"I'm sure Dr Jekyll had misophonia": A Reflexive Thematic Analysis (RTA) examining lived experience patterns in misophonia and the usefulness of Reddit as an online support network.

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Abstract

Misophonia, commonly referred to as the 'hatred of sounds' disorder (despite lack of official classification in the diagnostic tools), has largely been investigated with the purpose of establishing a mechanism responsible for the disorder. Perpetuating the emergence of two main gaps within the literature; i) lack of large-scale lived experience research, and ii) lack of investigation towards the online support networks that are becoming increasingly utilised and available to misophonic individuals. To address these gaps, this project utilised the r/misophonia subreddit as a data collection source to examine the presence of lived experience patterns in people with misophonia, and to assess the usefulness of online support networks. The dataset included 26 reddit posts (10 from the year 2021, and 16 from the year 2022) which were randomly sampled using an application programming interface (API), and then analysed qualitatively using reflexive thematic analysis (RTA). Overall, the findings portrayed that misophonic individuals share a plethora of lived experiences, and regarding the use of online support networks, such as the r/misophonia subreddit, these were represented as largely positive environments (via. Providing support, freedom of expression, and a place to vent). However, there were also negative implications of using online social networks, for example they can become environments of perpetuating negativity where discussions of self-harm, and suicide may take place.

Introduction

Misophonia, the 'hatred of sounds' (Jastreboff & Jastreboff, 2002) is traditionally characterised by its tendency to provoke unwanted negative emotional and/or behavioural responses to typical day-to-day sounds – these are termed "trigger sounds" (Jastreboff & Jastreboff, 2002; Kumar et al., 2014). Individuals with misophonia are often regarded as sharing a common set of trigger sounds, such as those produced by people eating, drinking, chewing, and breathing (Edelstein et al., 2013; Wu et al., 2014). With the common response to these trigger sounds including anger, anxiety, irritation, and distress, combined with the overwhelming desire to escape the situation (Edelstein et al., 2013; Schröder et al., 2013). Due to the emotional/behavioural impact, and largely inescapable nature of trigger sounds, there is an established consensus within the literature that misophonia can have extremely debilitating effects on an individual's quality of life – particularly their occupational, familial, and social life (Edelstein et al., 2013; Schröder et al., 2013). Jager et al., (2020) illustrated the impact of misophonia on an individual's mental health, particularly the socially isolating consequences, which in severe cases of misophonia have been shown to result in suicide and/or suicide attempts. Coinciding with Rouw and Erfanian's, (2018) observations that up to 20% of individuals with misophonia have experience suicidal ideation.

Despite the debilitating effects of misophonia, it is still a relatively unexplored disorder and does not have an official classification in either the Diagnostic and Statistical Manual of Mental Disorders (DSM) or the International Classification of Diseases (ICD). As there are no official diagnostic criteria, the 'full extent' to which

misophonia affects and individual's life cannot accurately be presented to professionals, despite the fact it can be seen to have devastating consequences. There have been some attempts to provide some unofficial diagnostic criteria for misophonia (Dozier et al., 2017; Schröder et al., 2013), based largely on what is currently known about misophonia, and the disorders misophonia has been evidenced to co-occur and share comorbidities with. More recently, literature has begun to advocate for misophonia to be regarded as its own independent disorder (potentially discrete disorder), with Jager et al., (2020) continually describing misophonia as its own psychiatric disorder, advocating for further refinement of proposed diagnostic criteria, to assist in establishing a more accurate diagnosis for individuals. In relation to treatment, tinnitus retraining therapy (TRT; Jastreboff & Jastreboff, 2014), and cognitive behavioural therapy (CBT; Schröder et al., 2017) are the 'conventional treatments' utilised for misophonia. Less conventional treatments, which are growing in recognition, include, relaxation and counterconditioning therapy (RCT), and applied relaxation training (Dozier, 2015). Most highly appraised is CBT, Jager et al., (2021) demonstrated using a randomised control trial that CBT has both short-term and long-term efficacy when treating misophonic individuals. Potgieter et al., (2019) highlighted that the current treatments for misophonia are strong foundations for future literature wanting to establish diagnostic tools/methods, and trial treatments.

To further inform diagnostic and treatment approaches, research should continue to expand and develop the understanding of misophonia. To date, a large majority of the literature has focused on investigating the causal mechanism/s facilitating the disorder, with the 'auditory processing framework' in particular dominating the field, regarding misophonia as a disorder of sound processing (Jastreboff & Jastreboff, 2002; Kumar et al., 2014). This framework proposes that trigger sounds cause impaired processing in the auditory and emotional parts of the brain, subsequently driving the negative emotional response exhibited after a trigger event (Kumar et al., 2014, 2017). Ash et al., (2023), highlighted the 'detached' nature of this framework, specifically its lack of acknowledgement of contextual factors – particularly as misophonia has been demonstrated to be a highly socially impacting disorder (Edelstein et al., 2013; Schröder et al., 2013). Coinciding with Dozier et al., (2017) proposal that misophonia should be explored from a multi-sensory perspective. There are a plethora of studies illustrating that contextual factors do indeed affect how the brain processes information, such as, social, and non-social signal cues (Molapour et al., 2021). A newer emerging perspective attempting to explain misophonia is the 'motor basis for misophonia', primarily proposed by Kumar et al., (2021). This perspective suggests that misophonic distress may potentially link to the action of triggers (and therefore the people that produce the trigger sounds) as opposed to the sound itself, which they suggest has been misinterpreted as the main trigger source – illustrating there to be a social element involved in explaining misophonia (Ash et al., 2023; Kumar et al., 2021).

Numerous small-scale case studies, typically involving individual case descriptions or a series of case reports, have also been used to develop and inform an understanding of misophonia (Dozier, 2015; Dozier & Morrison, 2017). Historically, case study literature has been perceived as lacking rigour and objectivity in comparison to other research methods, however, regarding new research areas the use of case studies has been praised as being well-suited and useful for exploratory purposes (Eisenhardt, 1989). Gilson, (2012) highlighted that health-related research fields in particular lack an appreciation for case study approaches, when in actuality case studies are necessary for allowing more in depth and multi-faceted examinations of real-life complex issues. Although lived

experience research has been produced in relation to misophonia typically through using small-sale case studies, which while good and rich in information, these experiences are not widely generalisable and/or explored amongst a plethora of individuals with misophonia. In support of this, Enzler et al., (2021) highlighted that the 'true' understanding of misophonia from a lived experience standpoint is largely unexplored to date by the literature, further implicating that without examining the subjective experiences of individuals (on a larger scale), this will in turn hinder the progression of psychiatric tools, treatments, causal research, and overall understanding of misophonia. Furthermore, Vázquez et al., (2023) stressed the importance of including lived experience at all stages of research development, as they argue that patients can offer 'specialist expertise' about their disorder, that most researchers cannot, due to them living with their disorders daily. This prominently relates to the movement of patient and public involvement (PPI) in the design and conduct of health research, as PPI has been demonstrated to increase the value, integrity, and overall quality of literature (Biggane et al., 2019).

With the increasing examination of misophonia from a social perspective and the apparent importance of examining lived experiences, it is essential to discuss the growing development/utilisation of online forums designed to help people with misophonia cope and educate themselves about their disorder. Some prominent forums include 'Allergic to Sound' (https://allergictosound.com) which is an online resource developed for people living with sensory processing disorder (SPD), misophonia, and misokinesia ('hatred of movements'; Jaswal et al., 2021), and the r/misophonia subreddit forum (https://www.reddit.com/r/misophonia/) which is an online support network exclusively for misophonia. Online social networks consist of a set of interconnected individuals who interact using computer-based technologies as opposed to face-to-face interactions (American Psychological Association, n.d.; APA). As misophonia can have detrimental effects on an individual's ability to engage socially (Edelstein et al., 2013; Schröder et al., 2013), these online social network tools in theory may allow for individuals with misophonia to express themselves socially. Naslund et al., (2020), highlights that it is not uncommon for people with mental health conditions to turn towards online platforms in search for online peer-to-peer connections where they can share their experiences and gain advice. There is overwhelming evidence that online support networks provide positive and supportive environments that instil a sense of belonging within individuals (Naslund et al., 2016). However, research also illustrates that there can be considerable risks of engaging in online support networks, perhaps most prominent is the risk of creating environments of perpetuating negativity, or promoting unhealthy coping mechanisms, such as self-harm (Ziebland & Wyke, 2012). Contrastingly, Highton-Williamson and Giacco, (2015) indicates that these potential risks may not apply as heavily to people with mental health issues as their review found limited evidence for extreme negative engagement.

In retrospect, there appears to be two apparent gaps in misophonia literature: firstly, the lack of large-scale lived experience literature, and secondly, the lack of research examining the social networks available to those with misophonia. To address these gaps, this project aims to utilise one of, if not, the largest online support networks currently being used exclusively for misophonia, this is the r/misophonia subreddit. The researcher decided to utilise the r/misophonia subreddit as a source for data collection as it could arguably provide the 'raw' lived experience of misophonia, untampered by researcher involvement and therefore maintaining high ecological validity. Reddit defines itself as a home for thousands of communities which promote endless communication and authentic human interaction. The r/misophonia subreddit was created on the 9th of March 2011, and currently has

62.5k members (as of March 30th, 2023) subscribed to its page. In comparison, the misophonia Facebook support network is a closed forum created on the 16th of January 2012, and only has 24.9k members (as of March 30th, 2023). Thus, illustrating the growth of this platform and its involvement in recording the experiences and supporting people with misophonia. Through using the r/misophonia subreddit, this research will examine the presence of lived experience patterns between those with misophonia, and the usefulness of online support networks, such as Reddit, therefore addressing these gaps and incorporating PPI, through showcasing of individuals' raw lived experiences at the core of misophonia research.

Method

Participants

This dataset was comprised of 26 Reddit posts (10 posts from the year 2021, and 16 from the year 2022) that were randomly sampled from the r/misophonia subreddit using an application programming interface (API). Initially, 100 posts (50 from the year 2021, and 50 from the year 2022) were collected using the API, though this was reduced when applying the exclusion criteria, which was: posts explicitly indicating that the user was under the age of 18-years-old (for example, *"I am a 16-year-old boy with misophonia"*); and if the post URLs had expired. URL expiration typically occurs if the Reddit posts have been removed by the user directly or removed by a subreddit moderator, due to violating the r/misophonia subreddit's rules (see Appendix A). Application of the exclusion criteria resulted in 74 posts from the original 100 collected being removed from the analysis. Demographic details could not be obtained for this project, due to Reddit being a platform which prioritises its users anonymity, and thus has a largely anonymous user base.

Materials

Application Programming Interface (API) – An API is a library of coding functions that allow for a website or application to be interacted with. In this project, the API interacted with the subreddit r/misophonia (website) to extract Reddit post URLs and directly transfer them into an excel file, where they could then be cleaned in accordance with the exclusion criteria, and then subjected to analysis.

Methodological approach

As this project was exploratory in nature, focusing on exploring individuals' lived experience of misophonia, it was organised around three guiding questions: 1. Are there patterns of lived experience between users? 2. How can lived experiences in the r/misophonia subreddit be utilised to inform the existing literature surrounding misophonia? and 3. What is the r/misophonia subreddit being used for?

The posts in this project largely indicate that they have been created by people that have misophonia themselves, however posts on this subreddit can be made by anyone that interacts with misophonia to some degree in their lives (for example, an individual may be using the subreddit for a family member with misophonia).

A Reflexive Thematic Analysis (RTA) was used to analyse the data. This is theoretically a flexible method used for developing, analysing, and interpreting patterns across a qualitative dataset, and therefore was deemed appropriated for use in this project (Braun & Clarke, 2006). The data was analysed using a critical realist

framework, which acknowledges that whilst all users will have differing experiences of the world, they all have situated experience of misophonia and using the r/misophonia subreddit platform. The researcher was a 21-year-old white cis-gendered woman who does not have misophonia but has been a member of the r/misophonia subreddit for approximately two years for previous research purposes.

Procedure

Due to the nature of this project, consent did not need to be obtained, as Reddit data is public domain and according to Reddit's privacy policy users are aware that their posts may be accessed by external sources (https://www.reddit.com/policies/privacy-policy). However, out of consideration, an information sheet (see Appendix B) was sent directly to the moderators of the r/misophonia subreddit informing them that the project would be taking place and what it entailed. The r/misophonia subreddit moderators responded to this information sheet, expressing that they were happy for the study to be conducted (thus illustrating a form of consent; see Appendix C). This study was granted ethical approval by the Institution's Research Ethics Committee (see Appendix D).

After receiving a response from the moderators, an API was coded using the programming language Python (2009), to extract 100 posts from (specifically their URLs) from the r/misophonia subreddit and store them into a singular excel file where they could be systematically reviewed before including them in the dataset for analysis. The API was not coded to exclude any specific topics from the r/misophonia subreddit, the only coded criteria was that the posts would be from the years 2021 and 2022, this was to ensure that the dataset was a true representation of current topics/issues that were important to individuals with misophonia. The r/misophonia subreddit however does have some page rules (see Appendix A), advising users to avoid discussing certain topics, such as, suicide, shaming, venting, rudeness etc. Once the URLs were stored into an excel file, systematically each URL was opened individually to ensure they had not expired. After cleaning the excel file, 26 Reddit post URLs remained, the content of these posts was then screenshot and transferred into a word document where they could be anonymised ready for analysis.

In relation to anonymity issues, Adams (2022) illustrated that one of the major ethical concerns of using data from Reddit was that reverse engine searching on 'Google' (the copy and pasting of statements into google) could be used to obtain the original Reddit post URLs, thus no longer maintain user anonymity. Therefore, to address this ethical concern, the feature examples (sentences and words) used to illustrate information in relation to the themes in this project have been re-worded only for the purpose of the write-up – with the original features being used in the data analysis stages. Importantly, these re-worded features have been reviewed externally by the project supervisor to ensure the meaning of the original features has been maintained, and therefore is still an accurate representation of the r/misophonia subreddit and its users. As well as this, the re-words were then typed into Google using *"r/misophonia [insert quote]"* and if the original URL no longer showed on the first page of Google links, the re-word was considered effective and could then be included in the write-up of the project.

Data Analysis

For data analysis, this RTA utilised Braun and Clarke's (2006) six steps of thematic analysis framework. Braun and Clarke (2006) highlight that for a thematic analysis to be considered 'good' it must maintain transparency to its readers, thus the detailed process of each six step is provided below to ensure transparency.

Step 1: Familiarising yourself with your data.

Once data collection was completed, the researcher spent some time away from the data and revisited it again later (specifically one month). This was done to ensure that the Reddit posts were examined using an impartial perspective. To familiarise themselves with the data, the researcher conducted multiple read throughs before beginning the analysis. The first read through consisted of the first half (Reddit posts 1-13) of Reddit posts being read and then the second half (Reddit posts 14-26) – without making notes. The second read through oppositely consisted of the second half (Reddit posts 14-26) being read first and then the first half (Reddit posts 1-13) – again without making notes. This was done to ensure that equal attention was applied to all the posts, which research has stated to be a crucial step when examining qualitative research, as it promotes the use of a standardised methodology (Braun & Clarke, 2006; Nowell et al., 2017). This process was then repeated, this time with the researcher making short notes in the margins, these notes demonstrate the researcher's initial thoughts about the data and demonstrate reflexivity.

Step 2: Generating initial codes.

Next, initial codes were generated by systematically reading the posts and extracting (copy and pasting into a separate word document) features, which at this stage in the analysis appeared relevant to the research topic of examining the lived experience of misophonia. During this step, the researcher also began to look for initial patterns amongst the features of the Reddit posts. An example of some features which were coded into the same initial code within the current dataset is, "I did some research on that earlier and didn't turn up too many articles.", "I've done some research, and this is what I have gathered.", and "I've spent the last four hours looking at scholarly sources and research of experts of misophonia," are all features which have a pattern of individuals with misophonia mentioning seeking to educate themselves further about misophonia, thus these features were coded under the code 'Education'. By the end of step 2, there were 45 initial codes.

Step 3: Searching for themes.

Once the initial codes were finalised, the next step was to sort the codes into candidate themes (as defined by Braun & Clarke, (2006)), that were all independent of each other, but similarly related to the projects research aims. This was done by cutting out the initial codes and physically mapping them onto a cork board, sectioning each area of the cork board for a new candidate theme. The candidate themes and the corresponding initial codes are listed in Appendix E, there were 19 candidate themes in total.

Step 4: Reviewing themes.

The candidate themes were then examined individually to determine whether they appropriately addressed the three research questions; 1. Are there patterns of lived experience between users? 2. How can lived experiences in the r/misophonia subreddit be utilised to inform the existing literature surrounding misophonia? and 3. What is the r/misophonia subreddit being used for? This was done in two parts; part one examined the codes and decided

if they were logically related to each theme and then part two examined the full original dataset of 26 Reddit posts looking for whether the themes could be effectively applied to the dataset. This review concluded that whilst all candidate themes were relevant there had to be a reduction in the number of themes, therefore this resulted in the collation of many candidate themes. The review of these themes formed a final four themes with six subthemes in total.

Step 5: Defining and naming themes.
The aim of this step is to capture the 'essence' of what each theme and its corresponding subthemes represent, through defining and naming them appropriately. Braun and Clarke (2006) suggested that these names need to be concise, punchy, and immediately demonstrate to readers what that theme is about. See 'Findings' section for the names and definitions of the themes.

Step 6: Producing the report.
This step involves the production and write up of the RTA report, see 'Results' section.

Results
An RTA of 26 Reddit posts from the r/misophonia subreddit revealed four main themes; 1. Characteristics of misophonia (containing three subthemes), 2. Effects on relationships (containing three subthemes), 3. Traumatic experiences (containing no subthemes), and 4. The use for Reddit (containing no subthemes). These main themes and their subsequent subthemes are displayed in Table 1 below. All themes were generated with the aim to explore and address the potential lived experience patterns of misophonia and the usefulness of reddit as a support network. Each main theme and subtheme are discussed in turn, providing quotes to support.

Table 1. Table of themes

Main Theme	Subtheme
Theme 1: Characteristics of misophonia	1.1 Triggers
	1.2 Responses
	1.3 Solutions
Theme 2: Effects on relationships	2.1 Relationship with others
	2.2 Relationship with self
	2.3 Relationship with academia/research
Theme 3: Traumatic experience	N/A
Theme 4: The use for Reddit	N/A

Theme 1: Characteristics of misophonia
This main theme encapsulated the various discussions that occurred between individuals (users) on the r/misophonia subreddit, in which they shared information about their personal misophonia characteristics, such as *"I get paralyzed with anxiety", "My biggest trigger is my mam sniffing",* and *"My worst trigger is loud noises".* These discussions wholly centred around three topics; one topic being the types of triggers users experienced misophonic distress to, another topic being the responses users elicited to their triggers, and the third being the

methods/techniques individuals implemented to help them cope with their misophonia. Thus, the three subthemes were generated, 1.1 Triggers, 1.2 Responses, and 1.3 Solutions. Notably, it appeared second nature for users on the r/misophonia subreddit to discuss personal details about their misophonia characteristics with each other, and there were many instances in which users directly prompted these types of discussions through the use of questioning. For example, *"Does anyone experience trigger sounds when they aren't actually happening?", "Do doorbells trigger anyone?", "Anyone else experience this?", "Anyone else have thoughts on trigger formation?",* and *"Does anyone relate to this also?".* The apparent use of questioning illustrates that the r/misophonia is a platform where individuals with misophonia feel comfortable to express and voice their various characteristics. Furthermore, it suggests that the r/misophonia subreddit is an online platform misophonic individuals utilise to seek out other people with misophonia that share similar characteristics – highlighting a desire for relatability amongst users.

1.1 Triggers

This subtheme comprised the types of triggers that users on the r/misophonia subreddit associated as characteristics of misophonia and personally reported experiencing. Many of the trigger sounds presented in the dataset were consistent with the common trigger sounds highlighted in the current misophonia literature – with eating related triggers being the most prevalent in the dataset. Some reoccurring triggers were as follows, *"Very loud chewers", "Reflux issues", "Sticky mouth sounds", "S and T sounds are too harsh", "I get bothered by all stimuli", "Bass sounds", "Rhythmic ticking", "Slurping and smacking",* and the list goes on. In relation to lived experience, these triggers demonstrate that although people with misophonia may have differing individualised sound sensitivities, for example some individuals may perceive repetitive tapping related sounds as more triggering/intense than nasal related sounds, there is still a common set of trigger sounds that individuals with misophonia are likely to experience as characteristics of their misophonia – these trigger sounds being largely consistent with those presented in the literature. Thus, illustrating the first pattern of lived experience, that pattern being that people with misophonia likely share the lived experience of enduring similar characteristics of misophonia – specifically triggers in this instance.

Further to presenting triggers that were consistent with the literature, the dataset also brought forth new triggers which have largely been unexplored by misophonia research to date. Most prominently, users discussed experiencing auditory hallucinations of their typical triggers – sometimes referred to as *"ghost triggers"* by users. One user stated *"sometimes ghost sounds will get stuck in my head… they repeat like an echo each time triggering me again. It can last a few minutes or a couple of hours",* with another user adding *"I can hallucinate sounds through my headphones when they aren't even happening at all",* and another following up with *"Triggers replay in my mind anywhere from 30 seconds to 15-30 minutes".* Parallel to these experiences, individuals with misophonia described being fearful of appearing *"crazy"* due to experiencing auditory hallucination as a characteristic of their misophonia, with statements such as *"I feel like normal people will think I'm going crazy for hallucinating"* being direct evidence of this. Additionally, this statement illustrates that people with misophonia do not regard themselves as *"normal people".* In relation to what the r/misophonia subreddit is being used for, the nature of the users conversations here arguably demonstrates that the r/misophonia subreddit is

somewhere that individuals with misophonia can express themselves freely, without the need to apply a filter, and without fear of judgement – specifically a fear of being deemed *"crazy"*.

Another trigger that became an apparent pattern in the dataset was visual triggers, which although have been briefly discussed in the misophonia literature, there is no clear indication of the relationship between misophonia and visual information. Instead, visual triggers have been more closely associated with misokinesia. Evidence of the presence of visual triggers within the dataset include, *"Visual triggers only add to my misophonic distress"*, *"I try so hard, but my visual triggers are just too much to deal with"*, and *"My trigger intensifies when I can see the action of that trigger"*. Visual triggers appeared to be a great concern for many misophonic individuals, which begs the question as to why research has not investigated this element of misophonia more closely. Especially as the involvement of visual information would largely suggest that misophonia is not solely a disorder of suffering from sounds. These new trigger findings (both auditory hallucinations and visual triggers) within this subtheme advocate for further exploration of misophonia characteristics, especially if research is to begin establishing an accurate symptomology for the diagnostic criteria.

1.2 Responses

Moving on, this next subtheme investigated the emotional and/or behavioural reactions that users reported experiencing in response to their triggers. Users within the dataset consistently portrayed their emotional and/or behavioural responses as negative, for example *"I am enraged every time I hear triggers", "I just want to scream what is wrong with you", "That shit is paralyzing!", "I have to leave immediately or I WILL lash out", "It just feels so inescapable",* and *"Intense frustration, anger, and tension"*. These findings propose that individuals with misophonia largely share a similar set of negative emotional/behavioural response characteristics – presenting another pattern of lived experience.

A particular statement that stood out in the dataset, due to many users resonating with it, through confirming comments, such as *"yes I get this!"* and 'upvotes', was as follows *"Eyes glow red. Intense rage… I'm sure Dr Jekyll had misophonia. Sound was the potion… he'd listen then BOOM! Mr Hyde",* referring to the novel the 'Strange case of Dr Jekyll and Mr Hyde' (Stevenson, 1886). The intention of this novel was to illustrate the duality of human nature, particularly through the utilisation of Freud's (1923) psychoanalytical structural theory of the id, ego, and superego. The character Dr Jekyll is supposed to represent the ego; conscious and rational, acting in accordance with the rules of society (Singh & Chakrabarti, 2008). Whereas Mr Hyde's character is designed to represent the id; fuelled by his aggressive instincts, with no moral and lack of regard for social norms (Singh & Chakrabarti, 2008). A conflict between good and bad (Yildirim, 2020). Interestingly, this is how many users on the r/misophonia subreddit felt best described their response to triggers, as a conflict between good and evil – their id and ego – with their id response often winning, for instance *"I just want to punch the person and run away haha"* and *"I get wildly angry at the person"*. Towards the end of the novel, it is revealed that Dr Jekyll and Mr Hyde are in fact the same person, with Dr Jekyll taking a potion which allows him to transform into Mr Hyde. It could be deduced that like in the novel, Dr Jekyll slowly loses himself to Mr Hyde (eventually resulting in Dr Jekyll's suicide to stop Mr Hyde), and therefore does this mean that individuals with misophonia share this lived experience pattern of feeling like they are losing themselves slowly due to their misophonia.

1.3 Solutions

This subtheme referred to the methods/techniques that users on the r/misophonia subreddit used to best equip themselves to cope with their misophonia, with many of these methods being shared as advice/tips between users. Some common coping mechanisms detailed throughout the dataset were as follows, *"I wear various types of headphone brands"*, *"Cover my ears with my hands/fingers"*, *"Remove myself from the situation by going for a walk or to another room"*, *"Take care of your mental health to cope better"*, *"Use a box fan it is such a necessity"*, and *"White noise... brown noise... pink noise... playing through my headphones"*. This sharing of coping mechanisms that occurs amongst users on the r/misophonia subreddit, displays that there is an established level of support that the subreddit provides to its users. As well as a shared set of common coping mechanisms (which are consistent with the literature) that people with misophonia are likely to engage in to reduce their misophonic distress.

A coping mechanism of notable importance that was presented within the dataset was mimicry, as illustrated by the following statements *"I mimic my mother's sounds to cope. It helps me feel in control of the situation and does an overall good job of bringing down my heart rate. But it probably isn't the healthiest way to cope, and I wouldn't recommend it as it can be a hard habit to break"*, *"Mimicking helps, but I would avoid it as people can take it really personal"*, and *"Others think I am crazy and are hostile towards me when I mimic"*. Which is a coping behaviour consistent with recent literature which highlighted mimicry to be highly prevalent amongst misophonic individuals (Ash et al., 2023). However, although mimicking is being utilised amongst users, it is interestingly a behaviour they *"would not recommend"*, as it is a *"bad habit"*, and an *"unhealthy way to cope"* – illustrating that people with misophonia regard mimicry as a maladaptive behaviour. Further to mimicry, users also discussed engaging in other maladaptive coping mechanisms, for example *"Try a primal scream and thrash about"*, *"Mild self-harm to bare it"*, *"I just want to punch the person and run away haha"*, and *"I want to jump out a window"*. Thus, establishing another lived experience pattern that individuals with misophonia are likely to engage in maladaptive behaviours to cope. It is essential to note that when referring to the r/misophonia subreddit roles, under the 'No Violence' rule it states that suicide/suicidal ideation should not be discussed under any circumstance and provides users with the contact details for a suicide prevention hotline. Meaning that the presence of these suicidal and self-harm statements within the dataset reflect negatively on the r/misophonia subreddit, as it highlights that the subreddit riles are easily violated and therefore the platform is not accurately protecting its userbase from exposure to destructive behaviours and thoughts like it arguably promises.

Finally, users also shared what they believed to be 'long-term solutions' for misophonia on the subreddit. Notably, the two main solutions presented were again extremely destructive; one being permanent isolation and the second being to become deaf (ranging from non-permanent self-deafening techniques to permanent deafness). Some examples of the desire for isolation were as follows, *"The best and only universal solution to misophonia is ultimately to isolate"*, *"I live in a fucking room 24 hours a day... only leaving for the bathroom"*, *"I have to isolate from everything, so I don't freak out over sound"* and *"I'm going to move into the middle of the woods, so I don't have to hear sound"*. Alongside this, users also praised the isolating consequences of the coronavirus (Covid-19) pandemic, for example *"it was a wonderful time"* and *"Everything was remote, and when we met up*

in person we wore masks, so no one ate, and it was bliss". Secondly, the desire for deafness is exhibited by the following statements, *"It is almost enough to wish I were deaf. How can something make me suffer like this?"* and *"I've got my headphones on… hoping the volume will make me deaf"*. Overall, this subtheme illustrates that whilst some of the coping mechanisms for misophonia are expected and consistent with the literature (such as, *"Remove myself from the situation…"* and *"Cover my ears…"*), many of the solutions and/or coping mechanisms for misophonia are maladaptive/destructive behaviours, and therefore, as this is a prevalent lived experience pattern, indicates the importance of research working towards more constructive methods of coping and further assessing the appropriateness of these online support networks, such as Reddit, which arguably promote and/or do not protect their users from being exposed to maladaptive/destructive behaviour discussions.

Theme 2: Effects on relationships

This main theme examined the effects of misophonia on an individual's relationships, there were three subthemes included within this main theme: 2.1 Relationship with others, 2.2 Relationship with self, and 2.3 Relationship with academia/research. Some general examples are, *"My dad is beginning to resent me due to my misophonia, and that hurts me so much"*, *"I told my mom, she took it personal, and even became very angry with me"*, *"Crying in the bathroom at work is an everyday thing for me"*, *"The professional handling my diagnosis was not well-versed in misophonia"* and *"Research is new and shaky"*. In relation to the lived experience patterns indicated within this main theme, there was an established consensus amongst users that misophonia has had an overall negative effect on their various relationships – with lack of understanding displayed by others (both in a personal and academic situation) being a reoccurring complaint from users. In retrospect, this main theme largely represented that due to the lack of understanding users received in their personal lives, the r/misophonia subreddit was somewhere they could come to freely express themselves, with there being an established level of trust and understanding exhibited amongst the r/misophonia subreddit userbase.

2.1 Relationship with others

This subtheme focused solely on investigating the effects of misophonia on an individual's personal relationships, specifically their familial and occupational relationships (as these were the most prevalent within the dataset). Examining familial relationships first, there was an established consensus amongst users that misophonia had negatively impacted their relationships with family/partners, for example *"I make my partner tense and stressed because I am dramatic about noises that they don't even notice"*, *"My dad is beginning to resent me due to my misophonia, and that hurts me so much"*, and *"My mother has COPD… I love her, but sometimes it is painful to be around her"*. With users also discussing having experienced a diminished quality of life due to their poor familial relationships, as evidenced by the following statement *"I wish our diminished quality of life caused by our shitty familial relationships could be fixed"*. Regarding patterns of lived experience, these findings suggest that the majority of individual's with misophonia have likely experienced a breakdown in their personal relationships and potentially feel that they lack the ability to foster positive/meaningful relationships.

In relation to users' occupational relationships, there was again a largely negative portrayal of the effects of misophonia on these relationships, for example *"It is like working in your absolute worst nightmare"*, *"Crying in the bathroom at work is an everyday thing for me"*, and *"Since the mask mandate has been lifted and work feels*

like my own personal hell, our meetings have food and drink for the teams. I just absolutely cannot do it anymore… it's a multidisciplinary team though so I don't know what accommodations they can make". This is consistent with the perspective that personal relationships are affected by misophonia. However, it is important to discuss that there was an instance in which a user described that their fellow colleges have made some active attempts to make the work environment more misophonia-friendly. For example, "The two co-workers I've became friends with eat in the back of the room and I am forever grateful to them". These findings display contradictory evidence to the perspective that people with misophonia are unable to foster good relationships, as when there is some level of understanding displayed towards the misophonic individual (as shown by the "two co-workers") there is greater possibility for good relationships to form. Thus, highlighting that a potential factor that facilitates the rates of which misophonia can impact an individual's relationships is the levels of understanding that people with misophonia are met with by others.

Users on the r/misophonia subreddit largely discussed having received low levels of understandings from others in their personal lives – especially *"loved ones"*, such as family members and partners. For example, *"My mother took it personal and became very angry with me and started making fun of me, that isn't understanding!"*, *"No matter how much I asked them to stop, no one cared"*, and *"I asked them not to bring their glass water bottle full of ice in my car… it causes anxiety for me… and they just got so mad and said they weren't going to come anymore"*. There were many users that attributed the lack of understating that they received from others as being due to *"pure ignorance"*, with some prominent examples in the dataset being *"People are ignorant of their noise impact because quite frankly it is not a constant battle for them. It must be pure ignorance"*, and *"It is easily stopped if a person wanted to stop"*. In contrast to this perspective, there was another section of users on the r/misophonia subreddit that were more empathetic, and attributed the lack of understanding displayed by others to the fact that misophonia is a relatively new and difficult disorder to understand currently. For example, *"It's difficult to convince people that misophonia is a legitimate problem and I'm not just being a brat"* – thus, presenting an expressed need from users for the diagnostic legitimisation of misophonia. Regarding lived experience patterns of misophonia, these findings suggest that people with misophonia are largely met with little understanding towards their disorder, and this in turn facilitates their negative relationships.

2.2 Relationship with self
This subtheme examined the effects of misophonia on users' perceptions of themselves. Typically, when users would refer to themselves in the dataset they would use self-deprecating language, such as *"My misophonia leaves me feeling guilty and intolerable"*, *"Just having misophonia makes me feel like a selfish person"*, *"The guilt piles onto me because the only people I snap at are the ones I hold dearest"*, and *"Misophonia is like a constant reminder that I am a burden to everyone I love"*. Subsequently, proposing the narrative that people with misophonia see themselves as a *"burden"*, *"intolerable"*, *"selfish"*, as well as exhibiting a level of *"guilt"* just for merely having the disorder. These findings within the dataset present that people with misophonia may share the lived experience of having a negative self-image (low self-esteem and negative self-regard) as a result of their misophonia, as well as undergoing reoccurring feelings of guilt and selfishness for effecting both the lives of those around them as well as their own. In relation to the r/misophonia subreddit, these findings demonstrate that the

r/misophonia subreddit is a place where users can ruminate on their negative relationship with themselves – perhaps again forming an environment of perpetuating negativity.

2.3 Relationship with academia/research

This subtheme focused solely on investigating how users felt towards the research that academics have produced about misophonia, as well as their personal experiences when engaging with professionals. A prominent finding within the dataset was that users often questioned the competence of both professionals and research, as exemplified by the following *"The professional handling my diagnosis was not well-versed in misophonia"*, *"Research is new and shaky", "Misophonia is so confusing, especially since there is very little reputable scientific literature about it",* and *"I hope misophonia awareness increases in the future so we can develop better treatments"*. These findings demonstrate that users exhibit a lack of trust towards professionals, as well as regarding current misophonia research as underdeveloped in comparison to other fields of research (*"new and shaky"* and *"very little reputable scientific literature"*). In relation to users' expectations for future research, there was a reoccurring hope that literature would focus on developing new treatment methods and work towards further promoting misophonia awareness. Regarding, users experiences when seeking help from professionals, users often detailed that their issues were met with dismissive remarks, for example one user wrote *"I mentioned misophonia to my psychiatrist and he brushed it off reefing to it as a 'pet peeve'… so I no longer press further… I couldn't talk about the fact that I have a sound related meltdown every day",* and another reported that *"Professionals did very little testing on my sound sensitivities… focusing more on my social interaction, repetitive behaviours, tactile sensitivities etc"*. These negative experiences reinforce the lack of trust between professionals and users, demonstrating users' inability to express their 'true concerns' to professionals – due to fear of judgement and/or lack of regard.

Further to this, users displayed a strong desire to educate themselves about misophonia, using self-education techniques, as exemplified by the following *"I've spent the last four hours looking at scholarly sources and research of experts of misophonia", "I've done some research, and this is what I have gathered",* and *"If you research comorbidity and misophonia it may turn up a few articles to explain"*. Demonstrating that whilst misophonia research is regarded as somewhat underdeveloped, users are still able to utilise the research to develop a greater understand of misophonia.

Interestingly, a prominent discussion that occurred between users on the r/misophonia subreddit centred around a BBC iPlayer short film about misophonia that was produced by someone that had misophonia themselves. This short film received an overwhelming amount of support, some examples being *"This made me so emotional", "I finally feel represented and understood",* and *"This film nailed what misophonia is"*. The intention of this short film was to portray to a lay audience what misophonia is and the daily struggles that people go through when suffering from this disorder – using both research and the producers own personal experiences of misophonia to do so. As users want academia to increase misophonia awareness (for example, "*I hope misophonia awareness increases"*), and the short film was intended to display misophonia to a lay audience, this perhaps explains the overwhelming positive reactions displayed within the dataset to the short film. As well as presenting a potential

solution to improving misophonic individual's relationships with academia, through the utilisation of lay audience techniques.

Theme 3: Traumatic experience

This main theme encapsulated the primary factor that users of the r/misophonia subreddit attributed to being the cause of their misophonia and/or where their misophonia originated from. This factor being traumatic experiences – typically traumatic experiences that occurred during an individual's childhood. For example, *"Triggers definitely have their origins in trauma"*, *"My triggers are related to sounds that occurred during my abuse"*, *"When my dad would walk towards my room during childhood, I knew to expect a punishment... so when my partner now enters a room when I don't expect it I feel myself get worked up, without realising why"*, *"[heavily detailed trauma redacted] I gradually learnt to dread dinner time, there would be verbal tirades, made obvious by my parents silence, eating, and nose blowing... now I will hate mouth and nasal sounds forever",* and *"All of my triggers can be pin pointed to a stressful time in my life"*. To note, some of the specific details of users traumatic experiences have been redacted as they included too many identifying characteristics. It appeared 'second nature' within the dataset for users to discuss their traumatic experiences on the r/misophonia subreddit, again illustrated through direct questioning, such as *"Do people worry about having repressed trauma (childhood mainly) that has caused their misophonia?",* and *"I have trauma, does anyone else relate?"*. Thus, presenting the r/misophonia subreddit as a place where individuals with misophonia feel comfortable to express themselves – even as far as discussing personal traumas. In terms of lived experience patterns, these findings suggest that people with misophonia may share the lived experience of undergoing a trauma at some point in their lives (potentially their childhood), and typically regard these traumas as the causal factors and/or origins of their misophonia.

Theme 4: The use for Reddit

This main theme focused solely on answering the question 'what is the r/misophonia subreddit being used for?'. There was a common consensus amongst users that the r/misophonia subreddit was a place where users could feel understood (which has been demonstrated previously as something they lack in their personal lives), for example *"It is hard to be understood when suffering from misophonia... I think that's why people come to the subreddit and try to be nice and supportive"*. Regarding users' feelings towards the r/misophonia subreddit, there was an overwhelming amount of praise expressed by users, for example *"It is helpful reading your experiences because it's validating. Best of luck, my friends"*, *"Thank you for all the advice. I am so relieved I found this community; everyone has been so helpful and supportive!"*, *"I was having a breakdown and found this subreddit. It is such a relief to know I am not alone",* and *"I need to say thank you. I find comfort in forums like reddit as they help me feel I'm no longer alone"*. These findings illustrate that users typically utilise the subreddit to receive, *"validation"*, *"help"*, *"advice",* and a reminder that they are not suffering *"alone"* – essentially to receive support. In addition to this, users could also be seen as using r/misophonia subreddit as a place to vent, as exemplified through the following *"Every once and a while it helps me to vent",* and *"This is somewhere I can vent my frustration"*. Furthermore, r/misophonia subreddit is arguably aware of its purpose to provide support and a place for users to vent as one of the permanent threads on the platform (that is consistently updated), is the *"Weekly Venting/Support Thread"*. In retrospect, the r/misophonia subreddit represents itself and is considered by users throughout the dataset as a safe space for people with misophonia.

General Discussion

Ultimately, the aim of this project was to utilise the r/misophonia subreddit as a data collection source to examine the presence of lived experience patterns in people with misophonia, and to assess the usefulness of online support networks, such as Reddit. In relation to lived experience, the results demonstrated that misophonic individuals share a variety of lived experience patterns with one another, with many of these experiences confirming findings currently highlighted within the literature – as well as presenting new areas of interest for research. Firstly, theme 1 (*'Characteristics of misophonia'*) highlighted that people with misophonia largely endure a shared set of common misophonia characteristics (Edelstein et al., 2013; Schröder et al., 2013; Wu et al., 2014). Next, theme 2 (*'Effects on relationships'*) illustrated that misophonic individuals often had the shared lived experience of misophonia negatively impacting their relationships (both with others, themselves, and professionals) – regularly being met with a 'lack of understanding' towards their misophonia, and consequently resulting in a self-reported diminished quality of life (Edelstein et al., 2013; Schröder et al., 2013). Theme 3 (*'Traumatic experience'*) presented that misophonic users commonly attributed their misophonia to a traumatic experience. Finally, theme 4 (*'The use for Reddit'*) established that misophonic individuals shared the desire to be understood and this is what pushed them to online support networks such as the r/misophonia subreddit.

From a service user perspective, when examining the usefulness of the r/misophonia subreddit as an online support network, the results are overwhelmingly positive. Users consistently regarded the r/misophonia subreddit as a place where they felt comfortable to express themselves freely, seek advice/support from other users with misophonia, and ultimately vent about their problems – without the fear of judgement. As well as this, the results also identified that users predominantly engaged in the r/misophonia subreddit as they were often met with high levels of understanding from others, which is something those with misophonia reported lacking in their personal lives (as demonstrated throughout theme 2). Due to this, these findings suggest that online support networks, such as Reddit, may be useful for people with misophonia as they arguably equip users with the ability to combat the socially isolating consequences of misophonia (Jager et al., 2020). Therefore, coinciding with previous literature, outside of misophonia research, which represents that online support networks are positive environments, especially for individuals suffering from mental health issues (Naslund et al., 2016), that allow for individuals to foster healthy peer-to-peer connections and develop a sense of belonging in their lives (Naslund et al., 2020) – which is essential as this is something people with misophonia have reported lacking in their personal lives (again illustrated within theme 2). Overall, suggesting that online support networks are useful for individuals with misophonia.

Contrastingly, outside of the service user perspective, it is important to acknowledge that it was common for misophonic individuals to utilise the r/misophonia subreddit as a place to vent and discuss maladaptive and destructive coping mechanisms (such as, self-harm, direct aggression, suicide, etc; as presented in theme 1). According to Prescott et al., (2017), being able to vent online about issues (specifically mental health related issues) can provide users of online support networks with feelings of relief. However, from a long-term usage perspective, Zieband and Wyke (2012) present that online support networks that harbour these persistent negative orientated discussions can have detrimental effects on the long-term well-being of users, as oftentimes the

maladaptive behaviours (such as, self-harm) discussed on online support networks are later 'picked up' by other users. Meaning that being able to vent and discuss negative topics on the r/misophonia subreddit although may feel positive to users could have long-term detrimental effects unforeseen to the users. Another issue highlighted in the dataset is that despite the r/misophonia subreddit having presumably banned these destructive topics, according to the subreddits rules (see Appendix A), they still appear within the dataset and therefore implicates that the r/misophonia subreddit may potentially lack proper moderation as these posts are evidently 'slipping through the cracks'. Thus, the use of online support networks for misophonia is questionable as they arguably unintentionally promote and/or advocate for destructive behaviours. Perhaps to combat these issues and maintain the positive value that these online support networks provide to users further moderation of the r/misophonia subreddit should be implemented, or perhaps increasing moderation transparency (Jhaver et al., 2019).

Progressively, this project provides an overall large-scale lived experience of what it is like to have misophonia – highlighting various patterns within the dataset. Arguably, addressing Enzler et al's., (2021) concerns of the 'true understanding' of misophonia from a lived experience perspective being largely neglected by research. It is important to recognise that when investigating misophonic individual's subjective experiences on the r/misophonia subreddit, not only did the results reinforce previous findings within misophonia literature, but they also presented new areas of interest for research, such as auditory hallucinations, visual triggers, the desire for deafness, and mimicking behaviours. Coinciding with Vázquez et al., (2023) who suggested that incorporating lived experience into research allows for academics to be presented with service-user 'specialist expertise', consequently highlighting areas of interest that may not have previously been highlighted due to researchers largely lacking these 'specialist expertise'. In relation to the usefulness of online support networks, this demonstrates that as well as online support networks, such as Reddit, being useful for providing users with support, researchers could also potentially utilise these online support networks to generate new research questions etc.

Further to users discussing their misophonia experiences and presenting new areas of interest to academics, people on the r/misophonia subreddit also demonstrated a shared need to theorise, using their own personal knowledge (and sometimes research), about the potential reasons for some of their misophonia characteristics. Theorisation from users typically occurred when discussing the unexplored characteristics, and although many of the users' theories make logical sense, for example visual triggers potentially being facilitated by a relationship between misophonia and misokinesia (Jaswal et al., 2021). O'Sulivan et al., (2022) demonstrated that social media is one of if not the largest contributors to the spread of misinformation, specifically in relation to health-related subjects. Subsequently, Pennycook et al., (2021) illustrated that it is relatively easy for online users to spread and engage with misinformation unknowingly, as approximately 50% of participants in their study did so. Meaning that whilst on one hand these online support networks, such as Reddit, may be useful for identifying new areas of research in misophonia, they may also be susceptible to becoming sources for spreading misinformation about misophonia (primarily unintentionally).

Evaluating the strengths and limitations of this project, a prominent strength was that this project maintained high ecological validity. According to the APA, ecological validity is defined as the extent to which the results of a

research project can be regarded as representative to the conditions of the wider world. Arguably, by utilising the r/misophonia subreddit platform this project was able to capture the 'raw' lived experience of misophonia, untampered with by researcher involvement. As theme 2 presented, people with misophonia on this subreddit displayed a lack of trust towards academics and professionals. Guillemin et al., (2018) stressed the importance of developing trust with participants when conducting qualitative research methods (especially for interviews), as without an established level of trust the researcher runs the risk of dampening the fruitfulness/quality of the results. This proposes that establishing a level of trust with misophonic individuals may have been difficult to achieve due to their potentially already established lack of trust towards professionals (as highlighted in theme 2). However, now that research is aware of this lack of trust it may be appropriate for future research to work towards building a stronger trusting relationship with misophonic individuals. To do so, semi-structured interviewing techniques could be utilised to address, firstly, the limitation that this project could not get users to elaborate upon specific points, and secondly, incorporates greater PPI (which misophonia research lacks).

Another limitation of this project was that there was a noticeable lack of demographic details collected, such as age, gender, sexuality, race etc. As Reddit is a platform which prioritises its users anonymity demographic details could not be obtained in this project. Hammer, (2011) illustrated that demographic details can be an integral aspect within research, as these details can have important implications when it comes to interpreting results. An example of how demographic details may have potentially influenced some of the interpretations within this project is that if the r/misophonia subreddit was predominantly made up of one dominant gender, for example males, that would then completely change the tone for theme 4 which describes help-seeking behaviours and a desire to be understood, this is because research shows that males and females engage in help-seeking behaviours differently (Liddon et al., 2018) – meaning that with demographic details the themes of this dataset may have been completely different. Therefore, this portrays that in future large-scale lived experience studies, an attempt should be made to collect demographic details where possible.

Finally, it is essential to note that although this project examines one of, if not the largest, online support networks available to misophonic individuals, and thus the lived experience findings are largely generalisable to the wider misophonic population. The findings related to the usefulness of online support networks can largely only be applied to the r/misophonia subreddit (and the Reddit platform). Perhaps future misophonia research could utilise several online misophonia support groups, for example the r/misophonia subreddit, the 'Allergic to Sound' forums, and the closed Facebook 'Misophonia Support Group' to investigate patterns of lived experience and the usefulness of online support networks. Doing so would arguably allow for there to be greater generalisability of the results (cross-platform generalisability) and would also allow for researchers to identify if there were any comparisons between the different online support networks available to misophonic individuals – perhaps also assessing which support network was most effective in addressing misophonic individual's concerns etc.

To conclude, it is apparent that those with misophonia share a plethora of lived experiences with one another, both confirming previous literature findings (Edelstein et al., 2013; Schröder et al., 2013; Wu et al., 2014), and suggesting new characteristics for research to investigate. In terms of the usefulness of Reddit as a support network, from a service user perspective these forums were regarded with great positivity, allowing for individuals

to freely express themselves, seek advice/support, and ultimately vent about their problems – coinciding with previous literature in support of online support networks (Naslund et al., 2016, 2020). As well as providing academics with a deeper understanding of misophonia. There were also some negative consequences of these online support networks such as, the chance for them to become environments of perpetuating negativity (Ziebland & Wyke, 2012). Future research should continue to build from these findings and work towards developing an official diagnostic criterion for misophonia, ensuring lived experience is incorporated throughout to ensure misophonic individual's needs are being met by research. Arguably, this project establishes the beginning for large-scale lived experience research in misophonia, incorporating both PPI, and attributing a greater understanding to the research question "what does it 'truly' mean to have misophonia?" – as this is something researchers are still unsure of. This project is merely a snippet of the lived experience research that is yet to follow.

Declarations

Compliance with Ethical Statement

All authors certify that they have no affiliation and/or involvement with any organisations or entity with any financial and/or non-financial interest in the subject matter or materials discussed within this manuscript and thus have no competing interests to declare. Informed consent was obtained by the moderators of the r/misophonia subreddit allowing researchers to use an API to gather posts from the subreddit. The authors affirm that informed consent was also obtained by the moderators regarding publishing the data from the subreddit.

Ethics approval

This study was performed in line with the British Psychological Society (BPS) Code of Human Research Ethics and was granted ethical approval by the University of Sunderland's Ethics Committee (see Appendix C; Date 09/11/2022; No. 014934).

Data Availability

The data list of rewords that support the findings of this study are available upon request from the corresponding author. The raw dataset however is not publicly available due to the data containing information that could compromise the privacy of participants.

References

Adams, N. N. (2022). 'Scraping' Reddit posts for academic research? Addressing some blurred lines of consent in growing internet-based research trend during the time of Covid-19. *International Journal of Social Research Methodology*, 1–16. https://doi.org/10.1080/13645579.2022.2111816

American Psychological Association (n.d.). Online Social Network. APA Dictionary. Retrieved March 30, 2023, from, https://dictionary.apa.org/online-social-network

Ash, P. A., Benzaquén, E., Gander, P. E., Berger, J. I., & Kumar, S. (2023). Mimicry in misophonia: A large-scale survey of prevalence and relationship with trigger sounds. Journal of Clinical Psychology, 1–12. https://doi.org/10.1002/jclp.23605

Biggane, A. M., Olsen, M., & Williamson, P. R. (2019). PPI in research: a reflection from early stage researchers. *Research Involvement and Engagement*, *5*, 1–9.

Braun, V., & Clarke, V. (2006). Qualitative Research in Psychology Using thematic analysis in psychology Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Dozier, T. H. (2015). Counterconditioning treatment for misophonia. *Clinical Case Studies*, *14*(5), 374–387. https://doi.org/10.1177/1534650114566924

Dozier, T. H., Lopez, M., & Pearson, C. (2017). Proposed diagnostic criteria for misophonia: A multisensory conditioned aversive reflex disorder. *Frontiers in Psychology*, *8*(NOV), 2015–2017. https://doi.org/10.3389/fpsyg.2017.01975

Dozier, T. H., & Morrison, K. L. (2017). Phenomenology of misophonia: initial physical and emotional responses. *The American Journal of Psychology*, *130*(4), 431–438.

Edelstein, M., Brang, D., Rouw, R., & Ramachandran, V. S. (2013). Misophonia: Physiological investigations and case descriptions. *Frontiers in Human Neuroscience*, *7*(JUN), 1–11. https://doi.org/10.3389/fnhum.2013.00296

Eisenhardt, K. M. (1989). Building theories from case study research. *Academy of Management Review*, *14*(4), 532–550.

Enzler, F., Loriot, C., Fournier, P., & Noreña, A. J. (2021). A psychoacoustic test for misophonia assessment. *Scientific Reports*, *11*(1), 1–14. https://doi.org/10.1038/s41598-021-90355-8

Freud, S. (2019). *The ego and the id.* Simon and Schuster.

Gilson, L. (2012). The case study approach. *Health Policy and Systems Research. Geneva: Alliance for Health Policy and Systems Research, World Health Organisation*, 161–165.

Guillemin, M., Barnard, E., Allen, A., Stewart, P., Walker, H., Rosenthal, D., & Gillam, L. (2018). Do research participants trust researchers or their institution?. *Journal of Empirical Research on Human Research Ethics, 13*(3), 285-294.

Hammer, C. S. (2011). The importance of participant demographics. *American Journal of Speech-Language Pathology, 20*(4), 261.

Highton-Williamson, E., Priebe, S., & Giacco, D. (2015). Online social networking in people with psychosis: a systematic review. *International Journal of Social Psychiatry*, *61*(1), 92–101.

Jager, I., de Koning, P., Bost, T., Denys, D., & Vulink, N. (2020). Misophonia: Phenomenology, comorbidity and demographics in a large sample. *PLoS ONE*, *15*(4), 1–16.

Jager, I. J., Vulink, N. C. C., Bergfeld, I. O., van Loon, A. J. J. M., & Denys, D. A. J. P. (2021). Cognitive

behavioral therapy for misophonia: A randomized clinical trial. *Depression and Anxiety, 38*(7), 708–718.

Jastreboff, M. M., & Jastreboff, P. J. (2002). Decreased sound tolerance and tinnitus retraining therapy (TRT). *Australian and New Zealand Journal of Audiology*, *24*(2), 74–84. https://doi.org/10.1375/audi.24.2.74.31105

Jastreboff, P. J., & Jastreboff, M. M. (2014). Treatments for decreased sound tolerance (hyperacusis and misophonia). *Seminars in Hearing*, *35*(2), 105–120. https://doi.org/10.1055/s-0034-1372527

Jaswal, S. M., De Bleser, A. K. F., & Handy, T. C. (2021). Misokinesia is a sensitivity to seeing others fidget that is prevalent in the general population. *Scientific Reports*, *11*(1), 17204. https://doi.org/10.1038/s41598-021-96430-4

Jhaver, S., Bruckman, A., & Gilbert, E. (2019). Does transparency in moderation really matter? User behavior after content removal explanations on reddit. *Proceedings of the ACM on Human-Computer Interaction, 3*(CSCW), 1-27.

Kumar, S., Hancock, O., Cope, T., Sedley, W., Winston, J., & Griffiths, T. D. (2014). Misophonia: a Disorder of Emotion Processing of Sounds. *Journal of Neurology, Neurosurgery & Psychiatry*, *85*(8), e3–e3. https://doi.org/10.1136/jnnp-2014-308883.38

Kumar, S, Tansley-Hancock, O., Sedley, W., Winston, J. S., Callaghan, M. F., Allen, M., Cope, T. E., Gander, P. E., Bamiou, D. E., & Griffiths, T. D. (2017). The Brain Basis for Misophonia. *Current Biology*, *27*(4), 527–533. https://doi.org/10.1016/j.cub.2016.12.048

Kumar, S, Dheerendra, P., Erfanian, M., Benzaquén, E., Sedley, W., Gander, P. E., Lad, M., Bamiou, D. E., & Griffiths, T. D. (2021). The motor basis for misophonia. *Journal of Neuroscience*, *41*(26), 5762–5770. https://doi.org/10.1523/JNEUROSCI.0261-21.2021

Liddon, L., Kingerlee, R., & Barry, J. A. (2018). Gender differences in preferences for psychological treatment, coping strategies, and triggers to help-seeking. *British Journal of Clinical Psychology, 57*(1), 42-58.

Molapour, T., Hagan, C. C., Silston, B., Wu, H., Ramstead, M., Friston, K., & Mobbs, D. (2021). Seven computations of the social brain. *Social Cognitive and Affective Neuroscience*, *16*(8), 745–760. https://doi.org/10.1093/scan/nsab024

Naslund, J. A., Aschbrenner, K. A., Marsch, L. A., & Bartels, S. J. (2016). The future of mental health care: peer-to-peer support and social media. *Epidemiology and Psychiatric Sciences*, *25*(2), 113–122.

Naslund, J. A., Bondre, A., Torous, J., & Aschbrenner, K. A. (2020). Social media and mental health: benefits, risks, and opportunities for research and practice. *Journal of Technology in Behavioral Science*, *5*, 245–257.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods, 16*(1), 1–13. https://doi.org/10.1177/1609406917733847

O'Sullivan, N. J., Nason, G., Manecksha, R. P., & O'Kelly, F. (2022). The unintentional spread of misinformation on 'TikTok'; A paediatric urological perspective. *Journal of pediatric urology, 18*(3), 371–375. https://doi.org/10.1016/j.jpurol.2022.03.001

Pennycook, G., Epstein, Z., Mosleh, M., Arechar, A. A., Eckles, D., & Rand, D. G. (2021). Shifting attention to accuracy can reduce misinformation online. *Nature, 592*(7855), 590–595. https://doi.org/10.1038/s41586-021-03344-2

Potgieter, I., MacDonald, C., Partridge, L., Cima, R., Sheldrake, J., & Hoare, D. J. (2019). Misophonia: A scoping review of research. *Journal of Clinical Psychology*, *75*(7), 1203–1218.

Prescott, J., Hanley, T., & Ujhelyi, K. (2017). Peer communication in online mental health forums for young people: directional and nondirectional support. *JMIR mental health, 4*(3), e6921.

Rouw, R., & Erfanian, M. (2018). A Large-Scale Study of Misophonia. *Journal of Clinical Psychology*, *74*(3), 453–479. https://doi.org/10.1002/jclp.22500

Schröder, A., Vulink, N., & Denys, D. (2013). Misophonia: diagnostic criteria for a new psychiatric disorder. *PloS One*, *8*(1), e54706–e54706. https://doi.org/10.1371/journal.pone.0054706

Schröder, A. E., Vulink, N. C., van Loon, A. J., & Denys, D. A. (2017). Cognitive behavioral therapy is effective in misophonia: An open trial. *Journal of Affective Disorders*, *217*(November 2016), 289–294. https://doi.org/10.1016/j.jad.2017.04.017

Singh, S. M., & Chakrabarti, S. (2008). A study in dualism: The strange case of Dr. Jekyll and Mr. Hyde. Indian Journal of psychiatry, 50(3), 221.

Stevenson, R. L. (1886). *Strange case of Dr Jekyll and Mr Hyde and other tales*. OUP Oxford.

Vázquez, E., Kim, M., & Santaella, M. E. (2023). Lived experience experts: a name created by us for us. In *Expert Review of Hematology* (Vol. 16, Issue sup1, pp. 7–11). Taylor & Francis.

Wu, M. S., Lewin, A. B., Murphy, T. K., & Storch, E. A. (2014). Misophonia: Incidence, phenomenology, and clinical correlates in an undergraduate student sample. *Journal of Clinical Psychology*, *70*(10), 994–1007. https://doi.org/10.1002/jclp.22098

Yildirim, H. N. (2020). The Evil Side of Human Nature in The Strange Case of Dr. Jekyll and Mr. Hyde. *Journal of English Language and Literature Club, 2*(2), 9-11.

Ziebland, S. U. E., & Wyke, S. (2012). Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *The Milbank Quarterly*, *90*(2), 219–249.

Appendicies

Appendix A – r/misophonia Subreddit Rules

Appendix B – Moderator Consent

Appendix C – Ethical Approval

Appendix A

r/misophonia Rules

1. No Violence ^

No posts that mention violence, wanting to harm others, or visual images depicting this. This includes suicide.

If you are suicidal, please contact a suicide prevention hotline (1-800-273-8255), or a medical professional.

If you need support, please visit r/misophoniasupport or add to the weekly venting thread (the no violence rules still apply).

2. No Shaming ^

No posts "shaming" or insulting persons for triggering you. On the flip-side, no posts "shaming" or insulting people who have Misophonia. This includes images, videos, and text posts.

Please be inclusive of those who don't have Misophonia as well as those who do have Misophonia.

3. No Unethical Research ^

No posts linking to "research" that is unethical (not done in a lab, for profit, or otherwise nonviable).

10. No Memes ^

No memes. Please post memes in r/misophoniasupport.

11. No Screenshots ^

No Screenshots of PMs, Other Threads, or others' posts. If you'd like a person to share, ask them to share themselves on the thread.

4. No Venting ^

No venting. Venting should only be done on "weekly venting threads". Rules for violence still apply. If you would like advice on a specific problem, please visit r/misophoniasupport.

5. Unverified Treatment ^

All posts discussing unverified treatments are subject to removal. Do not suggest medications (this is unethical and can harm other sufferers) unless this is in the context of research studies.

Submissions discussing unverified treatments may be automatically removed. If you believe your submission was removed in error because you are discussing a legitimate and verifiable treatment option, please message the moderators (include a link to the post and an explanation).

6. Poor Quality Links ^

All links are subject to scrutiny from moderators. Our goal is to only link to high-quality sources, and moderator discretion will apply to all links. This includes for profit links, self-promo, or otherwise un-useful links.

7. Low-Quality Posts ^

Low quality posts that do not contribute to discussion will be removed.

This includes meta posts - please message the moderators directly if you have a question about the subreddit itself.

8. Rude/Offensive ^

Rude, offensive, or otherwise distasteful comments/posts (heavy profanity for no reason, bullying, etc.), will be removed.

Bullying any users, including the moderators, will result in a permanent ban.

9. Off-Topic ^

No off-topic posts are allowed. This includes derailing, or topics that are not being discussed in the thread.

This includes creating your own meta posts - please message the moderators directly if you have a question about the subreddit itself. If it's a discussion which requires community feedback, the moderators will create a post.

re: University of Sunderland Information Sheet - Paris Arizona Ash:

subreddit message via /r/misophonia [M] sent 2 months ago

Go for it

Permalink Delete Report Block Subreddit Mark Unread Reply

Appendix C

University of Sunderland

██████████████████████

████████

PROJECT TITLE: Misophonia "(insert quote from the data)": A thematic analysis examining the patterns between lived experience of people with misophonia and the usefulness of reddit as a support network?
APPLICATION: Reference Number 014934

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 09/11/2022 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 014934 (form submission date: 03/11/2022); (expected project end date: 01/07/2023).
- Participant information sheet 1022683 version 1 (02/11/2022).

If during the course of the project you need to deviate significantly from the above-approved documentation please email ethics.review@sunderland.ac.uk

For more information please visit: https://www.sunderland.ac.uk/research/governance/researchethics/

Yours sincerely

Mrs Andrea Howell
Ethics Administrator
University of Sunderland