized treatment protocol that pre-determines which cognitive behavioral strategies to use and in which sequence. Instead, the client and therapist figure out the patterns causing the problems, collaboratively prioritize which problematic thoughts, feelings, behaviors they want to address and in what order. They then collaboratively select the cognitive behavioral interventions they want to use to address these problems from the entire menu of evidence-based CBT strategies. The best intervention is the one that client is willing and able to do, and that helps improve their functioning the best. Once there is evidence that the problematic patterns are changing, the therapist and client move on to the next treatment target. Treatment is still somewhat structured and time-limited, but this is adjusted to meet the client's needs.

Using CBTs to Treat Misophonia: State of the Evidence

Evidence-based treatments are interventions that are known to work at treating a particular condition when repeatedly and rigorously tested in scientific studies. There currently are no evidence-based psychological treatments for misophonia. This will hopefully change as efforts to better understand and treat misophonia are underway. There have been 17 studies examining psychological treatments for misophonia, most of which have used CBTs since they are well matched to the difficulties associated with misophonia.

To date, 14 studies using branded CBTs or cognitive behavioral strategies have been conducted. Most (i.e., 11) of these studies have used a case study or case series design. Two open trials and one randomized control trial (RCT) have been done. The number of participants across all studies ranged from one to 90, and the number of treatment sessions ranged between 6 and 30. Studies tested whether misophonia symptoms improved pre to post treatment using validated self-report questionnaires that ask participants to indicate the frequency, intensity and level of distress and impairment associated with misophonia symptoms.

Case Studies/Case Series

Case studies and case series test an intervention with a small number of individuals and are often the first

step of testing a treatment. Individuals are given the treatment, and their progress is carefully studied and recorded. The goal of this type of research design is to first see if people find the treatment acceptable and are willing to participate until the study is completed. This is a really important step since treatment cannot be helpful to people if they will not actually complete it. These types of studies also give some preliminary information as to whether or not a treatment may be helpful and should then be tested with a larger number of people. However, they cannot conclusively tell us whether a treatment is effective.

Most CBT case series conducted so far involved only one adult participant; however, one case series using a treatment designed for youth included four children (Lewin et al., 2021). Four studies tested branded treatments including dialectical behavior therapy, acceptance and commitment therapy and the unified protocol (Kamody & Del Conte, 2017; Schneider & Arch, 2017; Lewin et al., 2021). Some studies also tested whether specific CBT strategies, such as exposure and response prevention and relaxation exercises, were helpful. Overall, studies found that most participants completed the treatment and many reported improvements in misophonia symptoms. This suggests that CBT may be an acceptable treatment approach for misophonia, that people will complete it, and that it may be helpful. Given these findings, research has begun the next stage of testing CBTs in clinical trials with a larger number of participants.

Open Trials

There have been three clinical trials that have tested CBTs for misophonia. Two of these trials were open trials. This means that everyone who participated in the study received the same treatment. Open trials cannot be used to draw conclusive results because they do not include what is called a control group, or a group of people who do not receive the intervention but are followed over time while their symptoms are measured. Without a control group, we do not know if any improvements observed after treatment are due to the intervention or if people might have gotten better over time anyway without the treatment. However, open trials give us more evidence that a treatment is helpful and should proceed with the next step of conducting larger, more expensive trials with more people and control groups.

One open trial included 90 participants with misophonia in a group therapy setting (Schröder, Vulink, van Loon & Denys, 2017). Treatment focused on helping participants shift their attention away from trigger sounds, disrupting learned associations between stimuli and negative emotional responses, allowing patients to manipulate trigger sounds, and teaching participants relaxation exercises. At the end of treatment, clinicians rated 48% of participants as having improved, while 30% of participants rated themselves to have significantly reduced symptoms.

Another open trial tested 18 participants with misophonia with an exposure and response prevention

(ERP) that used an inhibitory learning approach (Frank & McKay, 2019). ERP gradually exposes individuals to the stimuli (i.e., situations or things) that provoke emotional distress and prevents them from leaving the situation or engaging in behaviors that otherwise help them decrease or escape their distress. For example, a client with misophonia would be invited to intentionally sit with a triggering sound without leaving the room or covering their ears.

There are two categories of ERP: habituation and inhibitory learning. During habituation-based exposure, a client is repeatedly exposed to a feared stimulus until their distress begins to decrease. Often, clients believe that confronting something they fear will increase their distress more and more. However, it is often the case that clients habituate, meaning they become used to the feared stimulus and their distress lowers over time. Habituation models have not been shown to work for individuals with misophonia, and are generally not recommended as they may not be acceptable to clients or their families.

In an inhibitory learning approach to exposure, clients experience triggering stimuli in new contexts and learn new ways of approaching or responding to the stimulus. The expectation is not necessarily that the client will become less distressed by the stimulus just by being exposed to it repeatedly, but that the client will learn to cope with the stimulus in new ways and experience it more flexibly. The goal of inhibitory learning models is for clients to behave in adaptive ways

even in the presence of triggers. In Frank and McKay (2019), 18 participants with misophonia completed ERP using an inhibitory learning approach. Participants completed exposures to triggers either before or after they received stress management training and results showed client improvement. This indicates that inhibitory learning models may be promising and worthy of future study in the treatment of misophonia.

Randomized Controlled Trial (RCT)

Finally, there has been one randomized clinical trial (RCT) for the treatment of misophonia (Jager, Vulink, Bergfeld, Loon & Denys, 2020). Randomized trials provide the best information about the efficacy of certain treatments, because they control for variables that might otherwise confuse results. In this RCT, 54 participants with misophonia participated in 6 months of either a group CBT condition or a waitlist control condition. In a waitlist condition, participants are not given any treatment until after the experiment is completed. This allows researchers to determine whether the treatment provides benefits compared to participants who are not receiving treatment. The group CBT consisted of task concentration, arousal reduction, positive affect labeling, and stimulus manipulation. Clinical improvement occurred in 32 of the treatment participants versus 0% in the waitlist control condition.

Ultimately, treatment studies involving CBTs for misophonia are somewhat promising, but more research

is needed before we can conclude this and determine which CBT or CBT strategies are most helpful. In particular, RCTs will provide critical information about which treatments work, as well as which components of each treatment provide the strongest impact. Researchers can also start to determine whether adjusting a branded treatment to misophonia is as effective as developing a new, misophonia-specific treatment. Overall, these studies have shown initial success, and it seems likely that CBTs may be a helpful treatment for misophonia.

Using CBT for Misophonia: Current Treatment Recommendations

We still have much to learn about misophonia and how to help the many people suffering. Until evidence-based interventions are established, we rely on what we know so far to guide treatment recommendations, expecting that these recommendations will evolve as our knowledge of misophonia advances. In light of current research findings suggesting CBT may be acceptable, feasible, and helpful, coupled with the lack of any specific evidence-based option, we recommend flexibly offering CBTs to individuals experiencing distress related to misophonia.

Research has yet to determine whether a specifically branded CBT approach or a more individualized treatment using CBT strategies works best for misophonia. Given this, we first recommend that individuals are assessed for co-occurring mental health concerns

such as anxiety and depression, which are common among individuals with misophonia. If a mental health concern is present, then we recommend selecting an evidence-based treatment for that mental health condition and implementing it in a way that also addresses misophonia. For example, evidence-based CBTs for anxiety could be recommended to clients with anxiety disorders. CBT skills for addressing anxiety (e.g., mindfulness, acceptance, cognitive reappraisal, behavioral activation) can also be applied to unhelpful thoughts, emotions, and behaviors related to misophonia.

If no other mental health concerns are present, then we recommend considering a flexible and individualized framework for treatment. This approach may be especially useful at this stage because we do not yet know which CBT strategies are most helpful for misophonia, and a flexible transdiagnostic model (e.g., PB-CBT) tailor treatment to the specific needs of the individual. The client and therapist collaborate to create a treatment plan that the client thinks will be most useful and is willing to complete. This approach needs to be studied scientifically, however, before we can state with greater confidence that it should be preferred over other approaches.

At this time, we recommend against using ERP as a stand-alone treatment focused on habituation. There is no evidence that individuals with misophonia habituate to triggers with repeated exposure, and clients often indicate that they would not be willing to engage this type of treatment anyway (Smith et al., 2022).

However, as noted above, there are some pilot data suggesting conducting ERP using an inhibitory learning model may be helpful. Incorporating exposure practice in therapy can be helpful when the focus is on helping clients practice established coping skills to manage distress, rather than on habituation alone. We recommend doing this only after clients have already practiced using their coping skills in less distressing situations and feel ready and willing to engage this type of intervention.

Lastly, we recommend that all candidates for CBT undergo a comprehensive evaluation that considers additional treatment recommendations by a multidisciplinary team of providers. This may include evaluation by primary care or pediatric doctors, audiologists, psychiatrists, and occupational therapists (and perhaps other types of specialists depending on the needs of the individual) who can evaluate and provide treatment recommendations for other health concerns that may be associated with misophonia. For example, some individuals presenting with misophonia may have hyperacusis, which has audiologic interventions that may be useful in treating symptoms of misophonia. Others may benefit from occupational therapy for multi-sensory over-responsivity. This approach also includes referrals to psychiatry for evaluation and consideration of medication management if desired by the client, though there are no medications yet to be studied or considered to be efficacious for misophonia. All treatment for misophonia should be done with humility about the lack

of clear scientific evidence for any particular approach, with an emphasis on not causing harm to the client, without assumptions that there is a cure, and with flexibility to meet the client's needs in the context of their impairments in everyday functioning, goals, and values.

Chapter 7

The Duke Misophonia Questionnaire

By the Duke Center for Misophonia and Emotion Regulation

Introduction

The identification of misophonia and the support of people affected by it also happens through self-report techniques, as already mentioned in chapter 2 of this book. Among these techniques there are assessment questionnaires, of which we present here the Duke Misophonia Questionnaire (Rosenthal et al, 2021). This will offer the reader the widest possible view of the world of research that is currently interested in misophonia.⁶

The Duke Misophonia Questionnaire (DMQ) is the first psychometrically validated self-report measure of misophonia using factor analytic procedures combined with item response theory IRT. The DMQ can be used in its totality, as individual subscales or with composite scores of symptom severity or difficulties coping.

⁶ The editor would like to thank Prof. M. Zachary Rosenthal, together with the whole team of the Duke Center for Misophonia and Emotion Regulation, for kindly allowing the publication of the DMQ in this volume.

The final DMQ has 86 items and includes subscales:

- 1) Trigger frequency (16 items)
- 2) Affective responses (8 items)
- 3) Physiological responses (5 items)
- 4) Cognitive responses (10 items)
- 5) Coping Before (6 items)
- 6) Coping During (10 items)
- 7) Coping After (5 items)
- 8) Impairment (12 items)
- 9) Beliefs (14 items).

Composite scales are derived from overall Symptom Severity (combined Affective, Physiological, and Cognitive Subscales) and Coping (which combined the three coping subscales - before, during, and after). Subscales include:

- Affect Subscale Score (sum of Affect1-Affect8)
- Physical Symptom Score (sum of phys1-phys5)
- Cognitive Score (sum of Cog1-Cog10)
- Coping Before Score (sum of Bef1-Bef6)
- Coping During Score (sum of Dur1-Dur10)
- Coping After Score (sum of Af1-Af5)
- Impairment Score (sum of Imp1-Imp12)
- Beliefs Score (sum of Belief1-Belief14)

From these, Symptom Severity Composite Score consists of the sum of the 23 items (Affect + Physical Symptom + Cognitive), and Coping Composite Score is the sum of all 3 coping subscales combined (a sum of

the 21 items, from Coping Before, Coping During, and Coping After).

In regard to the DMQ Impairment and Clinical Ranges, Clinical Impairment Ranges (derived from the Impairment Subscale) are defined as follows:

- 0-13 is considered “minimal-mild impairment”
- 14-38 is considered “moderate impairment”
- 39-48 is considered “severe to very severe impairment”.

Duke Misophonia Questionnaire (DMQ)

General Instructions:

The following questions refer to the experience of being intensely bothered by a sound or sounds, even when they are not overly loud. These can be human or non-human sounds, or the sight of someone or something making a sound that you can't hear (e.g., the sight of someone biting their nails from across the room).

Please indicate whether the following sounds and/or sights bother you much more intensely than they do most other people.

Yes No

		Yes	No
1	People making mouth sounds while eating or drinking (e.g., chewing, crunching, slurping).		
2	People making nasal/throat sounds (e.g., sniffing, sneezing, nose-whistling, coughing, throat-clearing).		
3	People making mouth sounds when not eating (e.g., making the "tsk" sound, heavy breathing, snoring, whistling).		
4	People making repetitive sounds (e.g., typing, tapping nails on table, pen clicking, writing, construction work, using machinery).		
5	Rustling or tearing objects (e.g., paper, plastic).		
6	Speech sounds (e.g., "p" sounds, hissing "s" sounds, someone speaking with a lisp, high-pitched voices).		
7	Body or joint sounds (e.g., snapping fingers, cracking joints, jaw clicking).		
8	Rubbing sounds (e.g., hands on pants, hands against one another, styrofoam rubbing together).		
9	Stomping or loud walking (e.g., heels clicking, flip flops, etc.).		
10	Muffled sounds (e.g., voices separated by a wall, TV/music in another room).		
11	People talking in the background (e.g., phone calls in public, many people talking at once).		
12	Repetitive or continuous sounds not made by a person (e.g., clock ticking, air conditioner humming, water running).		
13	Animals making repetitive sounds (e.g., licking, chirping, barking, eating, drinking).		
14	Seeing someone making or about to make a sound that bothers you, even if you can't hear it (e.g., seeing someone reach into a bag of chips, seeing someone eating on TV with the volume off).		
15	Other (please describe)		
16	There are no specific sounds that bother me much more than they do other people.		

Score

In the past month, on average across ALL bothersome sounds, rate how often you were bothered by a sound/sounds.

-
- Once per month or less
 - 2-3 times per week
 - 1-3 times per week
 - 4-7 times per week
 - 2-5 times per day
 - 6 or more times per day
-

For the following sections, please use the scale below:

0 1 2 3 4
Never rarely sometimes often always/almost always

In the past month on average, when intensely bothered by a sound or sounds, please rate how often you felt each of the following.

1	I felt angry.	0	1	2	3	4
2	I felt anxious.	0	1	2	3	4
3	I felt disgusted.	0	1	2	3	4
4	I felt hateful.	0	1	2	3	4
5	I felt panic.	0	1	2	3	4
6	I felt hostile.	0	1	2	3	4
7	I felt jittery.	0	1	2	3	4
8	I felt frustrated.	0	1	2	3	4

Score

For the following sections, please use the scale below:

0 1 2 3 4
Never rarely sometimes often always/almost always

In the past month on average, when intensely bothered by a sound or sounds, please rate how often each of the following happened to you.

1	I became rigid or stiff.	0	1	2	3	4
2	I trembled or shuddered.	0	1	2	3	4
3	My heart pounded or raced.	0	1	2	3	4
4	I started breathing intensely or forcefully.	0	1	2	3	4
5	I reflexively jumped.	0	1	2	3	4

Score

In the past month on average, when intensely bothered by a sound or sounds, please rate how often you had each of the following thoughts.

1	“I am helpless.”	0	1	2	3	4
2	“I want to cry.”	0	1	2	3	4
3	“How do I make this sound stop?”	0	1	2	3	4
4	“Everything is awful.”	0	1	2	3	4
5	“I cannot handle this.”	0	1	2	3	4
6	“I need to get away from the sound.”	0	1	2	3	4
7	“I would do anything to make it stop.”	0	1	2	3	4
8	I thought about screaming at, yelling at, or telling off the person making the sound.	0	1	2	3	4
9	I thought about pushing, poking, shoving etc. the person making the sound.	0	1	2	3	4
10	I thought about physically hurting the person making the sound.	0	1	2	3	4

Score

For the following sections, please use the scale below:

0	1	2	3	4
Never	rarely	sometimes	often	always/almost always

Please rate how often you did the following in the past month, on average, BEFORE HEARING a bothersome sound.

1	I avoided certain people, places, or things so I would not have to hear sounds I dislike.	0	1	2	3	4
2	I used a different sound to drown the bothersome sound (e.g., turned on TV).	0	1	2	3	4
3	I used strategies to make myself less bothered by sounds I might hear (e.g., deep breathing, meditation, visualization).	0	1	2	3	4
4	I was on guard for bothersome sounds.	0	1	2	3	4
5	I distracted myself so as not to be bothered by a sound I might hear.	0	1	2	3	4
6	I made a plan to cope with bothersome sounds if they occurred.	0	1	2	3	4

Score

Please rate how often you did the following in the past month, on average, WHILE HEARING a bothersome sound.

1	I blocked the sound (e.g., covered ears with hands, headphones, ear plugs).	0	1	2	3	4
2	I used strategies to calm myself (e.g., self-talk, breathing exercises).	0	1	2	3	4
3	I focused my attention on an activity (e.g., watched TV or videos).	0	1	2	3	4
4	I produced an alternate sound (e.g., humming).	0	1	2	3	4
5	I reminded myself that it could be worse.	0	1	2	3	4
6	I increased the background noise to cover up the bothersome sound (e.g., turned on TV, rolled down car window).	0	1	2	3	4
7	I changed my way of thinking about the sound.	0	1	2	3	4
8	I looked away from the source of the sound	0	1	2	3	4
9	I listened to music or a different sound	0	1	2	3	4
10	I mindfully focused on current sensations without judgment.	0	1	2	3	4

Score

For the following sections, please use the scale below:

0	1	2	3	4
Never	rarely	sometimes	often	always/almost always

Please rate how often you did the following in the past month, on average, AFTER HEARING a bothersome sound.

1	I did something to comfort myself (e.g., exercised, went somewhere calming, pet animals).	0	1	2	3	4
2	I listened to a comforting sound (e.g., white noise, music).	0	1	2	3	4
3	I did some relaxation exercises (e.g., deep breathing, meditation).	0	1	2	3	4
4	I used the sight, smell or touch of an object to soothe myself (e.g. looked at a soothing picture, smelled a scent, or touched a soft blanket).	0	1	2	3	4
5	I thought about strategies to help me cope better next time.	0	1	2	3	4

Score

For the following sections, please use the scale below:

0 1 2 3 4
 not at all a little moderately quite a bit extremely

Please rate how often you did the following in the past month, on average, WHILE HEARING a bothersome sound.

1	My ability to be with other people	0	1	2	3	4
2	My performance at work or school	0	1	2	3	4
3	The quality of my romantic relationships	0	1	2	3	4
4	My ability to function in daily activities without help	0	1	2	3	4
5	How much I enjoy spending time with my family	0	1	2	3	4
6	My ability to work with others	0	1	2	3	4
7	My self-esteem	0	1	2	3	4
8	My ability to maintain employment	0	1	2	3	4
9	The quality of relationships with my friends	0	1	2	3	4
10	How connected I feel to other people	0	1	2	3	4
11	My ability to live with other people (e.g., roommate, partner)	0	1	2	3	4
12	My ability to "be myself"	0	1	2	3	4

Score

For the following sections, please use the scale below:

0 1 2 3 4
 Never rarely sometimes often always/almost always

Please rate the extent to which the bothersome sound/sounds and your reactions to them negatively affected the following in the past month on average.

1	"I hate being like this."	0	1	2	3	4
2	"People do not understand me."	0	1	2	3	4
3	"I will be rejected if people find out."	0	1	2	3	4
4	"I am crazy."	0	1	2	3	4
5	"My reactions to sounds are irrational."	0	1	2	3	4
6	"I should get over it."	0	1	2	3	4
7	"This is unfair."	0	1	2	3	4
8	"I am weak."	0	1	2	3	4
9	I should be able to control my reaction to these sounds	0	1	2	3	4
10	"I am a burden on others."	0	1	2	3	4
11	"I should have known how to cope earlier."	0	1	2	3	4
12	"My sound issues will only get worse with time."	0	1	2	3	4
13	"No one can help me."	0	1	2	3	4
14	"My whole life will be affected by sound issues."	0	1	2	3	4

Score

Total Score

Chapter 8

The Misophonia@School Innovative Approach and Tools

By the Misophonia@School partnership

The project “Misophonia@School - Including Students with Misophonia Disease in European Schools”,⁷ from which this volume originates, has benefited from the contribution of a team of ten organizations from eight different European countries, which have worked on the theme and developed a series of innovative tools over three years.⁸ The project consortium (involving the following countries: Italy, Austria, Slovenia, Cyprus, Iceland, Spain, Turkey and Poland) has included a variety of subjects (health & research centers, schools, organizations active in various educational fields, ICT agencies, publishers), bringing all the specific skills required to reach the expected goals.

The very first important aspect to be faced when working around misophonia is that if many people suffer from it (various surveys show that about the 12% of people

⁷ See the official website of the project: www.misophonia-school.eu.

⁸ From September 1, 2020, to August 31, 2023.

have misophonia symptoms), only a low percentage of them knows the origin and nature of their suffering. For this reason, the project has carried out an articulated activity about misophonia-related knowledge: as a disorder with severe consequences on a person's life in school circle as well as with family members, at work, with friends; and – at the same time – as a condition that can be easily recognized and effectively managed by misophonic people and people living or interacting with them.

The tools developed during the initiative, currently available in nine languages (Italian, English, German, Slovenian, Greek, Icelandic, Spanish, Turkish and Polish), are:

- The application for mobile devices Misophonia@School. An application for teachers, to be used in the classroom, and for parents, young people and potentially misophonic adults, which allows to apply an innovative screening protocol to identify subjects with misophonia.
- The eLearning course Misophonia@School. A distance learning course for teachers and educators that presents educational, environmental, and behavioral strategies to help pupils with misophonia during their daily school life.
- This manual, Discovering Misophonia. How to live fully with misophonic awareness. A book aimed at accompanying anyone who intends to deepen the theme of misophonia by presenting basic and scientific information related to the most recent discoveries and treatment strategies.

- The web resource center Misophonia@School.⁹ Aimed at families, schoolteachers, and educators in other informal education settings, it selects, collects, and organizes information and offers operational tools.

In this chapter, we will describe in detail the operation mode of the Misophonia@School mobile application, because it represents an easy-to-use tool to obtain a first indication of the presence of the disorder.

The Misophonia@School mobile application

The Misophonia@School mobile application, to be used in classrooms or other educational or family contexts, makes people able to apply and carry out an innovative screening protocol to identify subjects with Misophonia. The main idea beyond it is to provide a series of “trigger” sounds or situations (sounds and situations that usually cause misophonic subjects to feel bad) that can be presented to any kind of subject to observe/analyse his/her behaviour. Trigger events are well known now and not only related to sounds: chewing, breathing heavily, banging/tapping on desks, seeing someone shaking their legs or arms, being touched repetitively, and others. The screening tool has been produced as a mobile Android and iOS (Apple iPhones) application, to be easily usable and shareable. It is freely available on the respective stores (Play Store and iTunes).

⁹ Find it at: wrc.misophonia-school.eu.

The application also provides a set of ready-to-use tools and information, as guidelines on how to apply the innovative screening protocol, how to conduct the test to obtain reliable results and how to assess and evaluate subjects' responses and reactions to triggers. Furthermore, it allows people to share their results – in an anonymous way – through the Misophonia@School Web Resource Centre.

Although a few other similar mobile applications already exist, the Misophonia@School Mobile Application is the first one born from a Europe-wide collaboration (and not owned by a single expert, institution, or local initiative) and available in nine language-localised versions.

Taking the test

As already mentioned, the Misophonia@School mobile application is available for both Android and iOS devices: it can be downloaded from the respective app stores and is meant to be used with children and pupils aged 8 years and over.

The application can be installed on cell phones or tablets. To take the test in a school environment, it is necessary that each student has his/her own device (following BYOD educational method: Bring Your Own Device): tablet or cell phone, with headphones or ear-plugs. Where possible, sound equipment with frequency response of 20-20.000 Hz should be used, however, this frequency range is not always satisfied by all

common commercial products. If this kind of product is unavailable, it should not be regarded as an obstacle since previous experiences have demonstrated that the “trigger” effect arises in various conditions no matter the sound quality.

For youngest children (e.g., aged 8-10 years) we would suggest using it with the support of an adult (at school, a teacher) through PCs or laptops. Indeed, it can be installed on PCs using an Android Emulator (you can find many of them, for all operating systems, freely available on the web). In this way, an adult/helper can sit next to the student to assist him/her during the test, while he/she listen to the sounds. Using headphones to allow pupils to listen to the sounds is recommended. Be sure to be able to provide a silent environment and a sufficient timeframe for each student (if test is not conducted for more subjects at the same time, like it could happen for younger children).

Before carrying out the test, the organizer (teacher, parent) must obtain a quantity of tokens corresponding to the number of people involved in the experimentation. To this purpose, the organizer must use the dedicated web application that can be found on the Misophonia@School Web Resource Centre at the address: wrc.misophonia-school.eu. The registration is anonymous: the gender and age of each involved subject is only to be provided, with no further personal data.

The procedure to use the app is as follows. Each subject will listen to a set of 30 sounds in total, those sounds we commonly hear in our day-to-day life. Some

of these sounds could be unpleasant or distressing to hear. For each participant in the test, the sound samples are proposed in random order. Each sound can be played in loop (played continuously) and can be paused when required. After listening to each sound, the subject is asked to give his/her reaction by answering the following five questions:

- How pleasant was the sound?
- Did the sound make you feel happy?
- Did listening to the sound make you feel angry?
- Did you feel disgusted while listening to the sound?
- Did listening to the sound made you feel physically uneasy (for example, you want to move away from sound)?

For each question the user will indicate a value from 0 (not at all) to 10 (yes, a lot).

By clicking “Vote” the response will be registered and the next sound sample will be played, and so on. After the last sound (number 30/30), each participant in the test can access three result pages to discover the average score for different categories of sounds. At the end, by closing the test, the results for each participant are sent on the web database and will be available for consultation: all the data presented will be anonymous and only linked to the tokens obtained during the registration process.

Interpretation of the test result

At the end of the test, each participant can access three result pages to discover the average score for different categories of sounds. Categories are the following:

- Neutral sounds
- Unpleasant sounds
- Misophonic trigger sounds

It is expected that results for the three categories will be different for students with misophonia. In particular:

- Neutral sounds: misophonic and non-misophonic students will get the same results for the five questions.
- Unpleasant sounds: misophonic and non-misophonic students will get the same results for the five questions.
- Misophonic trigger sounds: misophonic and non-misophonic students will get different results for the five questions. Misophonic students will particularly give higher scores to the following question:
 1. Did listening to the sound make you feel angry?
 2. Did you feel disgusted after listening to the sound?
 3. Did listening to the sound made you feel physically uneasy?

Conclusions

“Misophonic Awareness”, an Action Plan for People with Misophonia

By Mario Campanino

In recent years and at the present time, many milestones have been reached with regard to studies on misophonia and the real conditions of people who suffer from it. Nevertheless, there is a lack of an integrated perspective of intervention on the various levels, from the institutional one (attention to misophonia by the bodies that deal with public health in the various countries) to that of the measures to safeguard people with misophonia in various social contexts (e.g., school, workplaces, means of transport). As we have seen during the reading of this volume, if, on the one hand, the results of scientific research and treatment techniques (primarily those referring to cognitive-behavioral therapy) appear satisfactory, on the other hand there is a lack of both widespread knowledge of the disorder in the population – which would guarantee a social security belt for the everyday life of the person with misophonia – and a formal recognition of misophonia by

the international scientific community, which hopefully should start – for example – from its inclusion in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) or in the International Classification of Diseases (ICD-11).

Knowing misophonia and working around it represented, for all those involved in the initiative “Misophonia@School - Including Students with Misophonia Disease in European Schools”, a moment of appropriation of a new awareness. The world of misophonia, in fact, is the world of research, study, care and experimentation but it is also the world of misophonic people with their sensitivity, their empathy, their strong attitude of propensity towards the other and understanding of the other – who then clash with the need for silence, solitude and quiet. At the center (people with misophonia) and in the contours (people who interact with them or who deal professionally with misophonia) of this world, there is a need for a complex and integrated plan of action, above all intimate and deep, which can only be that of “misophonic awareness”. People with misophonia require strategies in which all actors are equally aware of how to look at a child who has his ears plugged with his hands as well as they are acquainted with scientific research results and treatment protocols: an action plan that highlights and unveils the complexity and richness of the theme and of the people involved avoiding misophonia to be concealed or obscured.

In the world, this goal has been taken up – at least, in part – by research centers and universities or, on the

other hand, by individual professionals and private initiatives. However, the “misophonic awareness” that is assumed here as a strategy needs flexible tools and multiple approaches, which leads to the question: how do we achieve it?

Among the proposed models of intervention there is the Italian one represented by the Italian Misophonia Association AIMIF, whose activity has also stimulated the birth of the Misophonia@School project (Italy is, in fact, the project promoting and coordinating country). The Italian Misophonia Association AIMIF was born in November 2018 with the aim of spreading knowledge about the disorder in Italy, welcoming and supporting people with misophonia on the national territory and cooperating both within the European Union and internationally. Since its inception, AIMIF has shared its goals with clinical and research centers in Italy to promote the rising of joint research and clinical activities, based on findings and results from the international research and experimentations. Sukhbinder Kumar¹⁰ contributed to the first activities of the Association on the scientific front, later joined by M. Zachary Rosenthal,¹¹ who is one among the authors of this book.

In the common commitment of improving the condition of people suffering from misophonia in Italy, AIMIF and the linked research and clinical centers adopt prin-

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ciples of democratic and supportive participation, in full respect of professional roles and clinical needs. The therapists working for AIMIF associates contribute to guaranteeing competent and adequate communication during the periodic online meetings of the association; they also contributed during the first AIMIF congress on July 2 and 3, 2022, that was the first international conference on misophonia ever held in Italy.

In addition to the congress, as a result of its networking with the main international realities on misophonia (mainly from U.S.A.), the Italian Misophonia Association has been a planning partner of the Misophonia CARE Day – Conversations about research for everyone, the biggest online word event ever held on misophonia (May 16, 2023).

Nowadays, the association is working on the two fronts that appear to be the most important in Italy as well as in other European countries today: training health and education professionals, psychologists and psychotherapists on misophonia, and obtaining the inclusion of misophonia among the pathologies recognized by the National Health Service.¹² Given the effectiveness demonstrated and the potential expressed, it would be advantageous for the intervention model of the Italian Misophonia Association to be replicated

¹² As a historical data, it is perhaps appropriate to indicate here that, at the writing of these conclusions, the institutional portal of the Italian Ministry of Health offers the following number of results after searching for these terms: celiac disease = 1630; dyslexia = 43; misophonia = none. One can imagine that the situation is generally similar in other European countries.

in other European countries and in the world, until a full “misophonic awareness” has not yet settled in our common culture (at least at a European level) and in our national systems in the health, education, family, and work circles.

In the meantime, what we need to do is look at our goals and the paths that await us with optimism.

For many people with misophonia, perhaps almost for all, this acknowledgment and birth of “misophonic awareness” corresponded to the moment in which they came into contact with the word “misophonia”. *Having given a name* to what they suffered from enabled them *to distinguish misophonia from themselves*, making it become somewhat of an object *different from their own person*, allowing them not to feel alone anymore and being misophonia but finally knowing that they were simply a person with misophonia, like so many others. *Objectifying, distancing one’s self, observing with liberating detachment, knowing that what is other than me can be analyzed, managed, shared, overcome.*

And so may this word be revealed; may this disorder be given a name in the 24 official languages of the European Union and beyond, so that no one has to start from the obscurity of something that cannot be named; so that all people with misophonia, on the path indicated by this very important word, find along their way the most vital self-awareness:

Мизофония ↔ Bulgarian
Mizofonija ↔ Croatian
Misofonie ↔ Czech
Misofoni ↔ Danish
Misofonie ↔ Dutch
Misophonia ↔ English
Misofonio ↔ Esperanto
Misofoonia ↔ Estonian
Misofonia ↔ Finnish
Misophonie ↔ French
Misophonie ↔ German
Μισοφωνία ↔ Greek
Mizofónia ↔ Hungarian
Hljóðóþro ↔ Icelandic

Míofóin ↔ Irish
Misofonia ↔ Italian
Mizofonija ↔ Latvian
Mizofonija ↔ Lithuanian
Misfonija ↔ Maltese
Mizofonia ↔ Polish
Misofonia ↔ Portuguese
Misofonie ↔ Romanian
Mizofónia ↔ Slovak
Mizofonija ↔ Slovenian
Misofonía ↔ Spanish
Misofoni ↔ Swedish
Mizofoni ↔ Turkish

About the Authors

Sonja Bercko Eisenreich deepened her professional knowledge in the therapeutic schools of psychosynthesis and gestalt after completing her university studies of social and humanistic sciences. As specialization she also obtained a pedagogical andragogic study and holds an international license as a neurolinguist. In the last 20 years, she performed most of her professional work as the director of the Integra Institute - an institute for education and training in the field of vocational and mainly psychosocial rehabilitation for people with special needs. She has designed a series of successful community social projects. She is the author of an audio cassette designed according to the principles of suggestopedia and the children's book "Who is my friend?", for which she was awarded a national award in 2006. For the past eight years she has been teaching Communication and Ethics and Ethical Principles to professionals working in the field of employment and vocational rehabilitation. She is also a member of professional associations at home and abroad.

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Mario Campanino, Ph.D. is a schoolteacher, project manager at European level and founder, in 2018, and president of the Italian Misophonia Association. He has been researcher at the Italian National Institute for Educational Research (INDIRE) and, previously, responsible of the Project Area at the science center of Fondazione Idis-Città della Scienza in Naples (Italy). He graduated in Disciplines of Music at the University of Bologna in 2003 and was awarded a PhD in Sciences of Communication at the University of Salerno in 2008. He has been a member of various national committees for school and adult education, such as: the Commission for the Development of Science and Technology, Italian Ministry of Education; EdaForum-National Forum on Adult Education (European Association for the Education of Adults-EAEA) and others. He has been involved in several

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Wolfgang Eisenreich has studied biology and biochemistry at the University of Vienna. He is the founding member of Science Initiative Lower Austria (WIN) and has more than 25 years' experience in transnational project coordination, especially on adult education projects. He is the author of several Guidelines and Handbooks of Leonardo da Vinci and Erasmus+ projects, mainly in the health and nutrition sector.

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Keyword Glossary

Anterior insula

In the mammalian brain, in both hemispheres, it is the front of the so-called ‘insular cortex’. Anterior insula is known to be involved in emotion processing, motor control, interpersonal experience, and in control activity of our internal organs such heart/lungs (see Chapter 2, pp. 31-37).

Arousal

The reaction which occurs in a misophonic person when exposed to ‘trigger sounds’. It can be at sensory level, in the body or emotional. It consists in a distressing feeling and causes what is called a ‘fight or flight’ response (see Chapter 2, p. 28, and Chapter 5, pp. 34-35).

Biofeedback (see also Neurofeedback)

It is a training process that allows a subject to control body physiological response such as heart rate and skin temperature when exposed to different sensory stimulation or feeling emotions (see Chapter 2, p. 37).

Cognitive Behavioral Therapy (CBT)

Cognitive Behavioral Therapy (CBT) is generally oriented to make the subject aware of their own ‘beliefs’ (knowledge, thoughts, past experiences) related to cer-

tain situations or stimuli sources of discomfort, anxiety, or malaise. The awareness and reformulation of these beliefs is aimed at enabling the individual to develop skills of 'coping' regarding the situations themselves (see Chapter 6, pp. 87-103).

Comorbidity

The coexistence of two or more pathologies in the same person is an element of great interest, particularly with regard to pathologies subject to initial studies or first definition, such as misophonia (see Chapter 5, pp. 73-86).

'Fight or flight' response

It is a physiological neuronal reaction that occurs in response to a situation felt as dangerous and typically occurs in people with misophonia when they are hyperexcited by trigger sounds. It has a great impact on the subject in which it is unleashed because it affects the Autonomic Nervous System and then results in the release of various hormones (see Chapter 2, p. 30, and Chapter 5, p. 74).

Frequency (pitch of the sound)

In acoustics, it is defined as the number of vibrations per time unit (second). A high number of vibrations per second produces high-pitched sounds, like the chirping of birds, whereas a low number of vibrations per second produces low-pitched sounds, like the rumble of thunder (see Chapter 8, pp. 122-123).

Hyperacusis

It consists in the increased sensitivity to sound. In hyperacusis, sufferers experience quiet and normally comfortable sounds to be very loud (see Chapter 1, pp. 19-20).

Inclusion

Socially speaking, it regards individual inclusion and participation in various social spheres and includes school and work inclusion. Its ultimate goal is to ensure the active involvement of each individual within society regardless the presence of limiting elements (see Chapter 3 and Chapter 4, p. 58).

Learning

It is the key activity that allows the individual to build his/her own framework of knowledge about the reality that surrounds him. It can take place in formal contexts such as school, university, or vocational training, non-formal contexts, like visiting a museum and going on an excursion as a cultural activity, or informal contexts, like conversations with friends or information learned from movies or documentaries on TV (see Chapter 3, p. 50, and Chapter 4).

Loudness (sound)

In acoustics, it is the subjective perception of sound intensity (permitting the distinction between loud and weak sounds). Differently from hyperacusis, in misophonia loudness is not an issue: both weak and loud sounds can cause distress (see Chapter 1, p. 23).

Mimicry

It consists of the 'automatic' and unconsciously copying the action of others. The mimicry mechanism is believed to play an important role in the occurrence of the misophonic reaction (see Chapter 2, p. 34-35).

Neurofeedback (see also Biofeedback)

It is a kind of biofeedback that regards brain activity: it is usually based on the flow of information obtained through Electroencephalography – EEG (see Chapter 2, p. 37).

Neuroscience

It consists in all the studies concerning the nervous system and includes several biological fields such as molecular biology, cell biology, developmental biology, physiology, biochemistry, anatomy, genetics etc. Despite being very ancient, neuroscience received a decisive impulse in the second half of the twentieth century, thanks to the development of modern medical and information technologies (see the Introduction, p. 11).

Phonophobia

It is the fear of sound, generally also of sounds considered normal and at acceptable volume, but it is not exclusively caused by a specific set of sounds as in the case of misophonia (see Chapter 1, p. 19, and Chapter 5, p. 78).

Transcranial Magnetic Stimulation (TMS)

It is a therapeutic method that consists in the application of transcranial magnetic stimulators, non-invasive, with the function of remodulating the activity of brain centers associated with a series of medical and psychiatric disorders (see Chapter 2, p. 37).

Trigger sound

This indicates those sounds that, in a particularly violent way, trigger the misophonic reaction in the subjects who are affected. These are primarily the sounds of chewing, swallowing, and breathing produced by others (see Chapter 1, pp. 17-18).

White noise

It is the sound produced by the set of all audible frequencies produced with equal intensity: for this reason, it is very effective in masking environmental sounds that can be annoying, such as trigger sounds. It resembles the noise produced by pitter-pattering water, heard with a downpour or near a waterfall (see Chapter 2, p. 36, Chapter 3, p. 47, and Chapter 4, p. 69).

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