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Counseling for Patients with Hyperacusis

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Counseling for Patients with Hyperacusis

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CSD490: Senior Inquiry, Spring 2019

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Augustana College

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Abstract

Hyperacusis is the phenomenon of experiencing moderately loud sounds as overly loud and/or intensely annoying. Hyperacusis can also cause fear or pain in response to sound. There is no one known cause of hyperacusis, and because of the variety of ways it presents itself, the approximate prevalence is difficult to determine. Despite the ambiguity of hyperacusis, the audiologist is an important part of diagnosing and educating clients with hyperacusis. During this project we aimed to discover the challenges individuals with hyperacusis face. These include anxiety, depression and avoidance behavior, and sometimes co-occurring tinnitus and hearing loss. Another aim was to evaluate effective counseling techniques for hyperacusis, and furthermore, how effective individuals perceive these techniques to be. We found that meditation and progressive relaxation techniques, and sound therapy are most effective for managing hyperacusis symptoms. Participants reported that the educational counseling materials developed during this project were very useful. Counseling materials were adapted for hyperacusis from the Tinnitus Activities Treatment developed by Richard Tyler and covered the definition and types of hyperacusis, effects of hyperacusis on life, and management strategies. We hope the development of these materials and the results of interviewing individuals with hyperacusis can aid audiologists in educating and counseling clients with hyperacusis symptoms.

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Introduction

Consider this case: a 50 year old woman seeks services from an audiologist and complains of environmental sounds being uncomfortably loud, especially the sounds of traffic on her way to work, the beeping of the microwave and the clanking of dishes in the breakroom. At home, she is bothered when her neighbor's children play and yell outside, or when her partner mows the lawn. She has also noticed that whenever she goes to a restaurant with friends, the background noise is overwhelming that causes her to become annoyed and anxious. Her audiogram shows hearing thresholds within normal limits, binaurally. She has good speech recognition ability when tested in background noise. Her uncomfortable loudness levels (UCL) for pure tones are approximately 70dB. On her case history, she reports some exposure to loud noises, and occasional ringing in her ears.

From the case history and audiologic examination of this hypothetical situation, the likely diagnosis is hyperacusis. Symptoms of hyperacusis include annoyance in response to noise and perceiving sounds as louder than the average listener would. These, as well as lower than expected UCLs, would lead the audiologist to this diagnosis. There is no singular definition for hyperacusis, and it can be described in several ways. Generally, hyperacusis is the phenomenon of experiencing environmental sounds as uncomfortably loud, and includes hypersensitivity and even intolerance of sounds (Tyler, Pienkowski, Roncancio, Hyung, Brozoski, Dauman, & Moore, 2014). There are four main subcategories of hyperacusis. These include loudness, annoyance, fear, and pain hyperacusis based on the particular perceptions and reactions to sound experienced by each individual (Tyler et al., 2014). Loudness hyperacusis is described as perceiving moderately loud sounds as very loud; annoyance hyperacusis includes a pervasive negative response, such as irritation or anxiety to sounds; fear hyperacusis manifests in the

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anticipation of being uncomfortable and may lead to avoiding certain situations; and pain hyperacusis is the instance of sounds perceived as very loud causing pain (Tyler et al., 2014). Misophonia is another subcategory of hyperacusis and is sometimes used as a synonym of hyperacusis. Definitions of misophonia, however, focus more on the emotional and behavioral reactions to sound, and these reactions tend to be very strong (Aazh et al., 2018).

The prevalence of hyperacusis is difficult to approximate due to its varying nature, but it is estimated that between 6-17% of the population experiences hyperacusis (Perreau, Tyler, Mancini, Witt, & Elgandy, in press). More effective methods of diagnosing hyperacusis are being researched, but typically audiologists use UCLs and responses from patient questionnaires to supplement pure tone audiologic results. Hyperacusis also may co-occur with other diagnoses, making this a challenging diagnosis. For example, hyperacusis often co-occurs with tinnitus. Tinnitus can be perceived in the head or outside the head, but has no external sound source. It is described as a ringing, sometimes buzzing, roaring, or whooshing sound (Tunkel et al., 2014). There is no cure for tinnitus, but there are ways to manage it, such as using background noise generators or ear-level hearing devices to decrease the prominence of tinnitus. Hyperacusis may co-occur with other disorders. These may include autism spectrum disorder (ASD) and other psychological disorders, especially if the individual has high stress or anxiety (Aazh et al., 2018). There is still debate as to whether hyperacusis is a symptom of co-occurring psychological or mental health disorders such as post-traumatic stress disorder (PTSD), or whether the hyperacusis contributes to the cause of these diagnoses.

As is the case with tinnitus, there is no known cure for hyperacusis. Common ways of managing symptoms of hyperacusis include sound therapy, medications, and counseling. Contrary to what most individuals with hyperacusis assume, the use of hearing protection regularly may make the condition worse and can increase the reliance on the hearing protection (Pienkowski et al., 2014). Instead, gradually increasing exposure to sounds along with counseling from the audiologist is an effective way to help individuals manage their hyperacusis. However, more trials are needed to evaluate the effectiveness of the treatments (Pienkowski et al., 2014) and how well individuals perceive these treatments to work.

This project researched hyperacusis, or the phenomenon of experiencing environmental sounds as uncomfortably loud, and includes hypersensitivity and even intolerance of sounds (Tyler et al., 2014). We aimed to understand the subsets of hyperacusis, the problems associated with hyperacusis, and the current methods of treatment. Another aim of this project was to develop counseling materials for audiologists and other clinicians to use with individuals with hyperacusis. Research suggests that counseling for hyperacusis is an important aspect of treatment, in addition to education and cognitive behavioral therapy (Aazh, Moore, Lammaing, Cropley, 2016).

Research questions for this project included:

- 1. What difficulties are experienced by individuals with hyperacusis, and how can audiologists provide counseling and support for individuals with hyperacusis?
- 2. What counseling methods are most effective, and how effective do patients perceive these counseling methods for managing hyperacusis?

Literature Review

There is limited knowledge regarding the etiology of hyperacusis, and because it manifests differently for each individual, details on hyperacusis vary in the literature. Individuals with hyperacusis experience many difficulties such as anxiety and difficulty concentrating on tasks that can affect their daily lives. Additionally, it has been reported in literature that individuals with hyperacusis also experience tinnitus, have a hearing impairment, or both (Baguley, 2014). Although there is an association between tinnitus and hyperacusis, the actual prevalence of co-occurring tinnitus and hyperacusis varies from 40% to 86% (Tyler et al., 2014). This variance may be due to differing definitions of tinnitus and hyperacusis, as well as noisy situations exacerbating tinnitus that may mistakenly be labeled as loudness hyperacusis (Tyler et al. 2014). The connection between hearing loss and hyperacusis is less clear, as many individuals with hyperacusis have normal hearing; though no worse than a mild, sensorineural hearing loss may be present (Tyler et al., 2014). Some correlations also exist between hyperacusis and sensitivity to other senses such as sensitivity to bright light, taste, and smell (Andersson, Lindvall, Hursti, & Carlbring, 2002). In a study of the prevalence of hyperacusis in Sweden, 22% of participants (1,147 total via internet and post) reported sensitivity to lights or colors, 23% reported sensitivity to smells (Andersson et al., 2002).

Hyperacusis may also co-occur with autism spectrum disorder (ASD) and other psychological disorders, especially if the individual has high stress or anxiety (Aazh et al., 2018). Individuals with ASD may be more sensitive to environmental sounds and typically show more exaggerated responses to noise, such as tightly covering their ears with their hands or using hearing protections for loud environments. This exaggeration is likely the result of abnormal stimulation of the limbic system and autonomic nervous system (Aazh et al., 2018). A possibility for the co-occurence of ASD and hyperacusis (approximately an 18% incidence) may relate to superior semicircular canal (SCC) dehiscence, or a small hole in the bony labyrinth of the superior SCC. A study found that 29% of individuals with ASD who also reported hyperacusis had a superior SCC dehiscence (Thabet & Zaghloul, 2013).

Having hyperacusis and tinnitus can severely impact an individual's quality of life, creating many difficulties and challenges. More specifically, living with hyperacusis can easily disrupt activities of daily living (e.g., washing dishes), affect one's mood (e.g., more easily irritated), change one's ability to concentrate, and affect one's sleep patterns (Andersson, 2002). A testimonial included in Baguley's overview of hyperacusis stated that even the sound of their head against a pillow at night can be distressing (Baguley, 2014). It is also common for individuals with hyperacusis to experience anxiety, depression, and post-traumatic stress disorder (PTSD, e.g., post military service). However, it is difficult to determine if the symptoms of hyperacusis occur first and lead to anxiety and depression, or if those already struggling with depression and anxiety were more likely to develop hyperacusis (Baguley, 2014). According to studies from animal models, there may be correlations between hyperacusis and serotonin dysfunction that is associated with depression, anxiety, and migraines, and the brain's ability to perceive loudness and significance of sounds (Baguley, 2014). Anxiety may occur more frequently for those with fear hyperacusis, creating a constant state of anxiously anticipating and reacting to environmental sounds. Emotions associated with any type of hyperacusis can quickly lead to avoidance behavior, where individuals will deliberately avoid the situations that trigger their hyperacusis. This avoidance can negatively impact the individuals' social lives that can increase feelings of depression and isolation.

It is very important for the audiologist and the individual with hyperacusis to work closely together throughout the diagnosis and treatment process. For example, audiologists need to counsel patients with hyperacusis thoroughly during the evaluation stage. Audiologists can expand their view of counseling beyond explaining technical terms to providing the opportunity for clients to voice their concerns and emotions throughout the management of their hyperacusis (Aazh, Moore, Lammaing & Cropley, 2016). Audiologists can also help patients to have positive expectations of treatment. This can be achieved by listening to the individual's thoughts and concerns, being sympathetic, and creating a plan for therapy with the individual so that they feel included (Tyler, Haskell, Preece, & Bergan, 2001). Improving the individuals' expectations during counseling can lead to overall greater success during the treatment process (Tyler, Haskell, Preece, & Bergan, 2001). Meanwhile, the audiologist must be wary of misleading individuals or giving them false hope in a treatment plan (e.g., saying a therapy has higher success rates than it actually does). The individual may lose trust in their clinician if they are expecting better results than they experience (Tyler, Haskell, Preece, & Bergan, 2001). It is also important for the audiologist to be aware of the various methods of managing hyperacusis that are currently being evaluated by researchers.

One method that has shown promising results in studies of hyperacusis and tinnitus management in the United Kingdom is cognitive behavioral therapy (CBT). CBT typically consists of 6-10 sessions that focus on educating the individual, relaxing the body, habituating to sound, changing their thoughts and beliefs to more positive ones, evaluating emotional reactions, and improving their ability to concentrate (Anderson, 2002). A distinction must be made between the audiologists' role using CBT and a licensed psychologist. The clinician is not there to directly be a traditional "therapist", pointing out things that are "wrong" with the way the

individual is thinking, but rather to guide the individual to help them modify negative thoughts and emotions they feel because of their tinnitus or environmental sounds (Aazh, Moore, Lammaing & Cropley, 2016).

Sound therapy is often used in management of tinnitus, and it can also be applied to hyperacusis management. Jasterboff developed a *tinnitus retraining therapy* (TRT) method that uses sound generators to help individuals with tinnitus and hyperacusis habituate to background sound (Park, Kim, Ha, Han, Park & Park, 2018). Park et al. (2018) evaluated the effectiveness of sound generators in decreasing distress caused by tinnitus and hyperacusis during TRT with two categories of participants. Group one included individuals with tinnitus who had normal hearing. Group two included individuals from group one who also had hyperacusis. Individuals from both groups reported lower severity of tinnitus after six months of using a sound generator for at least eight hours of the day. Individuals with comorbid hyperacusis also had increased uncomfortable loudness levels upon follow up, suggesting that the use of a sound generator significantly aided in the individual's ability to tolerate sound (Park et al., 2018). The level of the sound therapy was gradually increased so that the individual can "strengthen" their tolerance level of background sounds.

Another option that may be helpful for some individuals with hyperacusis is using hearing aids, or amplification. Hearing aids with masking technology are particularly useful for individuals with tinnitus. Hearing aids are more effective for individuals with hyperacusis in addition to hearing loss, though there is not much conclusive evidence on their long term effectiveness (Aazh, Moore, Lammaing, & Cropley, 2016). Most patients with hyperacusis have normal hearing, or no worse than a mild hearing loss. Hearing aids, therefore, are not as effective with hyperacusis patients as they might be for patients with tinnitus who more often have hearing loss.

Education plays a large role in an individual's confidence level in managing their hyperacusis. If the patient is knowledgeable about the difficulties and triggers faced by having hyperacusis, they can better explain to others any accommodations they might need and utilize management strategies that are most effective for them. Conducting educational counseling sessions in a group setting can be beneficial as well. Groups may involve the individual's family members or significant others so that they can be made aware of hyperacusis and the treatment process. Individuals can discuss their experiences with others in similar situations, providing a platform to discover treatment methods that have worked for them as well (Perreau et al., in press).

Researchers will continue to evaluate how effective these various management methods are for individuals with hyperacusis. Different manifestations of hyperacusis and various cooccurring difficulties like tinnitus and psychological disorders will require different management methods. In a meta-analysis investigating the use of cognitive behavioral therapy for treating tinnitus, Andersson reported that CBT was most effective for reducing annoyance and the effects lasted to the one year follow up (Andersson, 2002). Based on an assessment of the effectiveness of different treatment methods for tinnitus and hyperacusis, individuals reported that counseling, education, and CBT were the most helpful and effective (Aazh, Moore, Lammaing, & Cropley, 2016). Regardless, it is critical that the audiologist play an active role in encouraging individuals with hyperacusis to share their thoughts so that they can work through negative emotions. By actively being involved with the management process, the audiologist and client can better determine the best course of action for the individual.

Methods

Participants

Two participants were interviewed for this project. The purpose of the interview was to analyze the different experiences of individuals with hyperacusis and document how their viewpoints about the disorder and its treatment in comparison to published research. Participants were individuals who were in contact with the project supervisor previously about their hyperacusis. The participants were contacted by the faculty advisor about the study, and were given the option to participate ensuring that the sample was free of bias. The project was approved by the Augustana College Institutional Review Board prior to contacting the participants (see Appendix A for IRB materials). Participant demographic data, including age, gender, and hyperacusis type are displayed in Table 1.

Materials

The educational counseling materials used to conduct the interviews were created using Microsoft PowerPoint. The content was adapted from the Tinnitus Activities Treatment (TAT; Tyler et al., 2006) that describes the importance of understanding an individual's needs and develops a management plan for tinnitus based on the particular problems. The sessions included in activities treatment are thoughts and emotions, hearing and communication, concentration, and sleep (Tyler et al., 2006), and emphasize use of sound therapy and the influence of tinnitus on one's life. In this project, the information and management strategies for tinnitus provided in the TAT sessions were modified to describe the types of hyperacusis, the effects on an individual's life, and the different management strategies. We used the Hyperacusis Activities Treatment that is described thoroughly by Tyler, Nobel, Coelho, and Roncancio (2015) and information from the group educational session that is explained in Perreau, Tyler, Mancini, Witt & Elgandy (in

press). Hyperacusis Activities Treatment (Tyler et al., 2015) also focuses on supporting healthy thoughts and emotional reactions to sound, hyperacusis and its effects on hearing, communication, sleep and concentration, as well as management strategies (e.g., sound therapy using increased background noise). Here, we included strategies for progressive muscle relaxation and meditation to manage tenseness and anxiety in response to environmental sounds. Questions about the individual's hyperacusis experience were included throughout the educational counseling slides to collect data from the participants (e.g., sounds that are too loud, annoying, the times during the day when sound is most bothersome). Refer to Appendix D for the slides used in the sessions. The Hyperacusis Intake Questionnaire adapted from the University of Iowa Department of Otolaryngology - Head and Neck Surgery was used to assist in data collection (see Appendix C).

Procedures

Interviews were conducted at the Augustana College Center for Speech, Language, and Hearing by the student researcher with the faculty advisor present. Participant 1 and 2 were interviewed individually, and interviews lasted approximately one hour. The interviews were audio recorded using a recording App on the students' phone, and then transcribed in Microsoft Word. All identification information was removed from these documents to maintain confidentiality of the participants. Before conducting the interviews, the participants were consented for the study, ensuring that they understood the risks involved with speaking about their experiences with hyperacusis that can cause distress. Participants were reassured that they could skip any questions that made them uncomfortable and were encouraged not to dwell on any negative thoughts directed towards themselves. Introduction interview questions were asked before beginning the counseling materials (e.g., how long have you experienced symptoms of hyperacusis?; do symptoms interfere with your daily life?; etc.). Refer to Appendix B for full list of the interview questions. Follow-up questions were asked after presentation of the counseling materials to assess the usefulness of the materials in learning more about hyperacusis (e.g., what was the most important takeaway?; do you feel more confident in exploring management strategies?, etc.; see Appendix B).

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	Participant 1	Participant 2
Age	75 years old	49 years old
Gender	Female	Female
Ethnicity	White/Caucasian	White/Caucasian
Known cause?	Unsure Diabetes	Unsure Medications Noise exposure- continuous
Duration of having hyperacusis	Approximately 5 years	Approximately 40 years
Hyperacusis in one or both ears?	Both	Both
Presence of tinnitus?	No	Yes
Presence of hearing loss?	Normal hearing except at 8,000 Hz	Normal hearing
Medications/ medical history	55 years with type 1 diabetes, uses insulin, blood pressure medication, Thyroxine thyroid medication	Anxiety medication

Table 1. Participant data (n=2) collected during the interviews.

Results

Results from the interviews revealed significant differences between the participants' interview responses and their overall experiences, especially with regard to the types of hyperacusis and situations that were bothersome. Participant 1 described experiences with loudness hyperacusis and being very uncomfortable in situations such as sports games and concerts. Participant 1 also mentioned that she was very easily startled by sounds. Participant 1 and 2 were both affected by annoyance hyperacusis, however, their annoyance triggers were very different. Annoyance hyperacusis was very problematic for participant 2, whereas loudness hyperacusis was only mildly problematic for participant 2. Participant 2 also had fear hyperacusis as well as co-occurring tinnitus whereas participant 1 did not report these at all.

The triggers and problematic environments differed for both participants, and the individual symptoms of hyperacusis were very situational for both participants (Table 2). Interestingly, participant 2 was not bothered by a majority of the common trigger sounds (such as babies crying, dishes being stacked, and loud music), but had several other sounds (e.g., chewing, brushing teeth, and repetitive tapping sounds) that caused symptoms of annoyance hyperacusis. Participant 2 was also more affected by fear hyperacusis, and stated that the anticipation of a loud sound occasionally affected her ability to fall asleep. Sudden loud vehicles passing close by caused them to startle and become anxious. Similarly, participant 1 reported a severe startle reflex when there is a sudden loud noise (e.g., if something bangs, a dish breaking, etc.). Loudness hyperacusis was exhibited by participant 1 as she was more uncomfortable in noisy environments (e.g., sporting events such as basketball games, and concerts). Participant 1 also reported issues with balance (e.g., feeling unsteady on her feet) approximately five times per month, and rated the severity of their balance problems as a 10 on a scale of zero (not

problematic) to 100 (very problematic). Both participants stated there were no particular times during the day when their hyperacusis was worse. Symptoms also subsided after the noise had ended or after they removed themselves from the environment where the trigger sound occurred.

These two participants were not sensitive to bright lights or particular tastes, however, both participants were affected by certain smells. Participant 1 mentioned being particularly affected by cigarette smoke, however, she rated the severity of the problem as 5 on a scale of 0 (not at all severe) to 100 (very severe). Additionally, cigarette smoke was also the only smell that she reported as causing a strong adverse reaction. Interestingly, participant 2 was much more affected by smell, rating the severity of the problem as 80 on a scale of 0 to 100. Cigarette smoke, perfume, and spices were most problematic. Strong cooking smells (e.g., cooking hamburger meat or microwaving foods) could also affect her ability to fall asleep. When asked how often participant 2 experienced smell adverse reactions per month, she reported having smell problems every day (30 times per month).

Responses to the follow-up interview questions regarding the participants' perspectives on the educational counseling were quite positive (full list of questions in Appendix B). Overall, participants rated the educational counseling materials as helpful, concise, and easy to understand. There were some aspects that they already knew, such as excessive noise exposure causing hearing loss and tinnitus. Participant 1 had previously used some relaxation techniques to manage stress, and after the session, she said she planned on using those techniques more regularly to help with her annoyance hyperacusis. Both participants reported that one of the most important takeaways from the session was the awareness that there are other individuals who experience hyperacusis, and that there are techniques they can use to manage their symptoms. In addition, both participants felt that the management strategies reviewed in the session would be easily integrated into their lives and would provide relief for their symptoms (e.g., using sound therapy and background noise).

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Table 2. Trigger sounds for loudness, annoyance, fear and pain hyperacusis. See

Appendix C for the complete list of triggers from the Hyperacusis Intake Questionnaire.

	Participant 1	Participant 2
Sounds/ events found too loud	Crowds/ large gatherings Music (loud rock concerts) Sporting events	Dog barking
Sounds/ events that cause annoyance	Dishes being stacked Music (loud rock concerts) Sporting events	Chewing Others brushing their teeth Repetitive sounds (e.g., clicking pens or tapping fingernails) Background speech and noise
Sounds/ events that cause fear	NA	Loud motorcycles and vehicles
Sounds/ events that cause pain	NA	NA
What makes hyperacusis symptoms worse?	Large crowds	Being in complete silence Dog barking Lack of sleep/ fatigue Loud voices Stress/tension

Discussion

The complexities of hyperacusis are still being researched, but audiologists play a key role in treating, supporting, and educating individuals with hyperacusis (Perreau et al., in press). This research project had two main purposes. The first aim was to research the difficulties experienced by those with hyperacusis and to identify the role that audiologists' play in counseling individuals with hyperacusis. The second aim was to determine the counseling methods that are most effective, and in particular, the client's perspectives on the effectiveness of the counseling for hyperacusis. A final aim of this project was to create counseling materials that audiologists and other clinicians could utilize to educate clients that may be experiencing symptoms of hyperacusis.

Results from interviews with individuals with hyperacusis revealed that hyperacusis affects people very differently and symptoms present themselves in various ways among patients with hyperacusis. This is consistent with our current understanding of hyperacusis. Individuals may experience consistent reactions to specific sounds, may react to certain patterns of sounds, or may be particularly affected by sounds in a particular environment (Jasterboff & Jasterboff, 2014). The interviews revealed some particularly interesting findings. Participant 1's extreme startle response is reminiscent of the startle response seen in some individuals with Post Traumatic Stress Disorder (PTSD; Anderson, Lindvall, Hursti, & Carlbring, 2002). This is interesting because participant 1 has no history of anxiety or occupations associated with sudden loud noises (e.g., military experience or factory work) that would lead to PTSD-like startle reactions.

In some cases, individuals with hyperacusis are sensitive to other senses such as sight and smell. Participant 2's reaction to smell was also particularly interesting. Individuals that

experience adverse reactions to smells often have a history of migraines, as migraines can reduce someone's tolerance for light, sound, and smell (Snyder & Drummond, 1997). However, participant 1 has not experienced migraines since they were a child, therefore, this relatively severe reaction to smell is intriguing. Participant 2 also has experienced symptoms of hyperacusis as early as four or five years old, that was also interesting. In a study of kindergarten children in Italy, only 15 out of 109 children were diagnosed with hyperacusis based on their reactions to certain sounds and a parent questionnaire (Rallie et al., 2018). In another study of 509 children age 5-12, only 3.2% of them reported annoyance hyperacusis, 1.2% reported loudness hyperacusis, and 9% experienced "phonophobia", or the fear of sounds (Coelho et al., 2007). Hyperacusis is more prevalent in adults, however, more attention is being brought to diagnosing and treating hyperacusis in children. Hyperacusis in children may be associated with developmental disorders or audiologic disorders, though causal data is limited (Rallie et al., 2018). Participant 2 does not have a history of developmental disorders or audiologic disorders other than her tinnitus, making her childhood hyperacusis experiences very interesting.

A limitation to this project was the small number of participants included in the interviews. Having only two different perspectives to analyze does not provide an adequate representation of the symptoms and difficulties experienced by individuals with hyperacusis. However, within these two participants, we did see differences in their experience with hyperacusis that is consistent with the literature about the nature of hyperacusis among a larger population. Participant bias may have also been present while asking follow-up questions. Results from the session follow-up questions may have been positively skewed because the interviewer was present, and participants could not report their feedback anonymously. If more individuals had participated and been given the opportunity to report follow-up impressions of

the counseling materials, we may have obtained different results. Future research should study the effectiveness of counseling for patients with hyperacusis by recruiting more participants and perhaps utilizing outcome measures to assess the effectiveness of intervention through questionnaires or other measures.

The results from the interviews and the counseling materials developed during this project are clinically applicable. Specifically, this project provides support for audiologists to treat hyperacusis. Because of the complex nature of hyperacusis, audiologists are more equipped to diagnose the disorder and the interview responses from the participants showed that they valued the information provided by the audiologist. Education and counseling were shown in previous studies to be the most effective treatments for managing hyperacusis (Aazh, Moore, Lammaing, & Cropley, 2016). Continuing to provide educational counseling to individuals who may be experiencing hyperacusis will increase the overall knowledge of hyperacusis for clients as well as the general public. Increasing knowledge will also help further determine and refine the management strategies that individuals find most effective. The educational counseling materials developed during this project will also provide the Augustana College Center for Speech, Language, and Hearing with a resource to use with future clients experiencing symptoms of hyperacusis. Information about hyperacusis in the clinic will make assisting future clients more accessible for the audiologists as well as reassure clients that there are resources available to them.

Conclusion

Hyperacusis is a complicated phenomenon. It manifests in a variety of different ways and can co-occur with other conditions such as anxiety and tinnitus, making it difficult to diagnose. Hyperacusis can generally be defined as experiencing environmental sounds that would normally be perceived as moderately loud as uncomfortably loud and annoying. Other types of hyperacusis include fear hyperacusis (environmental sounds causing a fear response) and pain hyperacusis (environmental sounds causing pain). Anxiety, depression, and situational avoidance behavior can co-occur with hyperacusis, and can severely impact an individual's quality of life depending on the severity. There are, unfortunately, no medications available to "cure" hyperacusis, however, there are strategies that can be incorporated into everyday life to manage hyperacusis symptoms. Management strategies include counseling, progressive muscle relaxation, sound therapy, and cognitive behavioral therapy.

One aim of this research project was to document two individual's experiences with hyperacusis and to connect their responses to current research. Another aim of this project was to create educational counseling materials to help define hyperacusis, its causes, and available treatment options. Participant data and their hyperacusis background information were gathered via interview questions before and during the counseling session. After the counseling session, follow-up questions were asked to determine the usefulness of the materials from the participant's perspective. Current research suggests that education and counseling are most effective for managing hyperacusis symptoms. The results from the interviews revealed that the participants valued the information presented in the counseling sessions. Both of the participants especially appreciated knowing that their experiences with hyperacusis were not singular, and that there are ways to manage the symptoms they experience. The results from this research project support the idea that audiologists should be involved in not only diagnosing hyperacusis in individuals, but also being an active part of the education and counseling process. Because of the complex nature of hyperacusis, it is important that the audiologist be confident in their ability to educate and counsel their clients with hyperacusis, and have materials or resources to rely on during counseling patients to make process of management more accessible and comprehensive.

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Appendix A Augustana Institutional Review Board

Request for Review of Research Using Human Participants

- Only faculty, administration, or staff may submit a Request for Review (RFR) form to the IRB (this excludes students).
- Electronic submission of this form and supporting documents should be made via electronic submission at: https://www.augustana.edu/academics/institutional-review-board
- Your answers to the following questions may be copied and pasted from a Word document, or typed in.
- You should receive a confirmation email when the electronic submission of your RFR is completed.
- If the IRB committee requested modifications to your documents or proposal, please resubmit all updated documents to the IRB committee via electronic submission.
- Please allow a minimum of one week for review.

Principal Investigator and/or faculty adviser: Ann Perreau and Mary Maraist

Department: CSD

Date Submitted: April 1, 2019

Project Title: Counseling for Patients with Hyperacusis

Review of this project is requested on which basis:

- X Regular review. Complete all items and attach questionnaires, non-standard tests, consent forms, cover letters, and other supporting documents.
- _____ To confirm exempt status. Complete items 1 through 8. Under which exempt category, as designated in section D. of the IRB guide, do you think this project qualifies for exemption? (Give paragraph letter/number.) _____

Please type your responses to items 1-11 below. Add additional space as needed to give sufficient information for the committee to be able to evaluate the risks and benefits of your research project.

1. If any pre-approved departmental or other protocols will be followed for this project, please indicate the name of the protocol.

2. **Brief Project Description** – Please write for a lay audience and explain any technical terminology

a. Purpose, hypothesis, or research question:

This project will research hyperacusis, or the phenomenon of experiencing environmental sounds as uncomfortably loud, and includes hypersensitivity and even intolerance of sounds (Tyler et al., 2014). We aim to understand the subsets of hyperacusis, the problems associated with hyperacusis, and current methods of treatment. Another aim of this project will be to develop counseling materials for audiologists and other clinicians to use with individuals with hyperacusis. The research suggests that counseling for hyperacusis is an important aspect of treatment, in addition to education as well as cognitive behavioral therapy (Aazh, H., Moore, B. C. J., Lammaing, K., & Cropley, M. (2016).

Research questions for this project include:

- 1. What difficulties are experienced by individuals with hyperacusis, and how can audiologists provide counseling and support for individuals with hyperacusis?
- 2. What counseling methods are most effective, and how effective do patients perceive these counseling methods to be?

References:

Aazh, H., Moore, B. C. J., Lammaing, K., & Cropley, M. (2016). Tinnitus and hyperacusis therapy in a UK National Health Service audiology department: Patients' evaluations of the effectiveness of treatments. *International Journal of Audiology*, *55*(9), 514–522. <u>https://doi.org/10.1080/14992027.2016.1178400</u>

Tyler, R. S., Pienkowski, M., Roncancio, E. R., Hyung Jin Jun, Brozoski, T., Dauman, N., Moore, B. C. J. (2014). A review of hyperacusis and future directions: Part I. Definitions and manifestations. *American Journal of Audiology*, *23*, 402–419. https://doi.org/10.1044/2014pass:[]AJA-14-0010

b. Procedures: The student researcher, Mary Maraist, is completing a thesis for her senior inquiry in CSD on the development of counseling materials (e.g., a powerpoint presentation) for individuals with hyperacusis. Along with reviewing current research, she would like to provide informational counseling to two patients with hyperacusis, and interview them to gather their perspectives about the educational sessions. She is seeking permission to conduct these interviews.

3. Participants

a. Age, sex, and approximate number: Two patients with hyperacusis, adults over the age of 18 years, male or female

b. Inclusion/exclusion criteria, if any: Individual must have hyperacusis.

c. Method of recruiting: We will recruit from the following: 1) patients from the Augustana College Center for Speech, Language, and Hearing, 2) from our familiar contacts of individuals with hyperacusis in our community, and 3) by referral from other providers.

d. Inducement for participation: None.

4. Are participants at risk? (Describe, if 'yes'.) We do not foresee risks associated with participating, however, hyperacusis can be difficult to manage. Asking questions about their hyperacusis might make some patients uncomfortable or distressed.

5. Steps taken to minimize any risks identified in #4. We will allow patients to skip questions if they wish, and will also discontinue the interview at any time without penalty. Because a licensed audiologist will be present, additional therapy can be offered if the patient needs it.

6. Are illegal activities involved? (Describe, if 'yes'.) No

7. Is deception involved (e.g., withholding information, providing misinformation, using confederates)? (If 'yes', please describe. Explain why it is necessary, explain how participants will be debriefed, and, if applicable, attach a copy of the debriefing statement.) No.

8. What are the anticipated benefits to the participants? By providing informational counseling about hyperacusis, participants will learn more about hyperacusis, what causes it, and how it can be treated. Having this information is often very helpful to patients who suffer from hyperacusis.

9. How will informed consent be obtained? (Attach copies of consent forms and/or cover letters if they are to be used. Please see Informed Consent Document checklist below.) The participants will sign a consent form prior to the interview that will be conducted face-to-face in a therapy room at the Brodahl building.

10. If extra credit is used as an inducement for participation, what alternatives for gaining extra credit are offered to participants?

NA

11. Describe the procedures relating to the anonymity of participants, if applicable, and procedures for keeping participant data confidential and secure. For example, what documents or databases will contain names or participant numbers, who will have access to these, and how will they be physically or otherwise secured? When will the research materials gathered from or about individual participants be destroyed? Will the data be used in future studies? Are identifiers removed for future research?

The interviewees' responses will remain confidential and no personal information will be included in the research paper written by Ms. Maraist. Mary will audio record the interviews, and then transcribe the interviews verbatim. The interview transcripts will be kept separately from the informed consent documents. The audio recording will be deleted after the transcription has occurred. All documents will be stored in the faculty member's locked office. All interview transcripts will remain de-identified and will be stored up to five years per the American Psychological Association guidelines.

By submitting this RFR to the Augustana IRB, I am agreeing that I have reviewed the Augustana College Policies and Guidebook for Research Involving Human Participants and I agree to adhere to the responsibilities of investigators as specified in Section B. I also agree to report any significant and relevant changes in the procedures or instruments to the Committee for additional review.

Informed Consent for Research Participants

Purpose and Description of this Research Project: You are being asked to participate in this study because you have hyperacusis in one or both ears. Augustana senior, Mary Maraist, is completing a project to create informational counseling materials for individuals with hyperacusis. This research project is a class project for Senior Inquiry, CSD 490. We plan to implement these counseling materials at the Augustana College Center for Speech, Language, and Hearing. Ms. Maraist would like to supplement her research paper with insights that you have as an individual with hyperacusis, and gather your feedback about our counseling materials

Description of the involvement by participants (procedures, duration, possible risks, or benefits): If you decide to participate, Ms. Maraist would like to conduct a 1-hour interview to provide the informational counseling materials, and gather your perspectives on how helpful these materials are for someone with hyperacusis. The materials will be presented via powerpoint, and we will discuss what is hyperacusis, what causes hyperacusis, how we hear, and how hyperacusis occurs.

There are no foreseeable risks to participating in this study. However, occasionally asking questions and talking about hyperacusis can make it worse. If you experience any discomfort or distress, we encourage you to skip these questions you wish not to answer. Additionally, you can discontinue the interview at any time without any penalty to you. Because a licensed audiologist will be present, additional therapy can be offered if you need it.

The benefits of participating in this study are that by providing informational counseling about hyperacusis, you will learn more about hyperacusis, what causes it, and how it can be treated. Having this information is often very helpful to patients who suffer from hyperacusis.

The faculty/staff sponsor that is available to answer any question regarding your participation is Ann Perreau, and her contact information is <u>annperreau@augustana.edu</u>. This research project has been reviewed and approved by the Augustana Institutional Review Board, which can be contacted at <u>IRB@augustana.edu</u>.

Your decision whether or not to participate will not influence your future relations with Augustana College Center for Speech, Language, and Hearing, or the researchers, Mary Maraist and Dr. Perreau. If you decide to participate, you are free to discontinue participation at any time and no harm will come to you.

I hereby give my consent to participate in this research study. I understand that:

• I must be at least 18 years old to participate in this study.

HYPERACUSIS COUNSELING MATERIALS

• My participation is entirely voluntary, and I may terminate my participation at any time prior to the completion of the study without penalty.

• Any information I may give during my participation may be recorded and will be employed for research only.

• Any information I may give will be kept confidential and physically secure.

• The results of this study will be reported without identifying you directly. The data and name/participant number list will never be stored in the same location or in the same computer.

• This data will be presented at an upcoming Communication Sciences and Disorders department presentation in May 2019. It may be presented at future audiology conferences and used in our clinic materials, though your name or identifying information will not be used.

• The interview transcripts gathered from you will be stored for 5 years.

Signature of Participant:	Date:	
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Signature of Investigator:

Date: _____

Appendix B

Pre-counseling introduction questions:

- 1. How long have you been experiencing symptoms of hyperacusis?
- 2. In what environments do you find the symptoms of hyperacusis most problematic?
- 3. How frequently do you notice symptoms of hyperacusis?
- 4. Do your symptoms interfere with your everyday life, such as at work or in your personal relationships? Have you noticed a change in your daily routine, or has it affected what you choose to participate in?
 - a. If so, how significantly?

Which of the following most accurately describes what you experience? Circle all that apply. (alternate wording: how would you describe what your hyperacusis symptoms?)

- . Certain sounds seem louder than they should be
- a. Certain sounds cause me to become annoyed more easily, and it tends to distract me
- b. I have a fearful reaction to certain loud environmental sounds
- c. Certain sounds are so loud to me that they cause pain

Do your family and friends know that you have hyperacusis?

Do you or your family members have a history of mental illnesses such as anxiety, depression, or post traumatic stress disorder?

Do you experience tinnitus, or any ringing in the ears, whistling, buzzing, or whooshing sounds that seem to have no environmental source? If so, how often and in which ears?

Are there medications you use on a regular basis? Have you ever taken any medications specifically to manage hyperacusis symptoms?

Have you tried any other treatments for hyperacusis, such as sound therapy?

. If so, what has been successful in helping your hyperacusis?

Would you be willing to try counseling to improve your hyperacusis?

Session follow up:

- 1. Overall, how useful would you rate the materials presented?
- 2. What would you say was the most important takeaway from the materials?
- 3. Was there anything you already knew?
- 4. Were the materials presented in a clear and concise way that was easy to understand?
- 5. Do you feel more confident about how to explore management of your hyperacusis?
- 6. Are you more or less likely to seek out education and management for your hyperacusis?
- 7. Based on the information presented, do you feel that there is a treatment that would work best for your situation?
- 8. How likely would you be to suggest these materials to others who also have hyperacusis?
- 9. How can we better improve our materials to facilitate treatment for hyperacusis?
- 10. What are your remaining concerns or questions?

Appendix C

Hyperacusis Intake Questionnaire

Patient name:_____

Date: _____

Some people report that many sounds are too loud for them, however these same sounds do not appear too loud to others. This is called hyperacusis.

		e on a scale from 0-100, 0 = stror 00 = strongly agree.	ngly disagree
1.	Sounds that others believe are mo	derately loud are too loud to me.	(0-100)
2.	Which ear(s) seems to be affected by the hyperacusis? (circle one)		Left Right Both
3.	How long have you had hyperacusis?		months OR years
4.	What do you think originally caused your hyperacusis? (Please choose only ONE answer)		
	a. Accident b. Aging c. Infection/virus d. Hearing loss (long term) e. Hearing loss (sudden) f. Medications	g. Ménière's Disease h. Noise exposure- continuous i. Noise exposure-impulsive j. Surgery k. I don't know I. Other	
5.	Has it gotten worse, better, or stay (circle		Same Better Worse
6.	Which of the following sounds or e	vents are often too loud for you?	

	 a. Baby crying/children squealing b. Crowds/large gatherings c. Dishes being stacked d. Dog barking e. High pitch voices/screaming f. Lawnmower g. Music (loud rock concerts) h. Music (religious service) i. Music (symphony, quartet, etc.) 	j. Power tools k. Restaurants l. Sporting events m. Telephone ringing n. TV/radio o. Vacuum cleaner p. Whistle/horn/siren q. Other	
7.	_	j. Power tools k. Restaurants l. Sporting events m. Telephone ringing n. TV/radio o. Vacuum cleaner p. Whistle/horn/siren q. Other	
8.	_	vents are those that you would fear e of your reaction to those sounds?	

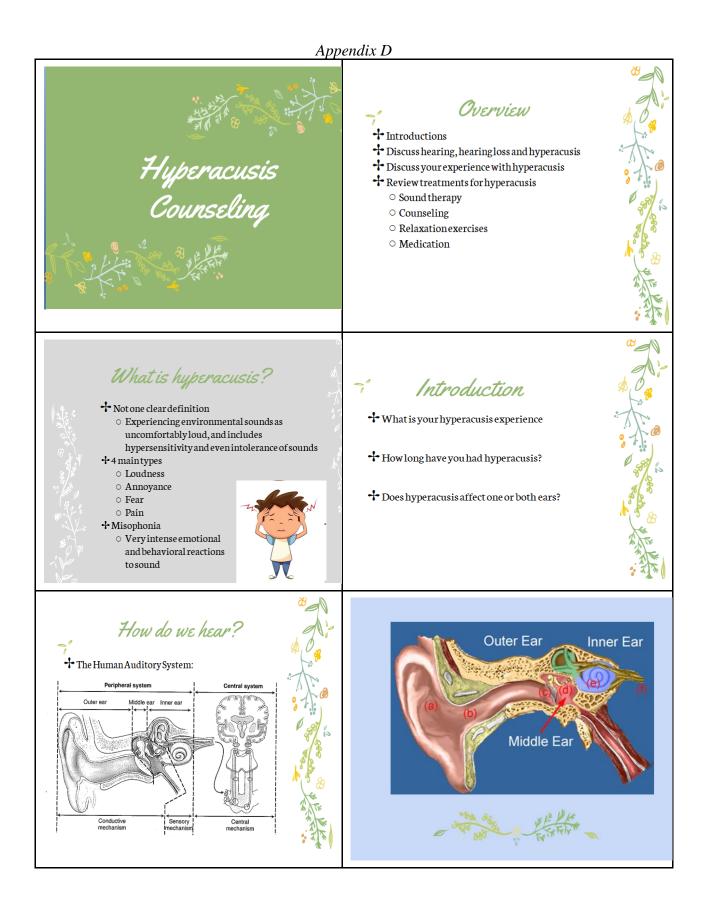
	 a. Baby crying/children squealing b. Crowds/large gatherings c. Dishes being stacked d. Dog barking e. High pitch voices/screaming f. Lawnmower g. Music (loud rock concerts) h. Music (religious services) i. Music (symphony, quartet, etc.) 	j. Power tools k. Restaurants l. Sporting events m. Telephone ringing n. TV/radio o. Vacuum cleaner p. Whistle/horn/siren q. Other	
9.	How often do you ex	perience headaches?	#/month
10.	Rate the severity of these	headaches from 0 to 100.	(0-100)
11.	How often do you exper	ience balance problems?	#/month
12.	Rate the severity of your bala	ance problems from 0 to 100.	(0-100)
13.	How often do brigh	t lights bother you?	#/month
14.	Rate the severity of how botherso	me bright lights are from 0 to 100.	(0-100)
15.	How often do you expe	rience smell problems?	#/month
16.	Rate the severity of these sn	nell problems from 0 to 100.	(0-100)
17.		s? If yes, please circle those below her you.	Yes No

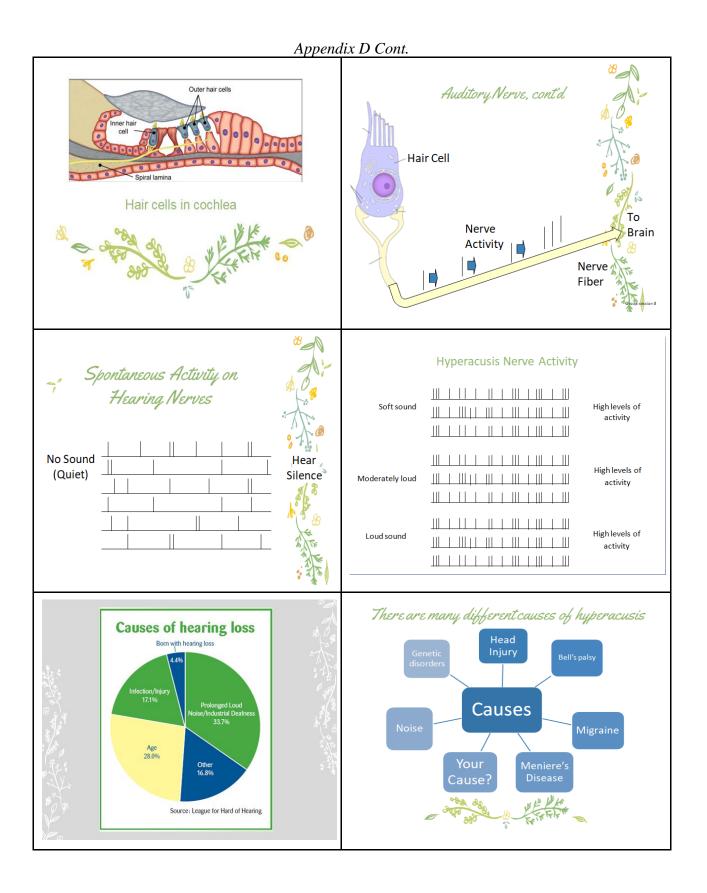
	 a. Bleaches, ammonia, cleaning solvents b. Car exhaust c. Cigarette smoke d. Coffee e. Farm odors 	f. Paint g. Perfume h. Pesticides/insecticides i. Spices j. Other		
18.		s? If yes, please circle those below her you.	Yes	No
	a. Cheese b. Coconut c. Peppers d. Salty foods	e. Sour foods (ex. Vinegar) f. Spices g. Sweet foods h. Other		
19.	Are you bothe	ered by touch?	Yes	No
20.	What makes your l	hyperacusis worse?		
	 a. Being in complete silence b. Dog barking c. Changes in pressure & humidity d. Lack of sleep, fatigue e. Large crowds f. Lawnmower/snow blower 	g. Loud voices h. Medications i. Sharp noises j. Stress/tension k. TV/radio l. Whistle/horn/siren m. Other		
21.	What makes your h	nyperacusis better?		

	 a. Being alone or with few others b. Being in a quiet environment c. Being relaxed d. Getting a good night's sleep e. Low constant sounds (fan, car) f. Medications g. Reading 	 h. Removing self from noise Soft music/TV f. Stress reduction exercises k. Wearing ear plugs/ear muffs I. Wearing noise generators When I wake up in the morning n. Other 	
22.	In which ear do you	wear hearing aids?	a. Left b. Right c. Both d. None
23.	Do you suffer	from tinnitus?	a. Yes b. No

Pain

24	Which of the following sounds or events cause pain in your ears?		
	Baby crying/children squealing		
	Crowds/large gatherings		
	Dishes being stacked		
	Dog barking		
	High pitch voices/screaming		
	Lawnmower		
	Music (loud rock concerts)/ Music (religious services)/ Music (symphony, quartet, etc.)		
	Power tools		
	Sporting events		
	Restaurants		
	Telephone ringing		
	TV/ Radio		
	Vacuum cleaner		
	Whistle/ horn/ siren		
	Other		











Appendix D Cont.