

UNIVERSITETET I OSLO

Main task

"I don't think people really understand the seriousness"

A qualitative study of experiences with misophonia

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Submitted as main thesis at the Department of Psychology

Autumn 2022

30 credits

The Faculty of Social Sciences, University of Oslo



Preface

The idea for this thesis originated in my curiosity and commitment to the condition misophonia. I am grateful to have been given the opportunity to immerse myself in this, and to work with this assignment has both challenged and developed me.

I would first like to say a big thank you to all the participants in the study. I am humbled to have been allowed to research their experiences. Thank you very much for the trust you gave me and for sharing your life stories and experiences. This task is both for and by you.

Many thanks to Marit Råbu for invaluable guidance throughout the project. Through your guidance, the unmanageable has become manageable and the confusing has become understandable. I am very grateful for your support and knowledge that has made this study possible.

Many thanks to the colloquium group for emotional and professional support through almost 6 years of studies and especially in the work on this task.

Many thanks to my family and friends for supporting me and teaching me to believe in myself. I am infinitely grateful.

Many thanks to Eirik, my spouse, for unconditional love and unconditional nourishment. You are the rock of life.

Finally, a special big thank you to Line. Thank you so much for allowing me to be a part of your journey in life and for everything I have learned from you. Without you, this task would never have been possible.

Summary

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Title: "I don't think people really understand the seriousness" - A qualitative study of experiences with misophonia

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Background and purpose: Misophonia can be a great burden for those who suffer from it and can affect relationships and life development. The condition is characterized by reduced tolerance for specific substances everyday sounds. In the last decade, misophonia has received increasing attention, but it is still there little research into the condition and the phenomenon is unknown to many. The purpose of this study is to gain more knowledge about what it is like to live with misophonia.

Research questions: 1) How do people with misophonia understand their own problems? 2) How people with misophonia experience being met by other people when it comes to their problems theirs? 3) What experiences do people with misophonia have with healthcare for their problems?

Method: The study is a qualitative interview study with phenomenological-hermeneutic grounding and is an independent research project. The selection consists of 9 women with misophonia who have considered seeking health care because of this. The participants were recruited through a post in a group on social media. The interviews were transcribed and analyzed based on interpretive phenomenological analysis and reflexive thematic analysis.

Results: The highest level of the analysis highlights two processes in the participants' experiences: How the knowledge of the concept of misophonia affected how they understood themselves, and how understanding of their own ailments affected the participants' relationships. The participants described a positive change in understanding their own problems after they became familiar with the concept of misophonia. It was great variation in experiences with healthcare. To a greater extent, they had been open about their own problems to others after they became familiar with the concept of misophonia. The troubles led to the participants in various ways "negotiated" with themselves or others about what they themselves had to endure or how much they could ask others to take into account.

Conclusion: Misophonia affects how people perceive themselves and others. It may involve major life limitation. Many people with misophonia keep their problems to themselves. The findings indicates that getting a concept for the ailments can contribute to a positive change in understanding oneself and others. It can also make it easier to communicate with other people and to reach out healthcare. The findings also show that there is variable knowledge about the condition among healthcare personnel. Increasing knowledge about misophonia in the population and among healthcare professionals can contribute to an increase quality of life for people with misophonia.

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1 INTRODUCTION

Misophonia is a little-explored condition that has received increasing attention in recent decades (Potgieter et al., 2019). The condition is characterized by reduced tolerance for specific substances everyday sounds that are often repetitive and created by other people, such as smacking or breathing. This is experienced as very unpleasant for the person suffering from misophonia and it triggers a strong negative emotional, physiological and often also behavioral response. This reaction is most often triggered to a greater extent when the sound is made by someone in a close relationship. People with misophonia reports that the condition can be a big burden, and that it can affect relationships or function in daily life (Claiborn et al., 2020; Swedo et al., 2022). Despite this is the condition is still unknown to many and the knowledge base about misophonia is very deficient. In that following, a presentation of misophonia and research into the condition will be given, followed by a presentation of this study's rationale.

1.1. Misophone

1.1.1 Misophonia's history

Misophonia can be characterized as a variant of reduced sound tolerance. Reduced sound tolerance is one collective term for conditions where an individual experiences an unpleasant reaction to sounds such as would not usually elicit the same reaction in other individuals. The reaction can be triggered regardless of loudness and the individual may have normal hearing abilities (Jastreboff & Jastreboff, 2015). The term misophonia (English: misophonia) can be translated as "hatred of sound" and was first used in 2001 by researchers Margaret Jastreboff and Pawel Jastreboff in an article in *Audiology Online* about various forms of reduced sound tolerance (Jastreboff & Jastreboff, 2001). One of them The first descriptions of the phenomenon can also be attributed to audiologist Marsha Johnson who on the end of the 90s suggested the term *selective sound sensitivity syndrome* (S4). Johnson obtained documentation on around 500 cases with S4 by discussing the condition in forums and support groups on the internet for people with hyperacusis – another form of impairment lydtolerance (Danesh & Aazh, 2020).

When Jastreboff and Jastreboff formed the term misophonia, they had been for several decades recognized for his research on tinnitus (ringing in the ears). In the 80s, Pawel Jastreboff developed among another, the treatment method Tinnitus Retraining Therapy (TRT), which eventually became very widespread and award-winning (The International Misophonia Research Network, 2018a, 2018b). In the article in *Audiology Online* they described that through their research and treatment of patients with tinnitus and reduced sound tolerance had noticed a group of patients with a specific

pattern of symptoms that were not adequately described by the terms they had available. Until now, they had used the terms *hyperacusis* and *phonophobia* in their work this patient group. Hyperacusis can be defined as an abnormally strong activation of the auditory system when exposed to sound. This causes the person to experience physical discomfort by exposure to sounds that others would not normally have reacted to, and the experience is often described as sound hurting. According to Jastreboff and Jastreboff, phonophobia is not due to one overactivation in the auditory system, but rather in the autonomic and limbic system, and resulting in a fear of certain sounds. The researchers described that a significant group of patients which was described with the term phonophobia did not exhibit a *fear* of sound at all, but rather a strong one aversive reaction. To describe this form of reduced sound tolerance, they developed the term misophonia, which was composed of the Greek prefixes for hate/dislike (*miso*) and sound/voice (*phony*). They also suggested that phonophobia could be understood as a subcategory of misophonia, then only one smaller group of the patients they worked with showed a fear of sound (Jastreboff & Jastreboff, 2001).

In 2002, Jastreboff and Jastreboff published the first article in a peer-reviewed journal that described the condition of misophonia. In this article, they described how the form of treatment Tinnitus Retraining Therapy could be used in the treatment of both hyperacusis, misophonia and phonophobia (Jastreboff & Jastreboff, 2002). Since this has misophonia received increasing attention. Until 2013, there were still only a handful of published articles about misophonia (Edelstein et al., 2013), but in the last decade the amount of publications about the topic increased considerably and the condition has been scientifically recognized within a number of professional fields such as audiology, neuroscience and psychology (Swedo et al., 2022). The term misophonia has been given a foothold both in the research field and in parts of the population. The term 'selective sound sensitivity syndrome' is also used somewhat in the research literature (Sanchez & Silva, 2018; Vitoratou et al., 2022). In the research literature, the term "trigger sounds" is also used to refer to sounds that trigger a misophonic reaction (Potgieter et al., 2019). In this task I will further use the terms *triggers* or *trigger sounds* to refer to stimuli that can trigger a misophonic reaction.

1.1.2 The development of a research field

In 2013, a research group at the Amsterdam University Medical Center (AMC) interviewed 42 people who reported having misophonia. This was one of the first scientific studies of misophonia and the researchers described that they found "a remarkably similar pattern of symptoms" in all participants: All participants reported that the trigger sounds were sounds created by others

people, largely sounds related to eating or breathing. Over half of the patients were also bothered by sounds such as typing on a keyboard or clicking with a pen. Trigger sounds could also develop into visual triggers, so that only seeing the activity associated with the sound was enough to create a reaction. Some of the participants also stated that certain repetitive movements such as shaking a leg could trigger the same reaction. Being exposed to a trigger sound immediately triggered an aversive reaction that began with irritation or disgust and quickly subsided over in anger. Participants reported that the intense reaction created a strong sense of loss of self-control and that they perceived their own reaction as exaggerated and irrational, and that to lose self-control in such a situation was morally unacceptable. All participants used avoidance strategies to avoid triggers, such as avoiding specific situations, wearing headphones or making "counter noises". In addition, they reported that constantly trying to predict triggers that can appear in the environment were a daily burden (Schröder et al., 2013).

In the article, Schröder and colleagues (2013) also presented a proposal for diagnostic criteria for misophonia. They argued that misophonia could best be understood as a separate psychiatric disorder and described how the condition differs from other psychiatric diagnoses such as specific phobia, social phobia, phonophobia, PTSD, intermittent explosive disorder, personality disorder and autism spectrum disorder. The research environment at AMC has since contributed to a number of publications on misophonia, and in 2020 they published a revised one version of their proposed diagnostic criteria for misophonia (Figure 1) (Jager et al., 2020).

Figure 1

Diagnostic criteria for misophonia as proposed by Jager and colleagues (2020)

Amsterdam UMC 2020 revised criteria for misophonia
A-R. Preoccupation ^a with a specific auditory, visual or sensory cue ^c , which is predominantly induced by another person ^d . It is required that oral or nasal sounds are a trigger. ^b
B-R. Cues evoke intense feelings of irritation, anger and/or disgust of which the individual recognizes it is excessive, unreasonable or out of proportion to the circumstances.
C-R. Since emotions trigger an impulsive aversive physical reaction, the individual experiences a profound sense of loss of self-control with rare but potentially aggressive outbursts.
D-R. The individual actively avoids situations in which triggers occur or endures triggers with intense discomfort, irritation, anger or disgust.
E-R. The irritation, anger, disgust or avoidance causes significant distress and/or significant interference in the individual's day-to-day life. For example, it is impossible to eat together, work in an open office space or live together. ^e
F-R. The irritation, anger, disgust and avoidance are not better explained by another disorder, such as an Autism Spectrum Condition (e.g. a general hypersensitivity or hyper arousal to all sensory stimuli) ^f or Attention Deficit Hyperactivity Disorder (e.g. attention problems with high distractibility in general) ^f .

<https://doi.org/10.1371/journal.pone.0231390.t005>

In the last decade, more and more research groups have argued in the same direction (Swedo et al., 2022) or published proposals for diagnostic criteria (Dozier et al., 2017). Preliminary prevalence studies have also suggested that the condition may be widespread. In a study of 483 university students in Florida in the USA reported as many as 20% of students clinically significant symptoms of misophonia (Wu et al., 2014). Another prevalence study based on 415 university students in Shanghai in China found that 6% of students reported a level of misophonia that was associated with functional impairment (Zhou et al., 2017).

Despite the fact that misophonia is not included as a diagnosis in the international ones diagnostic systems ICD and DSM, there is also increasing clinical interest in the condition (Cavanna & Seri, 2015; Ferrer-Torres & Giménez-Llort, 2022). Previously har dette patternet av symptoms, among other things, have been categorized under terms such as sound aversion or sound phobia. The symptoms may also have been diagnosed as OCD or general sensory sensitivity that is often associated with, among other things, autism spectrum disorder (Bernstein et al., 2013). Lack of guidelines for diagnosing misophonia is also a related challenge the validity of the findings in the research field as these can be based on different definitions of misophonia. Dozier and colleagues (2017) emphasize the importance of reaching agreement on diagnostic criteria to increase recognition of the condition, improve the validity of the research and quality in clinical practice.

Several have focused on validating self-report forms for misophonia, such as annet *Misophonia Questionnaire* (Wu et al., 2014), *Amsterdam Misophonia Scale* (Naylor et al., 2021) or *the Misophonia Response Scale* (Dibb et al., 2021). Guetta and colleagues published recently the first semi-structured clinical interview for misophonia and showed promise psychometric results (Guetta et al., 2022). As described in the previous section is The research field on misophonia is relatively newly established and with a scope of just over 100 peer-reviewed articles on the topic in 2022 (Hansen et al., 2022). It is still increasing consensus in the field that misophonia can best be understood as a separate disorder, and in 2020 it became initiated a research project by the Misophonia Research Fund (MRF) with the aim of develop a definition of misophonia based on consensus in a multidisciplinary expert panel (Swedo et al., 2022). In the project, a modified version of the Delphi method was used, which is a established method for achieving consensus in a group using several rounds of evaluation and voting on claims in an expert panel (N. Dalkey, 1969). The following paragraph will give an account of the results from this project, in addition to other research findings about the condition characteristics.

1.1.3 Characteristics of the condition

In the consensus-based definition published by Swedo and colleagues (2021) is characterized misophonia as a disorder in the form of reduced tolerance for specific sounds or associated ones stimuli. Trigger sounds are experienced as unpleasant or distressing for the person with misophonia and trigger one strong negative emotional, physiological and behavioral response. This response is not related to the trigger's loudness, but instead triggered by a specific pattern of sound or sounds meaning content. Trigger sounds are often repetitive sounds, mainly man-made, and especially often bodily sounds. People with misophonia may have their own pattern of triggers, but the most common triggers are sounds associated with the mouth (chewing, eating, slurping, coughing, throat clearing, swallowing) or the nose (breathing, sniffing). Other common triggers are repetitive sounds like typing on a keyboard or clicking a pen, or sounds from animals or objects, such as ticking clocks. Potgieter and colleagues (2019) refer to research findings where triggers are reported as specific sounds or ways of pronouncing words or letters. Triggers can too be visual. Swedo and colleagues (2021) describe that visual triggers can be the sight of something which is associated with a trigger sound, or the sight of various movements, such as shaking or rocking with a bone. Which triggers a person responds to can also change or expand over time (Potgieter et al., 2019).

The misophonic reaction is characterized by negative affect, and the most common is a experience of anger, irritation, disgust or anxiety. Some may experience rage. Many experience one increased activation of the autonomic nervous system and can feel muscle tension, increased heart rate and sweating (Swedo et al., 2022). Edelstein and colleagues (2013) investigated physiological components of the misophonic reaction and stated that the most common reported the physiological symptoms were pressure in the chest, arms or head and muscle tension. Some also reported increased body temperature, clammy hands, physical pain or difficulty breathing. Potgieter and colleagues (2019) argue that although anger is the most commonly reported the feeling in the misophonic reaction, there are findings that suggest that anxiety may be an underlying factor cause of this anger.

The strength of the misophonic reaction can be influenced by a number of contextual factors, as the person's experience of control over the trigger and the relationship between the person with misophonia and the person making the trigger sound (Swedo et al., 2022). Situations where one eats food together with a close relationship, especially with close family, is described as a typical very demanding situation and is often reported as the context in which the person first experienced symptoms of misophonia (Schröder et al., 2013). Potgieter and colleagues (2019) highlight that

misophonic reactions are often strongest when triggers occur in familiar situations such as with family, friends or at work.

To manage the reaction, most people with misophonia resort to avoidance strategies such as leaving situations, avoiding situations, using headphones or earplugs. Other strategies can be confrontation in the form of asking the person to stop making noise, or distractions such as make "counter-sounds" or imitate the sound, or force yourself to think about something else (Potgieter et al., 2019). Swedo and colleagues (2021) write that misophonia can be a big one strain and can have an impact on functioning in daily life or lead to psychological problems. People can have misophonia in varying degrees of severity, from mild to severe. Some people can the condition affects the ability to work and lead to difficulties with concentration and carrying out certain tasks. It can also affect social functioning and be a strain on social relationships or lead to social isolation.

The first symptoms of misophonia can usually be observed in childhood or early in life the teenage years. The condition has been observed in people both with and without other hearing challenges such as impaired hearing, tinnitus and hyperacusis. It can also be present in people with other neurological or psychological disorders such as anxiety disorders, obsessive-compulsive disorders, affective disorders, personality disorders, autism spectrum disorder, PTSD or ADHD. In several studies have it has also been reported that misophonia can occur frequently within the same family (Cavanna, 2014; Sanchez & Silva, 2018). In an online study with over 300 respondents with misophonia one third of the participants reported that they had family members with similar symptom (Rouw & Erfanian, 2018).

1.1.4 Etiology and neurobiological findings

Despite an ever-increasing amount of research and consensus in the field about several of the condition's characteristics, there are still many questions that need to be answered. This applies among another for the condition's classification and etiology, which is not yet established or understood. IN consensus project by the Misophonia Research Fund it was concluded that it is not yet sufficient scientific basis to publish a definition of the condition's classification or etiology. The interdisciplinary panel also commented that it is not possible to withdraw conclusions when it comes to whether misophonia can best be understood as a "medical" or "psychiatric" disorder, and that it cannot be ruled out that the condition has an organic nature causal explanation (Swedo et al., 2022).

Nevertheless, a number of hypotheses have been proposed for the underlying mechanisms. These hypotheses originate in different fields and perspectives. Jastreboff and Jastreboff described in

their article from 2002 that misophonia can be understood as an overactivation in the autonomic and limbic system. They further describe that this is due to increased connectivity between the auditory system and the autonomic and limbic system, or an increased reactivity in the two latter systems by exposure to sound. Tom Dozier, who, among other things, has created the organization "Misophonia Treatment Institute", argues that misophonia should be classified as a "conditioned aversive reflex disorder". He argues that misophonia is related to learning and associations, and that the condition gradually develops through classical conditioning (Dozier, 2015).

A limited amount of experimental studies have also shed light on those involved neurobiological mechanisms. The first experimental studies of misophonia investigated physiological activation and auditory processing and found significant differences between people with misophonia and fresh control groups (Edelstein et al., 2013; Schröder et al., 2014). In a later fMRI study, Kumar and colleagues (2017) found, among other things, an atypical activation in the brain "attention network". Kumar and colleagues recently published another fMRI study in which they also stated that the findings could have major implications for the understanding of the condition. The research group wanted to investigate a hypothesis that mirror neurons could play a central role in misophonia. In contrast to previous fMRI studies (Giorgi, 2015) this study found no atypical activation in brain regions associated with auditory processes. The study, on the other hand, shows an increase in activation in brain regions linked to mirror neurons in the motor cortex, which can be linked to "mirroring" movements in the mouth and face of other people. Kumar and colleagues argue that these findings support an understanding of misophonia as a reaction to *facial movements* to other people and that sounds also act as a medium. Treatment of misophonia should therefore focus on the brain's representation of movements (Kumar et al., 2021). Hansen and colleagues (2022) investigated this hypothesis further and researched brain activity during misophonic responses to repetitive finger sounds. Hansen and colleagues write that their findings show that the hypothesis advanced by Kumar and colleagues is not comprehensive for understanding misophonia, but also highlights that reactions to movements, and not only sound, can be central to the understanding of misophonia.

Other studies have reported that people with misophonia show increased functional connectivity between a number of brain regions, such as between the prefrontal cortex, hippocampus and amygdala (Eijsker et al., 2021a; Eijsker et al., 2021b; Kumar et al., 2017). Overall, these research findings show that the neurobiological mechanisms associated with misophonia is far from being sufficiently understood and that new research findings can have great significance for understanding of the condition. Further interdisciplinary research will therefore be central to understanding them

underlying mechanisms of misophonia and to be able to offer effective treatment.

1.1.5 Processing

There is currently a very limited amount of published studies on the treatment of misophonia. In a systematic review article by Potgieter and colleagues (2019), twelve studies were identified who investigated the treatment of misophonia in various ways. The studies reported on different approaches such as cognitive behavioral therapy, behavioral therapy with a focus on counterconditioning, dialectical behavioral therapy, exposure therapy, therapy based on mindfulness and acceptance, treatment with relaxation techniques, or drugs. All but one study were case studies, and Potgieter and colleagues therefore point out limited generalizability of the results on this the time. They nevertheless highlight that there are promising results for many of them the treatment approaches and request more clinical treatment studies.

The need for more treatment studies is also highlighted by, among others, Brout and colleagues (2018). In a review article published in *Frontiers in Neuroscience*, they emphasize a large need for further interdisciplinary research on misophonia and provides a statement on how clinicians can relate to patients who want treatment for misophonia today. They encourage openness in meetings with patients about the lack of evidence base for both understanding and treatment of misophonia. At the same time, they encourage people to try to help patients with deal with the problems based on available knowledge about misophonia and about change mechanisms for similar symptoms and conditions. Ferrer-Torres and Giménez-Llort (2022) also encourage to inform healthcare personnel about misophonia and about the progress in this field of research so that this patient group can receive the best possible help based on the existing knowledge. In Norway There are several treatment centers that use the term misophonia and offer treatment for it this. Examples of this are audio pedagogues and other hearing clinics or professionals knowledge about reduced sound tolerance (Audiopedagogene.no, u.å.; Bergseth & Sunde, 2016; HØR, u.å.; Nordlandshospital, 2017; Vestfold Hearing and Communication, u.å.).

1.1.6 Misophonia in the media and on the internet

Both the concept of misophonia and treatment options for this have apparently reached many through the internet and media reports. Bernstein and colleagues published a case study in 2013 on misophonia. In the article they write that a literature search with the term "misophonia" for the period 2002-2013 in the databases PsycINFO and PubMed showed only seven published articles or book chapters. A search for the term "selective sound sensitivity syndrome" yielded no results. Bernstein and colleagues nevertheless described an increased media interest in recent years and referred to a

number of American media that published news articles about misophonia in 2011 and 2012, which *The New York Times* (Cohen, 2011) or *Today* (Carroll, 2011). They also described that several people had come forward with their ailments following the media coverage.

Since then, the term misophonia has had a great impact, among other things on the internet and a large number of people seem to both identify with the ailments and seek help and support Online. Examples of this are the Facebook groups *Misophonia Support Group* (n.å) and *Misophonia: Coping and Solutions* (n.å.) with over 25,000 and 10,000 members respectively (as of September 2022). In recent years, a number of Norwegian media have also paid attention to misophonia. Among other things, newspapers such as *NRK*, *VG* and *Dagbladet* have produced reports about people who experience misophonia as a major burden in everyday life (Halvorsen, 2019; AH Hansen, 2017; Sfrintzeris, 2018). In the TV program *Practical info with Jon Almaas*, a features about misophonia which were later posted on social media and received thousands of views comments (Practical Info with Jon Almaas, 2018). In a number of radio programs broadcast on *NRK Radio* has also dealt with misophonia (Ibishi, 2017; Jemterud, 2017, 2021a, 2021b; Tarjem, 2020).

Misophonia also appears to be a phenomenon that some may perceive as comical. In 2020 researchers Damiaan Denys, Nienke Vulink and Arnoud van Loon were named winners of the *Ig Nobel Prize* in Medicine for their research into misophonia and diagnostic criteria for the condition. This award can be described as a humor award that is awarded to research that fits slagordet «research that makes people laugh and then think» (Abrahams, 2020). Professor Denys of the University of Amsterdam commented on the matter and stated that it was an honor to receive the award, but that it was also with a certain ambivalence, since the award is a humorous award, and misophonia is a serious disorder. He further stated that they still wanted to accept the award as it was important that the condition receives attention (Amsterdam University Medical Centers, 2020; NL Times, 2020). When this award ceremony was presented with a humorous tone i science program *Abel's tower* on *NRK Radio*, it created reactions among several listeners misophonia. Program leader Torkil Jemterud commented in a later broadcast that several people had taken contact with the radio program and followed up the matter with a report on misophonia and how it may be bothered by this (Jemterud, 2021a, 2021b).

1.2. The rationale of the study

1.2.1 Background for the research interest

My interest in researching misophonia stems from personal experiences. I got to know

to the phenomenon around a decade ago through a close relationship. A few years later, both I and the relevant knowledge that these ailments could be described with the term misophonia. This gave me an insight into how this condition can affect a person's everyday life and relationships. IN I also learned that this is an unknown phenomenon for most people and that it could be perceived as marvelous or comical. During my time as a student at the Department of Psychology, I also have previously used the opportunity to immerse myself in the topic of misophonia. In connection with a smaller thesis in 2018, I delved into the neurobiological basis of misophonia, and I thus got to know the research field. It became clear to me that it was a very limited amount of research into misophonia, but that research interest had been increasing last years. This led to my desire to contribute to research into misophonia and to correct it spotlight on the condition. As mentioned, several Norwegian media in recent years have created news reports about people with misophonia. I took this as income for my assumption that there is a certain incidence in Norway and that it could be thought that some of these people too wanted to contribute to a study. As described in the introduction, there are also more recent research findings which indicates that misophonia may be widespread, and more people are asking for more research that can contribute to this better understanding of the condition (Swedo et al., 2022). With this as a backdrop, I wanted to design a study with the aim of exploring what it is like to live with misophonia.

1.2.2 The study's design and scientific theoretical position

For the purpose of the study, I chose a qualitative methodological approach. A qualitative approach can be used to study people's lived experiences and experiences from this person's perspective (Hennink et al., 2020). A frequently used method within this research tradition is a qualitative research interview (Brinkmann & Kvale, 2018). An interview-based qualitative study can be described as *interpretive* research where the researcher tries to understand the content of meaning which people attribute to events or phenomena, how they understand this themselves and how they uses this meaning in negotiations with others (Magnusson & Marecek, 2015).

I chose to conduct a qualitative interview study based on a phenomenological one hermeneutic science position (Smith et al., 2009; Van Manen, 1990). I took starting from the method of interpretive phenomenological analysis as described by Smith and colleagues (2009). This qualitative method is rooted in the theoretical directions of science phenomenology, hermeneutics and ideography. The method is phenomenological as it lays emphasis on studying people's experiences and experiences. It is also hermeneutic as it emphasizes interpretation in the research process. It is also ideographic as it emphasizes studying the specific, rather than the general (Smith et al., 2009). Based on mine

literature search, there are very few studies that have used qualitative research methods to study misophonia and no studies that have explored misophonia from a pronounced phenomenological hermeneutic epistemological position. Using such a methodical approach gives the opportunity to obtain detailed and experiential knowledge of what it can be like to live with misophonia

1.2.3 Research questions

I have particularly wondered about two peculiarities of misophonia and their possible consequences this. One is that misophonia is a phenomenon where the reaction itself most often occurs *due to reason* of another human being. The second is that misophonia is an unknown phenomenon for most people. I have therefore wondered if little knowledge of the phenomenon in the population affects how people with misophonia understand themselves, the phenomenon they experience and how they navigate in interaction with it other people. In addition, I have wondered about the experiences of people with misophonia may have had meetings with healthcare personnel or in treatment. Based on this developed I the following research questions:

1. How do people with misophonia understand their own problems?
2. How do people with misophonia experience being greeted by other people when it comes to his troubles?
3. What experiences do people with misophonia have with healthcare for their problems?

2 METHODS

This study is an independent research project. The idea for the project was conceived by me autumn 2020 and the mentoring agreement with Marit Råbu was concluded in December 2020. During In the spring of 2021, I developed a research protocol with interview guide, data handling plan and information and consent letter. In May 2021, I sent an application to Regional Committees for medical and healthcare research ethics (REK). The project was considered to fall outside the scope scope of the Health Research Act and could therefore be carried out without approval from REK (Attachment 1). The project's plan for handling personal data was approved by the Norwegian Center for Research data (NSD) in October 2021 (Appendix 2). Recruitment started in December 2021 and the research interviews were conducted in February and March 2022.

2.1 Data collection

2.1.1 Planning

In the planning phase of the project, I investigated whether there were Norwegian online forums or groups on social media on the topic of misophonia. By searching for the term "misophonia" in the social network Facebook, I identified one Facebook group with around 300 presumably Norwegian speakers members (Misophonia, Phonophobia and Misokinesia (Norway), etc.). By using the keywords "misophonia" and "forum" in the Google search engine I also found Norwegian online forums that discussed the theme. Based on these investigations, I considered it likely that I could recruit Norwegian participants with misophonia through social media. I also considered taking contact clinics that offer treatment for misophonia in Norway and investigate possibilities for forwarding an information letter about the study. I considered recruitment through social media as the preferred strategy as this did not involve involving a third party and would probably reach more potential participants.

I drew up three criteria for participation which were specified in the information letter and in the text for publication in social media (Appendices 3 and 4). For the purpose of the study, I wanted to come into contact with people *1) over the age of 18 2) who suffer from misophonia 3) and who on a time in life have considered seeking professional help because of misophonia*. Eventually misophonia is a newly defined condition that is not subject to guidelines for diagnosis. I considered it sufficient that the participants themselves stated that they were troubled by misophonia. The it was also specified that participants should have considered seeking health care. The rationale for this was that I wanted to meet participants who experienced misophonia as a certain strain and I wanted too explore their experiences with healthcare. I wanted to explore the experiences of both participants who had sought help, but also any participants who had only considered doing so. For ethical reasons, a third criterion for participation was that the informant had to be over 18 years of age.

2.1.2 Recruitment

The participants were recruited through a combination of strategic selection and self-selection (Grønmo, 2021). The procedure for recruitment followed that of the Department of Psychology guidelines for recruitment through social media (University of Oslo, 2021). I contacted the administrator of the Facebook group *Misophonia, Phonophobia and Misokinesia (Norway)* (u.å.) and obtained permission to publish a post in the group that informed about the study. The post was published on 4 December 2021 (Appendix 4). Interested participants were encouraged to to read more about the study on the study's project page (Psychological Institute [PSI], 2021) and further

register your interest by providing contact information via the online form. The group consisted of around 300 members and to my knowledge this was the only Facebook group for the topic misophonia with mainly Norwegian-speaking members at the time of recruitment.

The online form for expressing interest in participating was open in the period from 4 December 2021 to 25 April 2022 and received 27 entries. A total of 12 participants were contacted by me by telephone or email to arrange a time for an interview. Of these, 9 people agreed to participate and 3 of the requests were not answered. The list of names of the registered participants indicated that only 1 registered was male and the remaining 26 were female. One of the requests that was not answered was the only male enrolled in the study.

The participants were contacted in parallel with the conduct of the interviews so that I could make an ongoing assessment of how many participants should be included. Brinkmann and Kvale (2018) describe that in qualitative interview studies where the purpose is to explore and describe a phenomenon, new interviews can be conducted until the data material is sufficiently saturated, so that several interviews are assumed to add little new knowledge. Number of informants must also be assessed based on the research project's available resources. In line with this Magnusson and Marecek (2015) also emphasize that the number of informants depends on both the research questions and the planned depth of the interview and analysis. Braun and colleagues (2019) highlight that in studies that explore patterns or meaning it can be difficult to assess whether the data material is saturated in advance of the analytical process. With this as backdrop, I assumed in advance that it might be relevant to include around 7-10 informants. During the interview process, I assessed whether the data material could be assumed to be sufficient saturated for the purposes of the study. After 9 interviews, I decided not to contact any more participants.

2.1.3 Interviews

To collect data, I used semi-structured interviews. I started from methods described by Brinkmann and Kvale (2018), and Magnusson and Marecek (2015). I developed an interview guide based on the research questions (Appendix 5) and this one was used in its original form throughout all interviews. The interview guide was designed with a desire to have great flexibility to follow the informant's story during the conversation. The interview guide was therefore organized semi-structured and to the greatest extent used as a thematic one checklist during the interviews. All participants were initially asked about their age, living situation and occupational situation. This information was obtained both as background information on

the selection and to be used as a pointer for the further exploration of the participant's experiences in the individual interview.

The interviews were conducted in the time period 7 February to 4 March 2022. Each of the participants were interviewed individually by me and the interviews lasted between 30 minutes and 1.5 hour. 4 interviews were conducted in a suitable room in Georg Sverdrup's house at the University i Oslo. 5 interviews were conducted digitally via Zoom due to the fact that the participants' place of residence was far away from Oslo. Audio recordings were made of the interviews, which were then transcribed verbatim. Personally identifying information was omitted or anonymized during the transcription and all participants were given a fictitious name. All interviews and transcriptions were stored and processed in Services for Sensitive Data (TSD).

During the interviews, I was concerned with facilitating a safe interview situation there the participant felt welcome to talk about his experiences and make suggestions descriptions. I emphasized this both as part of good research ethics, but also to increase the validity. I strove for good communication with the participant and opened up for the participant to be able to ask questions. During the interview I used regular summaries and reformulations to check whether the participant recognized himself in my understanding. At the same time I was conscious of ensuring that the participant was given space to elaborate on their descriptions.

2.1.4 Ethical considerations

During the design and implementation of the study, I strove for good research ethics in line with national research ethics guidelines (The national research ethics committees, 2019; The national research ethics committee for medicine and health sciences, 2019; The national research ethics committee for social sciences and humanities, 2021). The project was approved by the online committee at the Department of Psychology in June 2022. In connection with the application to REK I made an assessment of the study's potential risks and benefits for the individual, the patient group and society. I considered that the project would involve low risk and be possible utility for both the individual, the patient group and society. For the individual participant could it is thought to be burdensome to be interviewed about topics that may be vulnerable or private. I therefore emphasized good communication with the informants both beforehand, during and after the interview. Participants were sent information letters about the project in advance, which contained information about consent, privacy and anonymity. This was also summarized orally at the start of the interview. I informed the participants that they themselves decided which topics they were comfortable talking about. I considered that possible utility for the individual participant it could be to have the opportunity to contribute to research, to gain increased understanding

for misophonia, and an opportunity to convey their experiences to an interested researcher. I also considered that the study could be useful for the patient group and society by contributing to increased knowledge about misophonia, and what it is like to live with the condition.

2.2 Participants

2.2.1 Informants

The study included nine women aged 18-49 who have misophonia and who at some point in Life has considered seeking health care because of this. Seven of the participants had been in various types of treatment for misophonia and two had considered seeking treatment or starting treatment. All participants lived in Norway. There was great variation in the participants' backgrounds. It was variation in the participants' level of education and occupational situation, and the sample consisted, among other things, of a doctor, teacher, customer service representative, disabled person and student. Some of the participants stated that they had other psychological problems or diagnoses, but none of these were similar across the participants, and several participants reported no other psychological problems. Some of the participants lived alone, others lived with a partner and/or one to several children. The participants lived in different parts of the country in Norway, both in cities and in rural areas.

2.2.2 The researcher

Describing the reflexive aspects of the research process is important for the validity of the results in qualitative studies (Hennink et al., 2020; Merrick, 1999). Malterud (1993) emphasizes that the researcher's pre-understanding of what is to be studied can become a strength if it is done explicitly both for the researcher himself and for his readers. Through the research process, I have strove for a high degree of reflexivity and took measures to be able to make this explicit. I used a research journal so that I could go back and look at thoughts and reflections I have had earlier in the process. In the planning phase, I prepared a reflection note about my own pre-understanding of the phenomenon I wanted to study. This note became the starting point for section i this thesis about the background for the research interest. In this note I also reflected that my preconception could be used as a resource in the study as I tried to be aware of how my experiences will be with me in the meeting with the informants and in that analytical work. I therefore continuously tried to be aware of what knowledge I had had with me about misophonia based on my own experiences and previous studies, and how this could influence the research process. I also have a professional and cultural starting point, among other things as a female psychology student raised in Norway. This will affect how I

understands and interprets the participants. Among other things, this can be thought to have a connection with mine interest in researching a condition that affects subjective experience, emotions and relationships. This also means that there will be other ways of understanding what has been collected the data material on, and that my interpretation will highlight certain perspectives at the expense of other perspectives.

During the data collection and analysis I tried to have a wondering attitude, and to put aside my assumptions about what it might be like to live with misophonia. Under the interviews, I tried to meet the participants with a genuinely "not knowing" attitude about exactly their experiences, while I took advantage of my preconceptions to explore theirs experiences. As misophonia is a little-known condition, I wanted to convey to the participant that the condition was taken seriously in this study. This may have led to me being in my interview style particularly validating and to a greater extent self-revealing about my personal involvement, than about I had researched another condition. In some passages I was also involved in, among other things active in dialogue with the participant about the research field of misophonia in general. This was something I strove to be aware of during the process, so that this took up as little space as possible in the interviews, while maintaining a validating interview style. I found that I succeeded to a greater extent with this after the first two interviews.

During the interpretation of the data material, I constantly questioned the interpretation, and whether this could be anchored in the data material. Through the analytical process, interpretations also discussed and further developed in several rounds with the supervisor and Professor Marit Råbu. She has extensive experience with qualitative research methods and had little prior knowledge of misophonia before the start of this project.

2.3 Analyse

In order to analyze the data material, I started from both interpretive and phenomenological analysis, as described by Smith and colleagues (2009) and reflexive thematic analysis, which described by Braun and Clarke (Braun et al., 2019; Braun & Clarke, 2006, 2019).

The methods have several similarities and both can be used within a phenomenological field hermeneutic epistemological position. As mentioned in the introduction is interpretive phenomenological analysis rooted in the scientific theoretical directions phenomenology, hermeneutics and ideography. Thematic analysis as described by Braun and Clarke (2006) is on the other hand, a flexible method for qualitative analysis that can be used within several areas epistemological directions. Braun and colleagues (2019) have recently described various

approaches to thematic analysis, including reflexive thematic analysis. In this approach the goal is to provide an interpretation of the data material, and the researcher is an active interpreter and tells (Braun et al., 2019). These two approaches with associated step-by-step descriptions of how the analytical process can be carried out was used as a starting point for it analytical process in this study. This process will be described step by step in the following paragraphs.

2.3.1 Exploration of the data material

As I myself conducted the interviews and transcribed them, this can be considered as the first step of the analysis where I got to know the data material. After this I started an active analytical work with the aim of gaining more thorough knowledge of all material obtained. I read through each interview and both noted and coded using the computer program NVivo. This program was used to be able to have flexibility in the further analysis the work. During the first reading of the interviews, I coded all the data material into three codes which represented each of the research questions. I also noted descriptive, linguistic and interpretive comments (Smith et al., 2009) in a separate note sheet attached to each interview. In the next part of the process of getting to know the material, I started from each code for the research questions. All material that had been coded into one research question was read through again. During this review, I coded all material under each research questions in new thematic codes that I developed during the reading. These codes tried to capture in the meaning content of the material related to each research question and represented possible salient themes across participants.

2.3.2 Interpretive summary of each interview

After this process, I discussed the coded material with the supervisor. To get a better overview about the content of meaning in the data material, I prepared a textual summary of each interview on around 1-2 pages. This summary can be described as a condensed interpretive summarizing the interview in chronological order, where I emphasized getting a hold of it essential content of meaning in each individual's narrative and include exemplifying quotes. This summary was written by me re-reading one interview at a time in its entirety, and along the way also used previous knowledge of the material and previously coded information to extract meaningful content and salient themes. I also prepared one schematic overview of the participants to get an overview of recurring themes across the participants.

2.3.3 Discussion of meaning and prominent theme

The interpretive summaries and the schematic overview were shared with the supervisor and us used this as a starting point for discussion about the essential content of meaning in the participants' experiences and potential themes across participants. To the best of my ability summarizing the overall theme across the participants, we focused on processes that all the participants were active in various ways, such as paying attention to others or being caught regard to due to misophonia. We formulated proposals for the overall theme as best as possible could describe these processes. In working with the data material, we also noticed that there was great variation in the participants' experiences and experiences. To be able to reproduce the diversity of experience, we chose to present the results based on a phenomenological approach description (Dahlberg, 2008; Van Manen, 2014). The purpose of the description is to clarify formation of meaning in the participants' lived experiences of misophonia and to highlight similarities and differences between the participants.

2.3.4 Writing and further development of the theme

The writing process was an active process and a continuation of the analytical work. In line with I continued Smith and colleagues' description of the hermeneutic circle (2009). movements between parts and the whole in the analytical work. I moved back and forth between the phenomenological description, the interpretive summaries, the the schematic overview and the transcriptions. The schematic overview was gradually expanded to keep an overview of the participants' experiences and frequencies of topics that were stated in the results. Through the work on the description, I also continued the work on further develop formulations of overarching themes that could organize the content of meaning the participants' experiences. Different formulations and understandings were discussed with the supervisor. Finally we organized the description according to two overarching themes which are the highest in the analysis level of abstraction and which refers to two processes in all participants: "How affects knowledge of the concept of misophonia the participants' understanding of their own problems?" and "How affects the understanding of the participants' own problems and relationships?" In the latter theme, the term is used *negotiations* to describe the participants' experiences in meeting others, inspired by Safran and Muran's (2000) descriptions of negotiations in the therapeutic alliance. To state the occurrence of an experience among the participants I will refer to the categories *general*, *typical* and *variant* as recommended by Hill and colleagues (2005). Further in the thesis, the wording "all" participants refer to the category general which describes that the experience is found in all or

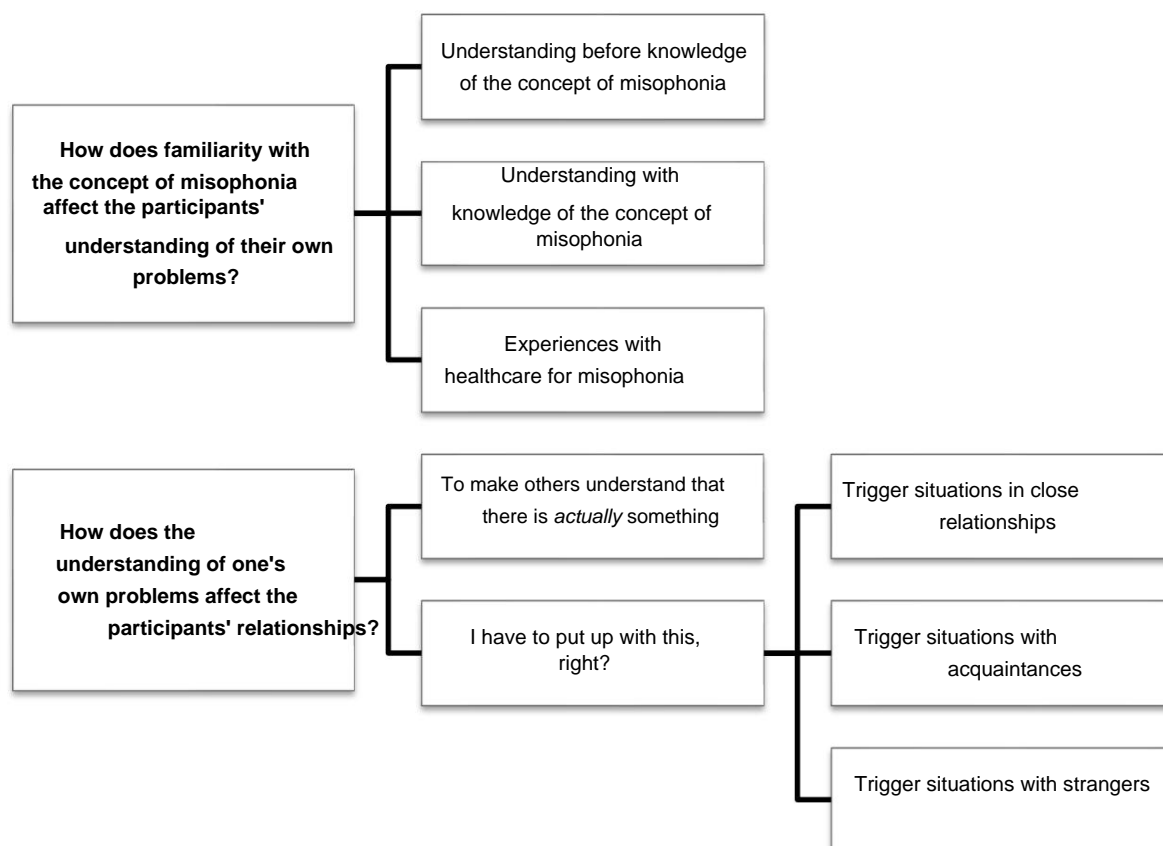
all but one participant (8-9 participants). "Most" refers to the category typical as describes that the experience is found among more than half of the participants (5-7 participants). "Some of" the participants refer to the variant category which describes that the experience is found at under half of the participants, but among at least two participants (2-4 participants). In some settings I will also state the exact number of participants.

3 RESULTS

The following description is divided into two overarching themes: "How influences knowledge of the concept of misophonia the participants' understanding of their own problems?" and "How affects the understanding of the participants' own problems and relationships?" Both themes have several sub-themes. Figure 2 shows an overview of the themes' structure.

Figure 2

Overview of themes in the results



3.1 How does familiarity with the concept of misophonia affect the participants' understanding of own ailments?

Most of the participants described a process where, over several years, they have tried to understand why they reacts more strongly than others to certain sounds. This process of opinion formation has taken place in different ways for the participants, but common to all is that they described memories of an understanding they had *before* they had knowledge of the concept of misophonia, and a change in understanding as a result of to have recognized themselves in the description of misophonia and to have identified with "having misophonia". This change in understanding can also be seen in the context of the participants' experiences with healthcare. This topic will therefore explain how to get to know the term misophonia has affected the participants' understanding of their own ailments. In the last paragraph I will describe the participants' experiences with health care and discuss connections with the participants' understanding of own ailments.

3.1.1 Understanding before knowledge of the concept of misophonia

All the participants described that the problems began in childhood or early teenage years. Most described his first memories of the pain as an experience of irritation or discomfort from hearing sounds like breathing, eating or chewing gum. Most also reported that this at first, only sounds from a specific person, such as mother, father, siblings or named friends, applied.

Yes, I've actually thought about that many times, when I kind of feel like that started, but at least it started when I was a child, so maybe about 7 years old. I already remember from school that I couldn't sit next to Anne and Per, because of them made such incredibly annoying breathing sounds, so... And at least it was from when I was 7 years, maybe even earlier. And then I had a friend who I also reacted strongly to on, with chewing gum for example.

Most of the participants also reported that the complaints gradually worsened and that since childhood had gotten more and more triggers. Some described that the reaction had also become progressively stronger. Most reported that today they can react if they only see a movement that is connected with a trigger sound. Some of these also described that they can respond to purely visual triggers without connection with sound, often in the form of repetitive movements. One of the participants stated that she had stronger reactions when she was younger and that she did not know the reason for this improved over the years.

Most of the participants described that the ailments eventually led to high suffering pressure. *"Now I've stopped wishing, but five years ago I wished I was deaf. It really was my greatest wish, 'I can go deaf, I'll be fine in traffic, I'll be able to manage in life, music is not everything, I can read lips, I can manage'".* Another participant described that she eventually began to compare the sound of ticking clocks to one torture method: *"When I was in primary school, I remember someone in my class told about when you had to torture people, you skinned them, and then it dripped regular drops of water on their heads, so that they would go mad. And... ticking clocks are yes, even that too, just like that".*

There was great variation in the understandings the participants had of their ailments before they got them knowledge of the concept of misophonia. A common feature of all the participants' descriptions is that they over for a long time had tried to understand something that they experienced as incomprehensible about themselves. The participants' formation of opinions about this took place in different ways and led to different results conclusions. Some had wondered a lot about the ailments and searched for explanations, while others to a greater extent had accepted not understanding, or settled down with another explanatory model.

One of the participants said that she had not thought much about the cause of the pain and described that she rather thought that *"something has to be bothered with"*. Most participants described that they had thought or wondered a lot why they felt that way. In their teens, some of the participants had first understood the reaction as irritability linked to puberty, while in later years some had thought about whether the concept of sound sensitivity could cover the problems. Some had intermittently thought that what they experienced was about problems with attention and focus.

Most described that the strong reaction they constantly experienced had been very strong difficult to understand: *"No, I guess I've really only felt that it has been, that this has been something very strange then, something that I really can't figure out what it is"*. Others highlighted that they thought this was not normal: *"I thought I was going crazy. That... this was it not normal"*. Some described thinking there was something wrong with them.

It wasn't like I was like... Is there like something else? I thought I hate
smacking to the point that it affects me so much. That there was something wrong with it
me. The level where I hated smacking, that there was something wrong with me for reacting like that
a lot, because I know that people don't like smacking, but there's a difference between not liking it and
that level then, that I sort of had an extreme level that was just wrong then.

Most emphasized that they had thought that it was about them being a difficult or wrong person person. *"Because I have always believed that I have always been alone and only one difficult person who is unable to put my voice down".* Some gave examples of have constantly heard comments such as *"No, now you have to pull yourself together. No, now you have to sharpen up you".* One participant described that all her life she had been told things like *"something is wrong with you".* All the participants described that they had had the impression that they were completely alone about having it that way. Some of the participants stated that they felt ashamed that they felt this way, and some emphasized that it had been very shameful.

So this was like my biggest secret. Because I didn't know what it was our. I just felt so incredibly special and weird. And when I look back, it was, right... (...) ...very many such types of suffering have been written about a lot a lot in the media. And then I thought "yes, they thought they were alone, but I really was alone!". In other words, there was no mention of misophonia anywhere.

Most of the participants stated that they had felt guilty for reacting in this way, or in other ways blamed himself for the troubles. *"Yes, that there was something wrong and why I should be so difficult then. You put a lot of the blame on yourself. Why do I have to react? _____ Because you don't understand that".* One of the participants described thinking of it as very unfair that she felt that way. Another described that it was difficult to imagine that it was something that was different in her experience compared to others.

Yes, in a way it's easy to put it on yourself then, just "ok, I'm the one who can handle it much less than others. Others probably hear the same as me, only I add notice". Like that... hard to think that there is anything different about me, or I don't know, that there is a reason why it is like that, that I sort of thought that I can't stand anything

3.1.2 Understanding with knowledge of the concept of misophonia

All the participants described a change in their understanding of their own ailments when they became in different ways introduced to the term "misophonia". Most gave detailed descriptions of the sequence of events and expressed that they remembered well when this happened. The participants described that this was between 1-10 years ago, and all the participants were then between 25-45 years old, with the exception of the youngest the participant in the selection who was around 14 years old. This participant had then had the problems for about two years

years, while the other participants had had the problem for at least 10 years before they became aware of it misophonia. Most people discovered the term through the internet. Some described coming by chance over news articles or similar on the internet about misophonia, while others described that they actively searched for information on the internet using terms such as "sound sensitivity" or "bothered by noises". Two of the participants were made aware of the term by a psychologist who was already undergoing treatment at

All participants described that they immediately recognized themselves in the description of misophonia. Everyone had also felt relief or joy at discovering the term. This feeling was linked to discovering that they were not alone in feeling this way and that the troubles were a phenomenon that had also been experienced, described or recognized by other people. *"To feel that yes, that I had, that there was actually something then. That it wasn't just me who was really weird and weird and stuff strange"*. Some described coming to terms with it as a highly emotional experience.

I probably had 20 conversations with him (the psychologist) . But once in a while in there he said "have you heard of something called misophonia?" And I had never. It was the first time I heard it. And then he told me what it was, and it just was like that... It hit me right on, rock hard! And I remember crying all the way home the bus both like that: "damn, that's what I've got!" and "god how nice that it's not just me who has it, it's not just me who's a damn kid, I'm not a damn kid, me have something that several people have, it's not just something I'm making up!"

Most described discovering the concept of misophonia as an exclusively positive experience, and used expressions such as *"when I found a name for it"* or that *"all the pieces fell into place"*. Some participants also described feeling ambivalent feelings. Some stated that it was disappointing that there is still no cure for the condition, or felt any discomfort associated with having one diagnosis or a disorder.

First of all, I was very relieved because finally there might be an opportunity to understand why I have struggled as much as I have. And then I really felt that... If you travel there and get a diagnosis in relation to it, then it might be a little easier for others to understand why you have been the way you have been in your youth and the like things, especially mum and dad, because they have often been a bit like that "but my God, stop it annoy you about it!" They have not known that this has been a thing before. And then know I'm also a bit stressed because... "ah... am I going to have a disorder like that?" (...)

It's actually still a bit taboo, I think, to have diagnoses. (...) It turned out a bit like that horrible feeling nonetheless. And thought that "it would actually have been a bit easier if only that I was the one who was wrong" (laughs).

In most of the participants' descriptions, it can be interpreted as finding a term for the condition contributed to a change in the experience of guilt for the ailments, and that they no longer thought on the troubles as being their fault. Most of the participants also highlighted that they had sought out more knowledge about it: *"What I think has been the best about it is that I have also read quite a bit about it, and taught me more about it. And a bit of that... nice thing about that, that there's not only to pull yourself together, in a way, it's actually a reaction that happens in the body outside of mine control".*

When asked what they currently think may be the reason they have misophonia highlighted all participants that they do not know the reason for this. Most stated that this is something they have thought about a lot on or have read a lot about. There was great variation in the potential explanatory models that remained described, and these placed different emphasis on environmental factors and heredity factors. Most highlighted one biological causal explanation and had thoughts that it was *"something with the brain"*. Many of these had also thought a lot about heredity. Several mentioned signs in their own surroundings which they interpreted as meaning that the condition can be hereditary or originate in genes, such as that of the mother, siblings or grandparents also disliked certain sounds. Some also reported that they had given a lot of thought to whether this was a thing their child could also inherit.

Some of the participants highlighted thoughts about environmental impact or associative learning. These described having memories from childhood of parents commenting on sounds or being extra attention to specific sounds, and two of the participants highlighted that this probably could contribute to the development of misophonia through a combination of heredity and environment. Others reported having read various hypotheses on the internet that it could be related early trauma or that people with misophonia were more moral than others. Some of the participants described an understanding that the cause deals with a gradual development of negatives associations with sounds. One of the participants highlighted that this associative learning could be especially related to sounds you hear during the falling asleep phase and that it occurs gradually development of anxiety throughout life for the sounds or for being bothered by the sounds.

3.1.3 Experiences with healthcare for misophonia

Most of the participants said that getting to know the concept of misophonia at the same time brought them in at the thought that this was something that could perhaps be treated. These therefore sought out

treatment soon after they became familiar with the term. Several of these participants were already in treatment for other mental health problems when this happened and started treatment for misophonia in parallel or instead of the original treatment. For some of the others participants took several years before making the choice to seek help for misophonia. Two of these described that the triggering reason when they sought help at a later stage was that the ailments had worsened: *"really that it has gone so far in relationships (...) and then I thought like "yes, but if I can't get help with this here, then I can't have children" so it was like... it was more on that level"*. One participant stated that she sought help because she experienced that her child was irritated by breathing, and this made her think that she had to deal with it and investigate whether it was possible to get help. Another participant stated that she had not been in contact healthcare professionals regarding misophonia. She stated that she was unsure about that was there treatment for it and possibly where. She described that she had not been able to bring it up with her GP, even though she thought she should.

The participants described different routes to health care and different experiences of the treatments. Two participants made direct contact with a private clinic they had found through an internet search which advertised specifically for treatment for misophonia. Both of these were still in treatment with an audio teacher until today and stated that he was satisfied with the treatment. Both described that the treatments involved exercises they could do at home. *"It is for the most part treatment that you have to do yourself, but it is very good to have someone to talk to about everything the feelings around it and treatment that can give you a little push then"*. Both stated that in the beginning it was difficult to notice any effect of the treatment. One of these said that she still trying to be patient and have faith that it helps. The other participant described that she now feels that it has had an effect and that it is important for her to continue with the treatment. IN during a period in which she took a break from the treatment, she noticed that the ailments were getting worse.

Two participants had been introduced to the concept of misophonia through their psychologist and had then been referred further by the psychologist for treatment by an audio pedagogue. One of these, the youngest participant in the sample, described that she had first taken a hearing test.

And then we were told by the otorhinolaryngologist that we just had to get our act together... That was not something to waste one's life on (laughs a little) (...) But... luckily, I just stayed I was then referred further by that psychologist, so we found out that it was misophonia that I had then. And then I got to start with audio therapy and start learning a few different techniques how could one live with it then. And now I live quite well with it. Some some days are worse than others, but it usually goes well.

This participant also described that she now *"controlled"* the degree of discomfort through holding blood sugar stable, exercise, avoid exhaustion, or use snuff so that she relaxed. It the second participant described that she experienced no improvement despite the fact that she *"went in wholeheartedly in the treatment"* with audio pedagogue. She had now finished her treatment with an audiologist, but described that she was still working on understanding and dealing with misophonia as part of therapy at the psychologist.

Four participants had discussed their complaints with their GP. These had different experiences with this. One participant had been pleasantly surprised by the meeting with the GP. *"I went to my GP and I was really ready for her to say, 'No, this.' is not something"*(laughs). *So I was ready to take the world's biggest fight there. But then she just said "yes, but I've heard of this before (...), I think I actually know of someone who can help you, I saw sends you on there"*. She began treatment with an audiologist and describes that this has been useful. She points out that she has gained an increased understanding of misophonia and terms to put it words about what she experiences, in addition to techniques for exposure such as listening training and muscle relaxation. Another participant had sought treatment both through the GP, the occupational health service and a private actor, where she had tried medication respectively treatment in the form of SSRIs, exposure therapy and acupuncture. She described experiencing improvement from acupuncture and drug treatment, but described having bad experiences with exposure therapy for misophonia and experienced that this therapist did not understand what it was was about. Despite the fact that she experienced improvement from the drugs, she described that she did not thought the GP was familiar with misophonia: *"On my prescription it has always read 'against obsessive thoughts". I have no idea about that, it feels a bit strange to me actually"*. The third of these participants stated that she had been referred by her GP to an audiologist and was now waiting to start treatment there. She described that getting help with misophonia had been a long process process: *"I feel it is very long-winded. I feel, in a way, perhaps, that I am being rejected all the time (...)* It's like all the time that *"well, but we can apply for you again psychologist" (...)* But I've gone to a psychologist a couple of times, or two periods, and then... Then After all, she has said herself that she doesn't know what misophonia is. So there is nothing she can do to help you with. So there's a bit of it there as well." The fourth participant described the process of seek help for misophonia as *"a bit of a... goose chase"*. She had brought it up with her GP, but described that the GP did not understand what she was talking about. She still had received a further referral and recommendations on where she could contact: *"But then I have I actually didn't get my finger out completely, because I got very vague answers from my doctor about where I was*

should approach me, "yes you can perhaps approach that centre, perhaps they can help you there" and then it somehow became a bit too vague".

All the participants who had been in treatment had tried some form of therapy. Terms that the participants used to describe these treatments were audiotape, exposure therapy, use of sound generators with "white noise", exercises to unlearn the stress response, listening training with audio files, relaxation exercises and progressive muscle relaxation. Some of the participants stated that getting a language for the problems or a model of understanding for why they react has been very helpful. Several of these also expressed having integrated the explanatory model of the forms of treatment into their own understanding.

As it is now, I've been receiving treatment for misophonia, so I've learned... Me have gained a much larger vocabulary to talk about it and ways to deal with it then. Although I don't fully believe that I will recover, I now know when I will grown up that I shouldn't expose myself to trigger sound, so now I wear earplugs and like that if I'm going to eat with my brother and I don't feel like I can mentally take the fight in a good way. If you understand... Because it will be a bit like exposure therapy, and if I I can't make it good exposure therapy, then it doesn't give me anything. Then I have to rather wear earplugs

As shown in this section, the participants described a range of experiences in the face of healthcare personnel. Among other things, both positive and negative experiences with taking were reported discuss the topic of misophonia with a GP, psychologist or audiologist. Set aside from the occupational groups audio pedagogue and audio therapist, there was variation in whether other healthcare personnel had knowledge of the concept of misophonia. Some of the participants who had undergone treatment at audio pedagogue or audio therapist were satisfied with the treatment and described what they experienced a gradual improvement, while some of the other participants who also underwent treatment at audio pedagogue stated that they had not experienced improvement.

3.2 How does the understanding of one's own ailments affect the participants' relationships?

I will now elaborate on how this understanding can affect relationships with other people, and how suffering from misophonia involves negotiations with oneself or others. Eventually a misophonic reaction most often occurs in the vicinity of other people, all the participants had pondered how much they themselves had to endure, and how much they could ask others to take into account. Everyone

the participants had also pondered whether, and when, they should talk openly about misophonia to others, and what reactions they could then expect. The participants' thoughts about how they should behave himself both to other people and to his own reactions, can be described as a kind of negotiation with himself, and in some cases also negotiation with others.

By exploring the participants' descriptions of experiences with other people, I noticed two general categories of situations where misophonia was actualized. The one the category was situations that were about talking to others about having misophonia, and that the second category was situations in which the participant responded to a trigger sound by another person, and had to choose a strategy to deal with this. I will further describe the latter as a *trigger situation*. These two types of situations were described both with and without connection with each other. To illuminate how the participants reasoned in different ways in these situations, I will explain these categories separately.

3.2.1 Making others understand that there is *actually* something

All the participants described that getting a term for the problems had made it easier to be open about what they experienced. All the participants also described that they had talked about very little the troubles with other people before they got the term misophonia. Some explained that they never had talked to someone about it, and for some it had been very important to keep it a secret.

"...because I have been so deeply afraid of being exposed. (...) I never dared to say anything to anyone before.

Apart from the one time to my mother many, many years ago, I haven't dared to say it to some friends, even those closest to me, before I knew what it was." Others described that they had one or more close relations who were to some extent aware of what they were doing *"found it annoying".*

A common feature of all the participants' experiences was a movement from a large extent secrecy to a greater degree of openness towards others about the ailments after they could use the concept of misophonia. The participants described various reasons for this movement. Some highlighted that getting a term for the experience made it easier to communicate with others: *"That's right someone who doesn't quite understand what it is, and then I find an article like that and then they can read it self. So they might understand it a little better than how I explain it then."* Someone highlighted that the term contributed to their problems being communicated as *"something real"* and something not was their *"fault"*.

Because then it was like something you could refer to in a way, that it is something that is real.

That "yes, there is something wrong with me, but it's not my fault!" (laughs). Because it kind of was

*that made that turning point, that made it a little easier. Although I don't think so
it's easy to talk about, because people are really like "huh? Are you kidding? Are you like meat?"*

(to read)

There was still a wide range in the extent to which the participants talked about misophonia to others people today. One participant had only told about the condition of his mother and brother and expressed that it was something she found difficult to talk about.

*I guess I've never really felt that there has been any will to understand that this is one
real problem with people then. That I have tried to talk to my mother a bit about it, and send
her a little links about what misophonia is, and a little different, but then... So I am
very happy for my mother, that's not what it's about. But exactly in that area there
she doesn't show much understanding and has actually laughed it off a bit, and... Yes. At all... have said that
"jaja". So it has been a bit painful. To not get that understanding then. (...)
And that's probably the experience I've gained from not being taken seriously in this
then that has in a way made me refuse to talk to others about it. Yes,
I have spoken to my brother, by the way. I did that about a year ago, maybe,
and he... He actually understood. Yes. So it was kind of good.*

Some participants wanted to be as open as possible about misophonia in order to spread knowledge: "so I would love to have a t-shirt that says "I have misophonia" just so people know what it is is". This can be understood as being about both being better understood yourself and also that others could benefit from the knowledge: "To be a bit like that... an ambassador for that. Because others actually must understand, because there are probably many more who suffer from it than we know about". The youngest the participant had made a conscious choice when she started high school to tell everyone around her. She described the transition from secondary school: "everyone knew me, but nobody knew ."
the. So starting to tell something new became a bit difficult. I rather took it when I started one completely new place, then I was rather completely open about it from the time people met me, because then it is much easier to understand it, when it comes in early".

Most of the participants described that it was not a goal to keep it a secret, but described various reasons why they often chose not to talk about it. Some of these described that this could be about an expectation of having to explain a great deal so that others would understand. One participant also linked this to shame: "But it is clear that it is... in a way shameful because people don't know about it. In other words, like "yes, I'm a lesbian", everyone knows what that is, it's possible

be a bit shameful, but at least people know what it is. But here you have to explain so incredibly a lot! You kind of just really have to... And that makes you reluctant, so to speak some". Others described an expectation that others would not really understand the seriousness of it.

So it's not like I wouldn't have bothered to tell you, really. So it's nothing like that... really aim to keep it a secret. But maybe it's a little that people don't understand the extent of it. How big a problem is it really... that it's somehow a bit easy to... as I've thought myself, isn't it just to pull yourself together then? Oh just... Yeah, it feels a bit like that. The thoughts I probably have myself then (laughs). I transfer them a little on what others will think.

All participants described that they used the term misophonia when they told others about it. Some of the participants described that they were most often met with understanding or curiosity when they told stories that they had misophonia to others. Some of the participants nevertheless described that even if they could stay met with understanding from others, they nevertheless had the experience that others did not *really* understand that's all the same. Here it was highlighted that an experience that others did not really understand the seriousness of the ailments. *"I feel like it's mostly being taken seriously in a way. But I believe people don't really... get the seriousness of it."* Some participants also described examples of situations where others showed in various ways that they had misunderstood what misophonia was about, such as making statements that the participant was sensitive to noise or sound in general. Another participant described that she mostly kept it to herself because she knew several people on occasions had experienced that others became self-conscious when she talked about misophonia.

I remember talking to a group of friends who were out to eat and then, when we were finished eating I talked a bit about it, or at least some of us did that, and then (gasp, acting out a friend's reaction) "oh my god! how did I eat then, believe?!" Then people think like that, and I don't want people to do that. Because of course I have one problem, then it's me who has to, that is... I don't want people who normally eat nicely must toughen up for me, because people have to have food.

She described that she also had a friend who believed that she was intolerant and that it was about jealousy. *"You don't spoil your food for others," he says.* All participants expressed that it was difference between having to talk about misophonia in general and talking about it in a trigger situation.

3.2.2 I have to put up with this, don't I?

A trigger situation involving a man-made sound can be described as a situation where the person with misophonia either negotiates me self or with the person making the trigger sound. In what follows, I will show similarities and differences in how the participants relate themselves to trigger situations. All the participants described that this took place in different ways based on what type of relationship they had with the person involved. The further description is therefore organized in three sections with the main focus on close relationships, acquaintances and strangers.

3.2.2.1 Trigger situations in close relationships

All the participants described that today they most often reacted to sounds created by close relationships and that the reaction had also started with family members growing up. Most people came along examples of how misophonia had led to arguments, frustration or a bad mood in family throughout his upbringing. One participant described that this had affected the relationship with mother i to a very large extent and described having struggled with a bad conscience and guilt throughout growing up for the strong reactions she had had to sounds from her mother. Most people came along examples of having received comments from parents throughout their upbringing that this was nothing one could get irritated about, or to pull together or toughen up.

So I wasn't allowed to leave the table. Mum's just like "no, stop bullshitting. He just smatter, it's fine, don't think about it. No, stop and don't go on like that, don't be like that difficult then". That's what I actually heard throughout my childhood. So I remember being very forced to sit, and actually sat and kind of scratched my arms, sort of pressed a little physical pain then, because there was... something else to focus on then.

All the participants described that during their upbringing they developed forms of avoidance strategies i the home. Some described starting to avoid certain situations, or that they often went to the bathroom to take a break. One participant recalled that as a child she had tried to discreetly cover her ears by having the arm above the head. Some stated that they started using earplugs.

Despite the fact that misophonia had been a source of much frustration in the family described some of the participants that parents and family members have also been a great support, especially after that they gained knowledge about misophonia. Most of the participants described that they now speak openly with the family about their problems. One participant said that the parents are involved in exercises she must do in the treatment.

For mum and dad, it is perhaps a little more difficult to understand that... there is only one response without my control in a way then. In the subconscious. And the way you work with that... and a bit... Yes, the exercises you have to do and the strategies there. That maybe it is a bit hard to understand. But they are in on it. Now I have been given the task of going put on white noise really loud when we sit and eat dinner then. Because I can be terrified... I think it's torture to sit and eat dinner with the family, for example. To have on that sound all the time along the way... it goes beyond them too, but they are involved the.

In one family, they had also made major changes to routines in the home after they gained knowledge about misophonia. The youngest participant in the sample said that she also has a sister with misophonia, and that those in her family therefore take a number of considerations. She described that her family is trying to limit specific types of noise in the home and that they have largely stopped eating meals together. They only do this when they "have a good day". She said that the whole family was very upset happy when they got knowledge about misophonia. *"They found that it was something we could learn to deal with a little better then. (...) Then it became much easier, because then people started to take it into account because it was something proper"*. She also described that although both she and her sister had misophonia, it was big difference in which sounds they reacted to the most and that they paid attention to each other in different ways.

In contrast to this participant, another participant described that all meals at home then she was younger was characterized by irritation. It has been many years since she lived with him the parents, but she described that meals together with the parents are still characterized by irritation, and that it gets worse the more she is with them. She described that despite having tried to tell her parents about misophonia, she did not feel that there was a will to try to understand this. *"So... it's... either we eat together or we don't. Yes. And then it's on a way I have to pull myself together then"*.

Some of the participants described that they still react most strongly to sounds from parents or siblings, while some of the participants stated that in recent times they react most to the sounds from one partner. *"My brother was probably the first to undergo the procedure, then it was dad, now it's him my roommate too, right? And that is a challenge! (laughs a little)"*. All participants described misophonia as a strain or a challenge in a relationship. Some of the participants stated that misophonia affected the relationship with a husband or lover to a much greater extent than others relationships. All the participants who were in a relationship stated that under certain circumstances could ask the partner not to make a specific sound. One participant described that when she was

together with her parents, she usually used to retreat to a separate room if she was tired and responding to sounds, but she did not want to use this strategy to the same extent together with the roommate.

It is very difficult to adapt to the world around you, so you have to try adapt yourself. In a way, you have to. It's hard to somehow get people around to be completely quiet, not to be annoying, not to make any noises. Or... nothing. So I... absolutely must. But I also speak up, for example, especially to my partner. If I feel that I am very tired, I just say that "now I am very tired, now I really can't stand anything. So if we're going to be together now, you just have to put up with me can certainly tell about things. But then you just have to put up with it, because otherwise I can't be together with you now". I just have to speak up, and he thinks that's very good too, because then does he know that.

Some participants stated that it could create irritation in the couple's relationship. *"He gets a little irritated, man I'm not very patient about it. I'm not the type to go around asking him to stop things all the time. Sometimes I just have to say "can't you eat that chocolate?", but I am very good at biting it in me and then".* A participant who did not live with his girlfriend described that trigger situations nevertheless led to her hurting her boyfriend every day: *"So he knows this, he takes an incredible amount of consideration, but he gets scolded every day. He gets hurt pretty much every time day because of this".*

Some of the participants described that misophonia was a challenge for them in the initial phase of a new friendship or a potential relationship. One of these described that she thought it was difficult to know how and when she should tell a new close relationship about it: *When I get new close relationships then I don't get triggered for a while, but then deeper relationships do the trigger comes, and I have to be honest and open about it, even though it's very difficult vulnerable, especially if you enter a new dating relationship or something like that, it's like very vulnerable like that. And you think like "is the other person really going to bother with this?".*

One participant described that misophonia greatly influenced how she thought about her own living situation.

Participant: And then there was... a guy I've met a bit lately, and yes if not us will move in together and... yes, "we will grow old together", he said. Damn... Damn it...(laughs) "You breathe! You eat! I can't live with anyone!" So... like hey, I like him and, like... But no, it won't work.

Interviewer: No, you think so, that it's out of the question, don't you? Living with someone else?

Participant: Ehh... So, there is no one who can pay enough attention that they can live with me, I think. (silence) I think I almost think so.

The participants approached trigger situations with close friends in different ways. The youngest the participant in the study had dealt with this in a way that differed somewhat from the others the participants. When she was in secondary school and found it difficult to talk about misophonia to others she had nevertheless told her close friends. She described that these could see on her that she was in a trigger situation, as she could then become quiet or irritated, or leave to take a break. She said that her close friends used to "stand up for her" in trigger situations and tell others to stop doing something. She described that the friends she was together with today in high school also were very understanding if she gave notice that she reacted to something: *"To the people I'm with the most, I say that 'I can't stand that we sit and eat now'. But if there are people I don't know as well, I withdraw a bit." ...* *"Usually if it's my friends, they're like 'oh, sorry! I didn't mean to, I forgot'. That it takes it very much like 'oh, I forgot that. But you just have to remind me that'".* She said that nowadays she usually tells the other person if she reacts to a sound and tries to be open about this to others. It appeared that this one to a somewhat greater extent than the others, the participant was open about the problems across situations and on across types of relationships. She also reported to a greater extent than the others that most people took her complaints seriously and stated the most positive experiences of letting others know in one trigger situation.

Some of the participants said that although friends could be very understanding when they talked about their problems, they still found it difficult to say something in one trigger situation with friends.

I think it's difficult with friends and such, even though I have the vocabulary for it, when I sit there and get triggered, and in a good way could communicate that "it's not something wrong with you, there's nothing wrong with you eating, but I need a little break" and I also find it difficult to ask others not to eat, because I feel naughty. *I feel like I'm telling them they're disgusting because they eat, but they're not. They are not disgusting. I feel like that's what I'm saying. I feel like I could be like, "uh, fuck you sounds so sickly gross when you eat, can you just stop eating?!" Although I try to put it in a good way, then I feel so guilty that someone has to change*

behavior due to not being able to handle it then. And that... they either have to change behavior or that I have to step back... So that's exactly what I find very difficult to do communicate. And it can be very wrong, and I have noticed that... noticed with friends and something like that when I've tried to say it that, it still gets a strange atmosphere, even though it knows the story then.

3.2.2.2 Trigger situations with acquaintances

All the participants described that before they became aware of the concept of misophonia, they almost never had it mentioned something to, for example, fellow students or colleagues if they reacted to a sound they made. IN In such situations, they used strategies such as "just letting it go", or finding excuses to withdrawing from or avoiding a situation. Some of the participants described that they did not use to experiencing such strong reactions among acquaintances, so that this was not a big problem. Some of them other participants, on the other hand, described that arenas such as school or work had always been very demanding.

I have suffered something insane in certain places, in high school, I remember it that way clearly. I was sitting on the computer with a friend who was sitting here chewing gum. So... Then my thoughts go like this "data, me, her, chewing gum, data, me, her, chewing gum", so that's how it goes. I don't sit there and work, so I fight. It is an internal war. At the same time as I have to be nice, get something written present, get to think and be calm. And in that, there's only one like that... so I'm going all red on the neck and on the chest because it's such a... So I want to run away. My body signals "danger, escape, escape, escape!"

Most of the participants also said that family parties and the like had always been special challenging. Some of the participants had periodically avoided going to such companies because of misophonia. One participant described that in her childhood she thought that acquaintances could perceive her as difficult.

Because there are some considerations or special things sometimes. Like on holidays and stuff like that (...) where I couldn't sit in the same car as my little brother (laughs). And preferably all the time wanted to sit with the other family, then he boy there could sit with my brother then. (...) That it is somehow not well received, that you don't quite understand why then. (...)

Like okay, she has to sleep in a room by herself and can't share a room with anyone. And yes... "Why will she be allowed to sleep alone when the others have to share?"

Most of the participants stated that if they were in a trigger situation today, they would think twice and assessed both the situation and the person for whether this was something they could comment on. The most stated that they very rarely chose to comment on something with acquaintances, and still in the majority degree chose to stand in it or to use other strategies to avoid it. Some described that they expected that this would be met with negative reactions or little understanding. Most described that despite the strong discomfort in such a situation they thought they had no right to decide over others.

You know what, I find it very difficult. That's one of the hardest things about it here, it's getting a reaction to a sound. And then you sit and fume inside yourself and get irritated and then in a way you can't... you can't tell anyone (...) I don't know, that is such a blocker who feels that... "but my God I have no right to ask you to stop doing that thing. I don't decide over you" (laughs).

The youngest participant, on the other hand, described that she mostly gave information to people around her if there were sounds that bothered her. She said that for the most part this went well and that others around her paid a lot of attention. She had also experienced that others could react negative about this: *"Then it's more like people can get more annoyed and say "but I'm sitting and eating" as it were. Or "I've just opened it, I've just started". And then I usually say "It's going well, but then I have to go. Then you can just let me know when you're done and I can come back""*

Some participants tried in other ways to facilitate fewer trigger situations among acquaintances. Some had chosen professions that gave fewer trigger situations, such as for the most part working alone or having a job where you mostly had to wear hearing protection. Someone described that it were specific people at work they always tried not to sit next to at lunch since they often responded to this person's eating sounds. This was something they did in secret and did not want that others should know about. *"People must have food, I think (...) In other words, people must be allowed to live their lives life, and I just have to pay attention."* One of these participants described that despite her holding this for herself, then everyone at her workplace knew that she has misophonia and that she reacts ticking clocks. She had replaced all the clocks at work with clocks that didn't tick and instead have "seventh" hands. Some of the participants also described that they were open to

the workplace that they were undergoing treatment for misophonia, and one participant described that she considered taking it up with the boss now that there might be an open office landscape. Some participants described that they were more likely to ask someone to stop making a sound if they considered the sound to be an unnecessary sound that other people could also think it was irritating. One participant said that this was something she practiced daring to speak out about.

3.2.2.3 Trigger situations with strangers

All the participants described that they had almost never said anything to strangers in one trigger situation and that they used avoidance strategies to the greatest extent. It was still big differences among the participants when it came to the extent to which they reacted to strangers. Some participants described that they largely reacted to sounds from strangers, while other participants described that this was not a problem and that the reaction most often occurred in close relationships. Everyone the participants expressed that they could also react to sounds from strangers, or had done so in periods of life. Some of the participants described that they always scanned their surroundings so that they able to avoid triggers: *"Yay! Always on guard. On the bus and the tram and the subway and everything like that... She who is eating an apple now and is going to get on the bus, where is she going? (laughs)".* Most participants stated that they had never asked a stranger to stop making a noise. *"I would prefer not to bother others with it, in a way. I feel that it is bothering others".* Some of the participants described having been in a few situations where they had expressed that a sound was troublesome to strangers, and that they were then met with negative reactions. One of the participants could remembering the only time she had done this with a stranger at work: *"And then I asked very nice, 'could you please stop chewing that gum? Because I'm getting quite stressed out', I said then. And then... And she got very angry and upset. And then when we finally were finished i said 'thank you very much for paying attention to me' i said. But I felt that look hers could kill me, then."*

Some of the participants described that they could feel strong anger when they reacted to strangers. These described the anger as *"I almost want to kill people, sort of"*. A participant described that *"it sometimes happens that I sit and fantasize about... twisting their heads off. And I am very surprised that it is said that no one has killed because of misophonia"*. None of the participants had acted out physically against others because of a trigger, and of those participants who expressed being able to have thoughts with violent content, all described that they simultaneously thought that the person had done nothing wrong. *"Those victims, or what should I say, they don't know what they are doing wrong rather, so it's somehow so difficult to... What they do is actually perfectly fine for others. Yes I*

I don't know, I sort of manage to separate my reaction and what that person is actually doing". One of the participants also described that this could lead to feelings of guilt.

There came a cough, there came a chew. I imagine myself taking an ax and chopping these people in your head. Because... I know that when I get there on foot, they are standing and assaults me. I know it's not like that, I know nothing is directed at me.

But everything goes straight to me. So... That's an anger. And later such exhaustion.

And then a feeling of guilt and that "no, but she's probably really nice" and "he hasn't." done some things", and worst of all when it's someone I know.

Another participant described that she had not had such thoughts, but that *"to the extent that I have thought something violent, it's probably more towards myself than anyone else, possibly then."*

For most of the participants, sounds from objects or animals could also be a big one challenge. The participants stated that they were bothered by sounds from, among other things, appliances, clocks, heat pump and aquarium. One participant described that birdsong from a particular type of bird had been a big burden, and another described that she could be very bothered by noise from building work or renovation. This participant described that in such a situation she could call the people who did the renovations and ask how long they were going to keep up the noisy work, since knowing how long the sound would last was a great help to her.

4 DISCUSSION

The purpose of the study was to explore what it is like to live with misophonia. All participants had experienced a change in understanding of their own ailments when they discovered the concept of misophonia. The there was great variation in the participants' experiences with health care. There was also variation in how the participants related to talking about their problems or in trigger situations with others human beings. In what follows, I will discuss how my findings can be understood, and which ones implications they may have for the understanding of misophonia. Furthermore, I will discuss methodological choices, as well as possibilities and limitations for how the findings can be used. Finally, I would like to discuss the findings' implications for clinical work and summarize implications for further research.

4.1 Living with misophonia

Misophonia affects how participants experience both themselves and other people. Everyone the participants have been through a process in which they have tried to understand their ailments. Everyone

negotiates with themselves and others about how they should relate to others when they are bothered by misophonia. In line with other research, it emerged that misophonia can be a burden in relationships or inhibit life development (Swedo et al., 2022). The ailments can also be a bigger one emotional strain when they are also perceived as strangers or incomprehensible. of the participants descriptions of how they experienced the problems before they were given a term were, for most, characterized by negative thoughts about oneself. The participants used words such as shame, guilt, alone, lonely, abnormal, wrong, difficult or crazy. Despite the fact that getting a term for the ailments in itself did not reduce symptoms, most of the participants experienced a reduction in negative thoughts about themselves himself and to a greater extent opened up about the troubles of those around him. This can also be thought to have had connection with a change in the participants' attribution of blame for the ailments. In the descriptions a movement can be seen from the fact that they largely placed the blame for the troubles on themselves before they had heard of misophonia, to the point that afterwards they understood the ailments to a greater extent as "something that has hit me".

The participants' descriptions have both similarities and differences. There are striking similarities across participants when it comes to how they describe the misophonic reaction and their patterns of triggers. All participants' description of their own ailments and their development reflects the consensus definition of the condition's characteristics (Swedo et al., 2022). Another findings in line with this definition is that the participants stated that they were troubled by misophonia in different degree. Some participants stated that this characterized most arenas in life and other participants described that it was to a greater extent limited to some situations. The participants also had different backgrounds, life situations and comorbid disorders. This lends support to the assumption that misophonia can best be understood as a limited disorder (Swedo et al., 2022). Most of the participants mentioned that they reacted to visual triggers without being specifically asked about this during the interview. This is an interesting finding in light of the hypothesis that misophonia is related to the brain's representation of movements (Hansen et al., 2022; Kumar et al., 2021). This indicates that the connection between misophonia and movement should be explored further.

The participants had different beliefs about the reason why they had developed misophonia. About half described that they had family members who were also in a greater or lesser degree degree responded to specific sounds. Some described seeing this as a sign of heredity, while others thought that this could have contributed to the fact that they had become extra goods for sounds through environmental impact in growing up. There were also participants who stated that family members on the contrary, were very tolerant of sounds. My findings are in line with other research findings such as indicates a somewhat increased incidence of misophonia within families (Cavanna, 2014; Rouw & Erfanian, 2018; Sanchez & Silva, 2018). There is still a very limited amount of studies

who have investigated this, and the findings cannot say anything about causal relationships. Brout and colleagues (2018) point out that misophonia is a complex neurophysiological phenomenon that involves processes such as attention, learning, memory, emotions, cognition and others basic processes that are both influenced by genetic and environmental factors. It is in day therefore no basis for drawing conclusions when it comes to misophonia and a any increased incidence within families is a phenomenon to a greater extent linked to heredity or environment.

There were differences between the participants when it came to experiences with healthcare. Some were unsure where it was possible to get help, and they were met in different ways when they approached for help. Some had positive and some had negative experiences with different treatments. This can be said to reflect the field of research when it comes to the treatment of misophonia. It is generally little knowledge about treatment, but also a small amount of case studies that show effect of different treatment approaches (Potgieter et al., 2019). Some of the participants in this study describes having experienced lasting symptom reduction as a result of treatment. The may indicate that it is possible to treat misophonia with the aim of reducing symptoms. Based to my knowledge of the research literature, there are no studies that describe having achieved full symptom reduction to such an extent that the patient is described as no longer having misophonia after treatment.

All the participants described that misophonia most affected close relationships such as family or couple relationship. Some expressed that this was a great strain on these relationships. Several were also worried about starting to react to own children. A unique aspect of misophonia that makes it stands out from a number of other psychological ailments is that relatives are often the very source of the troubles. This can create extra stress in these relationships, and be demanding for relatives to deal with. Several stated that they felt guilty for the strain they had put on themselves nearest. This is therefore an aspect of the condition that may be important to pay attention to for in future treatment offers.

Another aspect of the participants' descriptions that is worth noting is precisely that *no* all triggers are relational. All participants stated that they can also react to sounds from objects etc. This is also in line with the consensus in the research field and indicates that misophonia is not exclusively a relational phenomenon. It is conceivable that there is an underlying reason why trigger sounds are most often created by other people and are strongest in close relationships. To understand the patterns of trigger sounds will be an important area for further research and to be able to understand misophone

The participants' experiences with other people were seen in the light of the concept of negotiation as described by Safran and Murans (2000). This perspective highlighted that misophonia affects

how the participants interact with other people. The participants gave descriptions of what they assessed both person and situation before they would possibly talk about misophonia or comment on one trigger situation. Despite the fact that not all participants experienced strong problems among acquaintances or strangers, it still appeared that most participants could react to sounds from most people other people under certain circumstances. In line with other research on which strategies which is used to handle such a situation (Potgieter et al., 2019), the participants used in the largest degree strategies such as trying to anticipate and avoid trigger situations or to persevere in the situation. Under certain circumstances, they chose to try to stop the sound source. It also appeared that it was easier for most participants to talk about having misophonia in general or to pointing out trigger sounds from objects, than pointing out a trigger sound from another human in the situation. Some of the participants highlighted this as being mean and it appeared that they most believed that this was interfering with other people's autonomy. An interesting finding was that the participants to a very large extent expressed understanding that other people did nothing wrong when they made a trigger sound. Several participants emphasized a distinction between their own reaction and the other's the person's right to be himself. An aspect of this that was not sufficiently explored in this study is to what extent the ability to distinguish between these two things was related by getting a concept for the ailments. It was not clear in this data material whether or not the participants to a greater extent had second thoughts about the guilt of the other person before they had knowledge of misophonia.

One of the participants stood out somewhat from the others in several areas. This applied to the study youngest participant who was around 14 years old when she became aware of misophonia. She had then the problems for around two years and had the shortest time interval between when the problems started and when she got it knowledge of misophonia. It appeared that this participant was more open about the troubles across situations and relationships, and she described the most positive experiences of giving message to others in trigger situations. Her family had also made changes in routines such as stood out from the rest of the sample. She also stated certain strategies to regulate the degree of problems that none of the other participants stated, such as food, exercise and nicotine. We can wonder if this participant's early familiarity with the concept of misophonia has been a reason for her processes and strategies differ somewhat from the other participants. A topic for further research may therefore be whether early familiarity with the term can affect how it is to live with misophonia

The participants described different ways of dealing with meals within their families. One An interesting topic for further research related to this is connections between misophonia and culture. All participants in this study were raised in Scandinavian countries and none of

the participants stated that they had a different cultural background. There are big differences between cultures when it comes to traditions for meals and food, and the social aspect is also added more or less emphasis on in different cultures (Kittler et al., 2016; Montanari, 2006). Prevalence studies have indicated that misophonia is widespread in countries such as Turkey, Great Britain, the United States and China (Kyllyç et al., 2021; Vitoratou et al., 2022; Wu et al., 2014; Zhou et al., 2017). This suggests that the phenomenon exists across cultures. There are still many unanswered questions when it comes to that comes to connections between culture and misophonia and what it is like to live with misophonia in different cultures.

4.2 Methodological considerations and limitations

For the purposes of this study, I chose to conduct a qualitative interview study based on a phenomenological-hermeneutic scientific position. This methodological choice made it possible to be able to obtain knowledge about lived experiences with the phenomenon of misophonia and give descriptions close to experience of what it can be like to live with the condition. I have explored experiences with a specific phenomenon, understood by a specific group in a given context. I will further discuss the contextual aspects of my findings.

The sample consisted of 9 self-selected informants contacted through a group in social Media. No tools such as questionnaires or similar were used to survey the participants' symptoms before inclusion in the study. There was thus an opportunity for that included participants who self-identified as having misophonia could have a symptom picture as in large degree was deviating from the consensus definition of misophonia. To get an insight into this it was added questions in the interview guide that explored the participant's experience of triggers and the reaction. Through the analysis of the data material, none of the participants have been found to deviate from the consensus definition of misophonia, and there are also striking similarities between them all the participants' description of triggers and the misophonic reaction. It is also not indications that the symptoms that the participants in this sample report as misophonia may be better explained by another psychological or somatic condition.

As misophonia is a little-explored phenomenon, it is natural to ask the question about the extent to which these results are transferable to other people with misophonia. In addition to meet the criteria for recruitment, the participants were also members of a group about misophonia in social media and they wanted to participate in research. Set aside from these common features otherwise there was great variation in the participants' background. This applied, among other things, to age, level of education, occupational situation, family circumstances or whether they had comorbid mental disorders

troubles. This suggests that the findings across participants may be transferable to a proportion of other people with misophonia. There will naturally be other ways to live with misophonia, and my findings also show variation in the participants' experiences. There is still reason to believe that others with misophonia have experiences similar to those expressed here.

It is also worth noting that not only the selection, but also virtually all those registered participants for this study were women. It can therefore be questioned whether there are more women than men who have misophonia, or whether there are more women than men with misophonia who seek out support groups on the internet, have considered seeking health care or wish to participate research. An over-representation of women with misophonia is in line with some of the initial prevalence studies that have been done on misophonia (Wu et al., 2014; Zhou et al., 2017), but at this point it is not possible to know whether this is due recruitment strategies or whether misophonia affects women to a greater extent. Of the few the prevalence studies that exist today with a representative sample suggest a study that misophonia equally affects women and men in the UK (Vitoratou et al., 2022), while another study suggests that more women than men have misophonia in Turkey (Kılıç et al., 2021).

As described earlier, I assessed the number of included participants along the way the interview process, with the aim of obtaining a sufficiently saturated data material. By completion of the analysis, it may be questioned whether the data material was approximately saturated as there proved to be great variation in the participants' experiences and it is conceivable that more interviews would have added new information. Hennink and colleagues (2020) refer to research which shows that qualitative interview studies where the data material could be described as saturated at 9 included informants, but that more included informants added increased understanding and depth. Smith and colleagues recommend that students who want to undertake an interpretive phenomenological analysis, it may be an appropriate number to start with three participants (Smith et al., 2009). Fewer included informants in this study could thus have left room for one more in-depth analysis. It can thus be argued both for including fewer and more participants in this study. For the purposes of this study, an inclusion of more participants would probably meant that the project would have become too extensive for the framework of a main task Department of Psychology, and that it would be at the expense of the depth and scope of the analysis.

Another aspect that may have influenced the results is my preconceptions and interview style. I have throughout the research process strived for awareness of their own preconceptions of misophonia. As this contained an assumption that people with misophonia have experiences of not to be understood or taken seriously, I brought with me into the interviews a desire to validate

the informant's experience and recognize that this is a condition that causes great suffering. It should therefore be mentioned that my personal commitment to this group has been part of it the research process. As described earlier in this assignment, I took measures throughout the research process to increase the study's validity and reflexivity. That my interpretations were also discussed with a supervisor with a different understanding of misophonia than myself, consider I to have strengthened the validity.

4.3 Clinical implications

The participants were recruited based on a criterion of having considered seeking health care. This criterion was to capture those who experienced a fairly strong degree of distress. It is conceivable that there are other people with misophonia who suffer to the same extent, but who make use of it other strategies to deal with this, which do not involve seeking health care. This study nevertheless indicates that a certain proportion of people with misophonia want help for their problems.

In order to be able to help them as best as possible, an important first step will be to inform healthcare professionals about misophonia. My findings indicate that there is variation when it comes to knowledge of misophonia among healthcare professionals. It can therefore be random how people with misophonia are met by healthcare personnel and what form of healthcare is offered. Some of the participants described having received good help from health personnel without prior knowledge of misophonia, but most of the participants' negative experiences in meeting with healthcare personnel were related to little or no knowledge of misophonia. To increase knowledge among healthcare personnel can therefore contribute to people with misophonia feeling better looked after. The findings indicate also that interdisciplinary cooperation or knowledge exchange between different professional groups in professional fields such as audiology, psychology and medicine can contribute to this. The fact that misophonia does not only affect the individual, but also close relationships, underlines the need to develop a better help service for this group. In such an aid offer, it is conceivable that there is a need to involve relatives in the treatment.

The participants in this study described both positive and negative experiences with exposure exercises for misophonia. One who had bad experiences with this described that the therapist had no knowledge of misophonia. From the participant's descriptions of the therapy can it be believed that this treatment was based on principles of exposure therapy for phobic anxiety (Böhnlein et al., 2020). As misophonia has many similarities with specific phobias, it is reason to assume that practitioners may choose this approach when dealing with patients with misophonia. Schröder and colleagues (2013) highlight that an important difference between these two

the conditions are that in specific phobias the central feeling in the reaction is fear, while in misophonia is the central emotion aggression. As mentioned at the outset, there are findings that indicate that the underlying cause of aggression in misophonia is fear or anxiety (Potgieter et al., 2019). Despite similarities between the conditions, there is little evidence today that misophonia is best can be treated according to the same principles as specific phobias. Potgieter and colleagues describe in his systematic review article from 2019 that two case studies that used exposure therapy without further descriptions of the therapy's content reported limited effect of this due to of patients' lack of compliance and faith in the treatment. Other case studies that have reported reduction in symptoms for some patients have used approaches such as cognitive behavioral therapy with various adaptations to misophonia, including a focus on maladaptives thought patterns, shifting attention in a trigger situation, challenging avoidance strategies, psychoeducation, use of behavioral components such as relaxation techniques, or exercising. Others approaches with reported effect were methods taken from therapy directions such as mindfulness-based therapy, acceptance and commitment therapy and dialectical behavior therapy. These the methods had many similarities with the approaches taken from cognitive behavioral therapy with focus attention and on connections between thoughts, feelings and behaviour. Case studies with the use of drugs such as SSRIs or benzodiazepines, none reported moderate symptom reduction. Overall, the results from the case studies are reflected in this study's results. The participants state that various approaches have been effective, but not all of them have been in treatment have experienced an effect, and bad experiences with were reported exposure therapy without specific adaptations for misophonia. This suggests that the latter approach for treating misophonia at this time should be used with caution, and consideration should be given to choosing other approaches as described above.

As described in the introduction, Brout and colleagues (2018), among others, encourage openness in meetings with patients about the lack of evidence base for both understanding and treatment of misophonia, but at the same time trying to help patients to deal with the problems based on the knowledge available today. I will support this recommendation, but also add a call for healthcare personnel to be aware of preserve or convey hope to patients with misophonia who seek help. It has been for a long time established that hope can be central to recovery in the treatment of psychological ailments (Frank, 1961; Irving et al., 2004). Despite the fact that today it is unclear how best to understand or treat misophonia, several participants in this study and in other studies report having benefited of treatment, including psychological treatment approaches. The ever-increasing amount

research into misophonia will also be able to contribute to a better treatment offer in the future. This gives hope that there are ways to recovery for those who suffer from misophonia.

4.4 Implications for further research

In the preceding paragraphs, I have pointed out several aspects of misophonia that should be researched further on. Overall, my findings indicate that there is a great need for more research on misophonia in general. The findings also lend support to the assumption that misophonia can be a major burden for a proportion of the population. The findings also indicate that among people with misophonia is a proportion that wants help, and that there is currently a lack of help for this the group. There is therefore a need for further research into different treatment approaches and for clinical treatment studies. In order to increase the validity of these studies, efforts should also be made to reach agreement on diagnostic criteria and continue work towards developing diagnostic ones tools for misophonia. There is a general need for more knowledge about misophonia, and that this the knowledge reaches healthcare personnel and the population.

5 CONCLUSION

Misophonia affects how people perceive themselves and others. It can mean big life limitation. Many people with misophonia keep their problems to themselves. The findings indicate that the getting a concept for the ailments can contribute to a positive change in understanding oneself and others. The can also make it easier to communicate with other people and to seek health care. The findings also show that there is variable knowledge about the condition among healthcare personnel. To increase The knowledge of misophonia in the population and among healthcare personnel can contribute to an increased quality of life for people with misophonia.

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Region:	Case manager:	Telephone:	Our date:	Our reference:
REK south-east C	Anders Strand		25.06.2021	266604
Your date: 28.04.2021 /				

Marit Råbu

Project application: A qualitative study of experiences with misophonia

Application number: 266604

Institution responsible for **research:** University of Oslo

Project applications are considered to be outside the scope of the Health Research Act.

Applicant's description

Misophonia is a little-explored condition that has received increasing scientific attention in recent decades. Misophonia is characterized by the fact that everyday sounds can trigger a strong negative emotional and physiological response. The trigger sounds can be smacking, eating, chewing, heavy breathing or other repetitive sounds that usually come from other people.

The term has apparently reached many people through the internet and in recent years the Norwegian media have made several reports about people who experience misophonia as a major burden in their everyday lives. The purpose of this project is to obtain more knowledge about how it feels to live with misophonia. Interviews will be conducted with people who state that they suffer from misophonia and the data will be analyzed using thematic analysis.

The study will examine people's experiences with healthcare for these ailments and in meetings with healthcare personnel and other people. The study will also examine your own understanding of the condition. As of today, there are few qualitative studies of misophonia and none that examines these topics. The study can contribute to increasing understanding of what it is like to live with misophonia and will be a unique contribution to the knowledge base about the phenomenon.

We refer to the application for prior approval of the above-mentioned research project. The application was processed by the Regional committee for medical and health-related research ethics (REK south-east C) in the meeting on 03.06.2021. The assessment has been made on the basis of section 10 of the Health Research Act (etc.).

REK's assessment

The project applied for will investigate how people with misophonia, i.e. people who experience strong discomfort when exposed to certain sounds, experience their own condition and experience being met by others, including by healthcare personnel. The committee believes that the project will be able to generate knowledge about such experiences by living with the condition, but that this will not be new knowledge about illness and health as understood in the Health Research Act. The committee

believes that the themes emphasized in the interview guide underpin this understanding of the project's main purpose.

The project therefore falls outside the scope of the Health Research Act, cf. §2 and §4 of the Health Research Act, and can thus be carried out without prior approval from REK.

Resolution

The project falls outside the scope of the Health Research Act, cf. § 2 and § 4 letter a). Approval from REK is not required to implement the project.

The committee's decision was unanimous.

Access to appeal

You can appeal against REK's decision, cf. Norwegian Public Administration Act section 28 et seq.

The appeal is sent on a separate form via the REK portal. The appeal deadline is three weeks from when you receive this letter. If REK upholds the decision, REK forwards the complaint to the National Research Ethics Committee for Medicine and Health Sciences (NEM) for final assessment, cf. Research Ethics Act § 10 and Health Research Act § 10.

With best regards

Britt Ingjerd Nesheim Prof.
Dr. med.
Leader REK south-east C

Anders Strand
Senior Advisor

The document is electronically signed

Copy to:

University of Oslo
Jenny Kristin Staurset Langlo

NSD NORSK SENTER FOR FORSKNINGSDATA

Assessment

Reference number

120250

Project title

A qualitative study of experiences with misphonia

Institution responsible for processing

University of Oslo / Faculty of Social Sciences / Department of Psychology

Project manager (scientific employee/supervisor or research fellow)

Marit Råbu, mariraa@psykologi.uio.no, tel: 22845125

Type of project

Student project, master's study

Contact information, student

Jenny Havnes Langlo, jklanglo@student.sv.uio.no, phone: 91142245

Project period

01.11.2021 - 20.12.2022

Rating (1)

15/10/2021 - Assessed

It is our assessment that the processing will be in accordance with privacy legislation, as long as it is carried out in line with what is documented in the notification form 15.10.2021 with attachments, as well as in the message dialogue between the notifier and NSD. The treatment can start.

TYPE OF DATA AND DURATION The project

will process general personal data, special categories of personal data on health information until 20/12/2022.

LEGAL BASIS The project

will obtain consent from those registered to the processing of personal data. Our assessment is that the project requires a consent in accordance with the requirements in art. 4 nos. 11 and 7, in that it is a voluntary, specific, informed and unequivocal confirmation, which can be documented, and which the data subject can withdraw.

For general personal data, the legal basis for the processing will be the data subject's consent, cf. the Personal Protection Ordinance art. 6 no. 1 a.

For special categories of personal data, the legal basis for processing will be that of the data subject

express consent, cf. the Personal Data Protection Ordinance art. 9 no. 2 letter a, cf. Personal Data Act § 10, cf. § 9 (2).

PRIVACY PRINCIPLES

NSD considers that the planned processing of personal data will follow the principles in the Personal Data Protection Regulation:

- on legality, fairness and transparency (art. 5.1 a), in that the data subjects receive satisfactory information about and consent to the processing
- purpose limitation (art. 5.1 b), in that personal data is collected for specific, expressly stated and justified purposes, and not further processed for new incompatible purposes
- data minimization (art. 5.1 c), in that only information that is adequate, relevant and necessary for the purpose of the project is processed
- storage limitation (art. 5.1 e), in that the personal data is not stored longer than necessary for to fulfill the purpose.

THE RIGHTS OF THE REGISTERED

NSD assesses that the information about the processing that the registered will receive meets the law's requirements for form and content, cf. art. 12.1 and art. 13.

As long as the data subjects can be identified in the data material, they will have the following rights: access (art. 15), correction (art. 16), deletion (art. 17), restriction (art. 18) and data portability (art. 20).

We remind you that if a data subject contacts you about his rights, the institution responsible for data processing has an obligation to respond within one month.

FOLLOW YOUR INSTITUTION'S GUIDELINES NSD

assumes that the processing meets the requirements of the Personal Data Protection Regulation regarding correctness (art. 5.1 d), integrity and confidentiality (art. 5.1 f) and security (art. 32).

To ensure that the requirements are met, the project manager must follow internal guidelines/consult with the institution responsible for processing.

REPORT SIGNIFICANT CHANGES If there

are significant changes in the processing of personal data, it may be necessary to report this to NSD by updating the notification form. Before you report a change, we encourage you to read about the type of changes that need to be reported: <https://www.nsd.no/personverntjenester/fylle-ut-meldeskjema-for-personopplysninger/melde-endringer-i-registration-form> You must wait for a response from NSD before the change is implemented.

FOLLOW-UP OF THE PROJECT NSD

will follow up at planned termination to clarify whether the processing of the personal data has been terminated in line with the processing that has been documented.

Contact person at NSD: Olav Rosness, advisor.

Good luck with the project!



DO YOU WANT TO PARTICIPATE IN A RESEARCH PROJECT ON MISOPHONIA?

Are you troubled by misophonia? Have you sought help or considered seeking help because of this? This is a request for you to do an interview in connection with a research project on misophonia. In this document, we provide you with information about the project and what participation will mean for you.

The purpose of the project and current participants

My name is Jenny Langlo and I am a student on the professional course in psychology at the University of Oslo. As my final main thesis, I will carry out a qualitative study of experiences with misophonia. In this study, I will interview people who suffer from misophonia about their experiences and experiences with the condition. The purpose of the study is to obtain more knowledge about what it is like to live with misophonia and how this affects those who suffer from it. The study will particularly investigate how the participants are met by other people when it comes to these ailments. The topic of the interview will therefore be experiences and experiences with misophonia in meeting with other people - such as in everyday situations or in meeting with health personnel. I therefore want to get in touch with people who have misophonia and who at some point in their lives have considered seeking professional help because of this. Current participants may have both sought help for misophonia, or only considered doing so. The study is an independent research project and will result in my written main thesis at the Department of Psychology which will be delivered in autumn 2022.

What does participating mean for you?

Participation in the study will involve appearing for an interview with me, which will last around one hour. If you wish to participate, you can contact us via the website nettskjema.no/a/230347 or tel. 91142245. We agree together on the time and place for the interview, the interview can also be conducted digitally. During the interview, I will make an audio recording. The audio recording is deleted as soon as I have made a written version. Both the audio recording and the printout will be stored in Services for Sensitive Data (TSD), which is UiO's service for secure data storage. The information about you is anonymised and it will not be possible to identify you in the results of the study. In order to participate, you must sign the declaration of consent on the last page. You can withdraw your consent at any time without giving any reason. All your personal data will then be deleted.

What happens to the information about you?

The information about you must only be used as described. You have the right to inspect the information that is registered about you and the right to have any errors in the information that is registered corrected. You also have the right to access the security measures when processing the information. You can complain about the processing of your information to the Norwegian Data Protection Authority and the University of Oslo's data protection ombudsman. All information will be processed without names or other directly identifiable information. A code links you to your information through a list of names. Only psychology student Jenny Langlo and professor Marit Råbu (supervisor and project manager) have access to this list.

The information about you will be deleted at the end of the project in December 2022.

Possible advantages and

disadvantages Participants will be given the opportunity to contribute to a research project that aims to shine a spotlight on and increase understanding of misophonia. Participation in the study will only involve taking part in a research interview as described. You decide for yourself if there are topics during the interview that you do not want to talk about.

Approvals The

Department of Psychology at the University of Oslo and project manager Marit Råbu are responsible for privacy in the project. NSD (Norwegian Center for Research Data AS) has assessed that the processing of personal data in this project is in accordance with the privacy regulations. If you have questions related to NSD's assessment of the project, you can contact: NSD – Norsk senter for forskningsdata AS by e-mail (personverntjenesters@nsd.no) or by phone: 55 58 21 17.

Contact information If you

have questions about the project, wish to participate or wish to withdraw from participation, you can contact Jenny Langlo via nettskjema.no/a/230347 or on tel. [91142245](tel:91142245).

With best regards

Jenny Langlo

Student at the Department of Psychology, UiO

Marit Råbu

Professor at the Department of Psychology, UiO

Consent for participation in the study "A qualitative study of experiences with misophonia"

I agree to participate in the project and to my personal data being used as described.

Place and date

Participant's signature

Participant's name in printed letters



UiO : Psykologisk institutt

Det samfunnsvitenskapelige fakultet

PARTICIPANTS WANTED FOR RESEARCH PROJECT ON MISOPHONIA

AT UIO Hello! My name is Jenny Langlo and I am a student at the

Department of Psychology at the University of Oslo. In connection with my main thesis, I want to get in touch with people with misophonia for participation in a study.

I am looking for people over the age of 18 who have once in their life considered seeking professional help because of misophonia. You can participate both if you have sought help, or if you have only visited this tank once in your life, but chose not to. Participating in the study means taking part in an interview with me in February/March which lasts about 1 hour - we will agree together on the time and place for the interview (also possible to do digitally). The topic of the interview will be different experiences and experiences with misophonia. The information from the interview will be presented anonymously in my main thesis at the University of Oslo. The supervisor for the project is professor Marit Råbu.

Due to research ethics guidelines, the comment field on this post will be turned off and unfortunately I cannot respond to inquiries via Facebook. If you want to participate, have questions or want more information, you can follow this link and use the online form at the bottom of the page, and I will contact you:

<https://www.sv.uio.no/.../Erfaringer%20med%20misofoni/> I

hope you register your interest and will contribute to more research on

miss phone! 

Sincerely, psychology
student Jenny Langlo

Interview guide

Introduction -

Thanks, purpose, anonymity and consent.

- Information about today's interview and approximate duration. Questions?

Background information -

Can you describe your ailments?

- Triggers, experience, strategies, stress in everyday life, change over the years?
- When did these problems start?
- When and how did you become aware of the concept of misophonia?
 - How was this experienced?

Relational -

Have you told others about your misophonia?

- Who? When? (Family, friends, work, others)
- What reactions do you usually get when you tell about it?
- How do you usually describe it when you tell others about it?
- Have you kept your misophonia a secret from others?
 - Who? Why?
- When someone makes a trigger sound: what do you usually do?
 - Have you received reactions from others on this? Do others notice?

Health care

- Have you sought help because of misophonia?
 - Yes: When? Where? How was this? Met by others?
 - No: Have you considered this? Why not?
- Have you told a doctor/nurse/psychologist or similar about misophonia or the problems?
 - Yes: In what context? What happened then?
 - No: Have you considered telling about it? Why/why not?

Perception -

Have you ever wondered why you have misophonia? For now?

- What do you think is the cause of your misophonia?
 - Thoughts on what misophonia comes from? Born with it/triggered by something?
- Are there other words/diagnoses than misophonia that you intend to describe your ailments?

Conclusion -

Do you have questions or comments, something you are wondering about?

- How do you think it was to talk to me about this?

General follow-up questions:

Can you tell a little more about it?

Would you like to say a little more about it?

How did it feel for you??

Can you describe to me what happened?