DESIRE FOR CONTROL, SELF-EFFICACY, AND TINNITUS DISTRESS

EXAMINING THE RELATIONSHIP BETWEEN DESIRE FOR CONTROL, SELF-EFFICACY, AND TINNITUS-RELATED DISTRESS IN CANADIAN ADULTS WITH TINNITUS

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements for the Degree Master of Science

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Lay Abstract

Tinnitus comes from the Latin verb "tinnire" which means "to ring". It is often described as a persistent ringing in the ears that has no external source. Some, but not all, people find their tinnitus debilitating. This study examined whether people who strongly desire control but lack confidence in managing their tinnitus, experience higher stress because of it, compared to those with lower control needs or higher self-confidence. The results showed that having confidence in managing tinnitus is correlated with having lower distress, but there is no definite conclusion regarding the need for control. The results of this study suggest that a new method to measure the desire for control in a context specific to tinnitus is needed.

Abstract

Tinnitus is a common condition, characterized by the perception of ringing or noises in the head without an external source, that impacts numerous individuals worldwide, including those in Canada. The variability in tinnitus distress levels is thought to stem, at least in part, from diverse personality traits and the resulting emotional reactions to the condition.

This study contributes to the growing body of research investigating the individuality of tinnitus sufferers and seeks to shed light on specific factors that contribute to their levels of associated distress. The investigation focused on two main factors: Desire for Control (an individual's general inclination to assert control over life events) and Self-Efficacy for Tinnitus Management (confidence in effectively handling and managing tinnitus). The primary objective was to uncover any associations among these two factors and a patient's level of tinnitus distress. By understanding how these constructs interrelate, a deeper understanding of contributions to distress among those grappling with tinnitus can be gained. The significance of this research lies in its potential to enhance the support and interventions provided to tinnitus patients by healthcare professionals.

An online survey collected responses from 130 Canadian adults regarding their health status and experiences with tinnitus. The study confirmed a robust correlation between the Self-Efficacy for Tinnitus Management Questionnaire (SETMQ) scores and the extent of distress experienced by individuals with tinnitus. The SETMQ, therefore, holds promise as a valuable instrument for identifying domains in which patients could benefit from additional support to alleviate their tinnitus-related distress. The study also revealed that there was no correlation between generalised desire for control and tinnitusrelated distress. These results suggest the need for a new Desirability for Control scale similar in tinnitus-specificity to the SETMQ.

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List of Abbreviations

- DCS Desirability of Control Scale
- DSM-V Diagnostic and Statistical Manual of Mental Disorders, 5th edition
- EEG Electroencephalography
- EHFA Extended High-Frequency Audiometry
- fNIRS functional Near-Infrared Spectroscopy
- HHL Hidden hearing loss
- IHC Inner hair cells
- NGSE New General Self-Efficacy Questionnaire
- n.s. Not significant
- PTSD Post-Traumatic Stress Disorder
- SETM Self-efficacy for Tinnitus Management
- SETMQ Self-efficacy for Tinnitus Management Questionnaire
- SSHL Sudden Sensorineural Hearing Loss
- THI Tinnitus Handicap Inventory
- TFI Tinnitus Functional Index

Declaration of Academic Achievement

I, Keiko Gutierrez, hereby declare that this master's thesis is the result of my own research and academic work conducted under the guidance of Dr. Ian C. Bruce. Under his supervision, I designed the study, built the questionnaire in LimeSurvey, reached out to potential participants, collected the data, did the data and statistical analysis by programming in R, and wrote this thesis. I sought further guidance and support from subject matter experts in LimeSurvey, statistics, and R from those mentioned in the Acknowledgements section.

I assert that the contents presented in this thesis are my own. Any sources used in this thesis have been duly cited and referenced.

Preface

My interest in tinnitus research first began when a close drummer friend confided in me about the terrible noises in his head. He had one low-pitched tone in his left ear, and two distinct, high-pitched, dissonant tones in his right ear. As a musician myself, I understood that it must be an incredibly annoying experience to deal with. However, it wasn't until he shared the severe emotional distress that it caused, that I grew concerned and started investigating. Browsing tinnitus forums online and speaking to other musicians with tinnitus, I found that some people, like my friend, were being debilitated by their tinnitus; to the point where they longed for death to mercifully end their torture! Yet, I found others who reported having very loud noises in their head but had accepted it as part of their lives and were not bothered by it.

When I started exploring potential treatment options, the recurring theme was that there is no cure for tinnitus; yet some therapies worked for some people.

Why the differences, I wondered.

What is it about mindfulness therapy that makes it remarkably effective for some people, including military veterans, many of whom are known for being challenging to treat?

So began my journey into the human-psychology side of tinnitus research.

INTRODUCTION

A recent meta-analysis on the global prevalence of tinnitus estimated that there are 749 million adults worldwide that have tinnitus (a pooled prevalence of 14.4%) and 120 million are considered severe or bothersome (a pooled prevalence of 2.3%) (Jarach et al., 2022). Although they only included English language studies and excluded special population (e.g., military, musicians) studies, they did note that veterans and musicians were two populations which had a much higher prevalence of tinnitus (31% and 26% respectively) than the general population. In 2019, Statistics Canada reported that approximately 37% of adult Canadians (9.2 million) had experienced tinnitus in the past year, and that 6.5% (1.6 million) considered it bothersome (Ramage-Morin et al., 2019). This was one of the first reports to estimate the prevalence of tinnitus in Canada specifically, and although this report is a good start, more Canadian-focused tinnitus research is needed.

Defining Tinnitus and Tinnitus Distress

Tinnitus is a symptom that is not attributable to a single disease or pathology. Its name comes from the latin word "*tinnire*" which means "to ring" and is often defined as some variation of "a phantom perception of a tone or noise in the absence of any physical source" (Baguley et al., 2013; Cederroth et al., 2019; Cima, 2018). It can be subjective (only the individual can perceive the noise) or objective (a close observer can also hear it), and the sound can be pure in tone (e.g., a single frequency) or complex (e.g., chirping, hissing, buzzing, sizzling, multiple pitches simultaneously) (Han et al., 2009).

Importantly, however, most tinnitus definitions used by researchers are inadequate and do not differentiate between those that simply experience tinnitus as a harmless auditory perception, and the subset of people that develop varying degrees of tinnitusrelated emotional distress (e.g., anxiety, depression, thoughts of suicide) and/or cognitive dysfunction (e.g., attention and concentration difficulties) (Aazh & Moore, 2018; De Ridder et al., 2021; Cima, 2018). Although it is established that not everyone who experiences tinnitus necessarily experiences tinnitus distress, because the subjective experience of having "bothersome tinnitus" can have a significant negative impact on the quality of a person's life and their ability to perform simple everyday tasks, many argue that this type of tinnitus experience should be considered a "disorder" or an "illness" – which here is defined as the subjective experience of "being unwell" or "sick" (Ventriglio et al., 2017; Cima, 2018; De Ridder et al., 2021).

The absence of an unambiguous and commonly accepted definition for "tinnitus" and "bothersome tinnitus" or "tinnitus distress" continues to present challenges for performing reliable systematic reviews and meta-analyses on tinnitus research, comparing studies within and among different countries, identifying patient groups, and determining related health-care costs and regulations (Baguley et al., 2013; De Ridder et al., 2021). There are several reasons for the elusiveness of a commonly accepted definition, but the one main reason is the heterogeneity that exists across many dimensions associated with the condition (Baguley et al., 2013; Cederroth et al., 2019; De Ridder et al., 2021). Diversity exists not only in tinnitus presentation (e.g., symptoms, characteristics, severity, etiology) and patients (e.g., background, characteristics, reactions, comorbidities), but also in the

multidisciplinary makeup of the tinnitus research community (i.e., clinicians, medical professionals, and researchers who are psychologists, audiologists, otolaryngologists, family physicians, neurologists, and others) (Baguley et al., 2013; Cederroth et al., 2019; De Ridder et al., 2021). Finally, since each researcher has their own unique focus, beliefs, background, education, and experience, a single definition that can meet everyone's expectations and receive 100% consensus, is unrealistic (De Ridder et al., 2021).

Keeping the said challenges in mind, a multinational and multidisciplinary consortium of tinnitus experts from the Tinnitus Research Initiative (TRI) has proposed an unambiguous definition of Tinnitus and Tinnitus Disorder (TRI, 2020; De Ridder et al., 2021):

"Tinnitus is the conscious awareness of a tonal or composite noise for which there is no identifiable corresponding external acoustic source, which becomes Tinnitus Disorder when it is associated with emotional distress, cognitive dysfunction, and/or autonomic arousal, leading to behavioural changes and functional disability."

This definition is intended for consideration and adoption by the global tinnitus research community. De Ridder et al. (2021) explain that, in this proposed definition, the phrase "tonal or composite noise" encompasses ringing, hissing, buzzing, roaring, chirping and all the many unpleasant sounds described by those with tinnitus. It does not, however, include verbal or musical hallucinations, which are auditory phantom perceptions with specific etiology. They also clarify that the phrase "external acoustic source" here, signifies external to the body, and therefore, the absence of an external acoustic source covers both subjective tinnitus and objective tinnitus (which often refer to somatosounds, generated by

the body, such as blood flow, and can be heard by another person). They chose 3 months as the temporal demarcation between acute and chronic tinnitus, although they admitted that this was a somewhat arbitrary number taken from pain research and more research is needed to validate it. Still, they noted that some studies have shown that the mechanisms for the *generation* of tinnitus are not the same as the ones for its maintenance, and it is therefore worth capturing that difference. They also incorporated a commonly used minimum time criterion: the tinnitus percept lasts a minimum of 5 minutes per day and occurs on the majority of days (De Ridder et al., 2021).

The importance of differentiating tinnitus *without* suffering (Tinnitus) from tinnitus *with* suffering (Tinnitus Disorder) is to have a clear definition that could ensure the correct placement of Tinnitus Disorder in classifications such as the World Health Organization's (WHO) International Classification of Disorders (ICD11) and the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (De Ridder et al., 2021). Since disability claims related to tinnitus are some of the largest submitted to Veterans Affairs Canada and the Workplace Safety and Insurance Board, proper classification and differentiation can be of significant value for everyone involved (Wu et al., 2018). Again, although not everyone *suffers* from tinnitus, those that do can reach debilitating levels of emotional stress, anxiety, depression, and insomnia which often exacerbates their tinnitus, thus forming a positive feedback loop (Shore, Roberts, & Langguth, 2016).

Challenges in Diagnosing Tinnitus

There are still no reliable and reproducible, objective, quantifiable measures to diagnose tinnitus in the clinic; although outside the clinic, current artificial-intelligence (AI) based brain imaging (e.g., EEG, fNIRS) research is beginning to show some promise (Jackson et al., 2019; Shoushtarian et al., 2020; Deborjeh et al., 2023). Clinical assessment, therefore, still relies heavily on self-reporting of the patient via interviews and psychometrically validated questionnaires (Husain, 2021). This presents a problem not only in the proper diagnosing of tinnitus, but also in determining evidence-based efficacy of treatments and therapies (Langguth et al., 2023). The importance of this is highlighted with the large variability in treatment responses amongst patients in clinical trials (Cederroth et al., 2019). The common belief is that subtypes of tinnitus and/or subtypes of tinnitus patients exist, which would explain the heterogeneity in characteristics and in treatment responses, however, in a circular causality fashion, defining these subtypes has remained elusive largely due to lack of objective measures and standardized tinnitus assessment (Genitsaridi et al., 2020; Rademaker et al., 2021).

Animal vs Human Research in Tinnitus

Much of what we know about maladaptive neural plasticity, as it pertains to the generation of a phantom sound, comes from animal studies (Eggermont & Roberts, 2015; Shore et al., 2016). We learned that neural changes that are associated with tinnitus can begin as a result of reduced input from the cochlear nerve, and result in increased spontaneous firing and synchrony in different brain areas: originating anywhere from the

cochlear nucleus (CN) to the limbic system and inferior colliculus (IC), up to the auditory cortex (Eggermont & Roberts, 2015; Shore et al., 2016). There are many benefits to using animal models, such as, the ability to control the source and the cause of tinnitus; the ability to use many different methods and tools that would not be easy or ethical to use on humans; and the facility to randomly assign subjects to experimental groups which can strengthen statistics and allow for causal attribution (Haider et al., 2018; Galazyuk & Brozoski, 2020). Most drawbacks of animal studies pertain to limitations of generalizability; even the most purposely chosen animals are not identical matches to humans either in biology or in reaction (Husain, 2021). From a methodology perspective, while there are many means by which a person can get tinnitus, animal techniques usually choose either loud noise exposure or high doses of salicylate which make many treatments or determined mechanisms not replicable in human studies (Galazvuk & Brozoski, 2020). Because there are still no reliable and objective ways to determine the presence of tinnitus (and an animal cannot declare that they have it), up to now, animal researchers have predominantly used behavioural methods in their tinnitus assessments and their validity is still open to question (Fournier & Hébert, 2013; Galazyuk & Brozoski, 2020).

While we still do not have a dependable animal model that can accurately confirm the presence of tinnitus, what we do have are many humans with tinnitus who are generally eager and willing to participate in research studies to help find answers which may reduce their suffering (McFerran et al., 2019).

The main advantage of human research is that a person can be asked questions about their tinnitus experience, as well as many other questions about their environment, medical history, and mental health that a researcher may think could be associated. Eventually, with many researchers recording these variables, the goal is for enough data to be gathered to be able to determine any linkages that exist between tinnitus and its possible subtypes, to predict the degree of impact on subgroups of people, and ultimately, to be able to predict treatment outcomes (Cederroth et al., 2019; Genitsaridi et al., 2020; Ivansic et al., 2022; Langguth et al., 2023).

Multiple Factors to Consider

A long-standing challenge for researchers, has been the ability to predict which treatments might be successful for individual patients (Ivansic et al., 2022). Many different variables affect the presentation of tinnitus, including an individual's physical and psychological health, genetics, and surrounding environmental factors, which seem to impact their responses to different therapies and/or treatments (Cederroth et al., 2019).

It is well known that the psychological comorbidities of emotional stress, depression, and anxiety often make an individual's tinnitus more pronounced and may even produce tinnitus (Hébert et al., 2012; Mazurek et al., 2019; Husain, 2021; Szczepek & Mazurek, 2021). In addition, traumatic brain injuries and post-traumatic stress disorder (PTSD) have also been found to be tinnitus comorbidities (Fagelson & Smith, 2016; Husain, 2021). In such cases, tinnitus-related distress can be significantly reduced by effectively treating the core psychiatric distress (Husain, 2021).

In addition, there have been many associations found (some more supported than others) between various illnesses, medical conditions, injuries, and tinnitus (Cederroth et al., 2019; Genitsaridi et al., 2020) As an example, the COVID-19 pandemic has generated new research regarding the impacts of the SARS-COV-2 virus, the vaccines developed to protect against it, and related environmental stress, as numerous people have reported development or exacerbation of their tinnitus during this time (Schlee et al., 2020; Baig, 2021; Ahmed et al., 2022). Many drugs and medications have been found to be ototoxic, meaning temporarily or permanently damaging to the inner ear and/or vestibular system which can result in loss of hearing, tinnitus and/or dizziness in some patients (Skarzynska et al., 2020). The challenge remains that not all exposures to the same medication affect all people in the same way. For example, high doses of aminoglycoside antibiotics have been found to a genetic predisposition of ototoxicity to these drugs (Skarzynska et al., 2020). Because of this ongoing search for confirmed linkages, opportunities are often taken – as in this study – to ask a willing participant about their history, and to look for comorbidities, while asking about their tinnitus experience.

Personal experiences (e.g., jobs, recreational activities) are also relevant to information gathering because these can point to environmental factors which may have an influence on tinnitus, such as those which cause exposure to loud noise (Cederroth et al., 2019). As more environmental conditions are determined, they can be used to educate and empower people to reduce preventable risk factors.

A challenging and important area of human tinnitus research is that which deals with the psychological aspects of tinnitus, including individual personality and emotional reactions (Greimel & Kröner-Herwig, 2011). Why do some individuals strongly react to their tinnitus, while others with similar tinnitus loudness and characteristics seem to more readily accept their situation, experiencing less distress as a result? Research on personality characteristics that might mediate distress levels in tinnitus patients, found that people who have a tendency to experience a wide range of negative emotions and are uncomfortable with social interactions (known as a Type D personality), and who have higher levels of neuroticism, are more likely to perceive their tinnitus as more severe (Bartels et al., 2010). Individuals who appraise their tinnitus negatively and place a lot of attention and focus on it are also at risk of prolonging any tinnitus distress (McKenna et al., 2014). For this reason, questionnaires that reveal personality traits and characteristics are beneficial to include when assessing degree of tinnitus distress.

Habituation

Habituation is a natural neurological phenomenon that can be simply defined as the brain's determination that a repeated stimulus is not a threat, and that attendance to it can therefore be reduced (Burle et al., 2021). For example, although many people report feeling distressed at the onset of tinnitus, most individuals develop tolerance in 3 to 18 months and eventually report milder symptoms (Husain, 2021). Hence, although the tinnitus percept may still be present, many researchers believe that an individual's level of distress can be reduced by reaching habituation through decreasing tinnitus sound awareness and its corresponding maladaptive response (Cima, 2018; Husain, 2021; Burle et al., 2021). Ultimately, as a definitive cure for tinnitus remains elusive, a clinical objective for patients

is to achieve habituation as a means to alleviate distress. Facilitating patients in achieving this goal is a primary objective in ongoing human research (Cima, 2018; Husain, 2021).

Exploring the aspects of the human condition that hinder habituation can assist clinicians in tailoring targeted therapies and counseling approaches to help resistant patients in overcoming their unique challenges. Two examples of such therapies that have shown some success are Cognitive Behavioural Therapy (CBT) and mindfulness therapy (Cima, 2018; Rademaker et al., 2019). Traditional CBT helps patients use conscious thoughts and behaviours to change their negative response to tinnitus, while newer CBT therapies emphasize tinnitus acceptance and mindfulness of the thoughts and emotions that come with it (Rademaker et al., 2019). Mindfulness-based therapies help the person to be present in the moment, remain focused and alert, paying attention to sensations and thoughts without judgment. Instead of avoiding their tinnitus, they learn to accept it, which may reduce its severity and their related distress (Rademaker et al., 2019). The goals of these two types of therapies, therefore, are in line with what research has found may help habituation-resistant tinnitus patients to overcome their hurdles (Cima, 2018). Still, the question remains, why are these successful for some people and not for all? For these therapies to be more successful, and to predict which treatments would benefit specific patients, it would help to know what those challenges or barriers may be for each individual and develop specific methods to overcome them.

Desire for Control

One possible challenge to habituation that I have chosen to investigate is an individual's need or desire for control. The literature is sparse in recent studies on desire for control; however, substantial work appears to have been conducted from the late 1970s through the early 90s. From that canon, Burger and Cooper (1979) highlight two primary motivations underlying people's desire for control. The first involves the inclination to influence the outcomes of events in our lives, aiming to increase predictability and reduce uncertainty and disappointment by aligning our expectations with the actual outcomes. An example of this, is when a person experiences tinnitus and subsequently delves into research and educational resources to understand and explain the phenomenon, or to explore potential treatment options. The second perspective posits control as an independent motivator, where gratification and a sense of competence stem from the inherent ability to exert influence over our environment. An example of this, is when a someone decides to leave their corporate job and go to university to open more opportunities for a career they enjoy. A person's desire for control over different aspects of their own life is greatly influenced by their personality, their experiences, and their circumstances. In addition, individual, cultural, and situational factors must be considered (Hornsey et al., 2019).

Later research suggests that the desire for control may be a biological need for survival, and that even the *perceived* absence of control can lead to stress-related behaviour along with negative emotional and physiological responses (Leotti et al., 2010; Fritz & Gallagher, 2020). Having control over one's circumstances has the power to mitigate or

intensify an undesirable or stressful situation (Suls & Mullen, 1981; Shapiro et al., 1996). Given that tinnitus, in large part, can neither be ceased nor controlled by those afflicted, it is reasonable to think that an individual, particularly one who strongly desires control over life events, could feel more anxious or stressed due to their inability to control their tinnitus (Shapiro et al., 1996; Fritz & Gallagher, 2020). This mismatch of desire for control and ability to control might impede the process of habituation (Shapiro et al., 1996).

One question that this study sought to answer then, is: Does a person with tinnitus and a strong desire for control experience higher-than-average levels of tinnitus-related distress? In other words, is there a correlation between Desire for Control and Tinnitus Distress?

Self-Efficacy for Tinnitus Management

In the development of the Self-Efficacy for Tinnitus Management Questionnaire (SETMQ), Smith & Fagelson (2011) defined *self-efficacy for tinnitus management* (SETM) as "the confidence that individuals have in their abilities to successfully manage the effects of tinnitus". Building on the understanding that individuals with psychological comorbidities tend to report higher levels of tinnitus-related distress, Fagelson & Smith (2016) examined the role that mental health conditions might play in one's perceived level of SETM. They ran their study using three different chronic tinnitus patient groups: 1) tinnitus only 2) tinnitus + psychological health issue (other than post-traumatic stress disorder); and 3) tinnitus + PTSD. Their results showed that disabling effects of tinnitus, including self-reported distress levels and Tinnitus Handicap Index (THI) scores,

progressively increased as psychological health issues worsened. Importantly, the individuals with PTSD reported significantly lower levels of tinnitus self-efficacy than the other two groups. These results underscore the importance of considering the whole patient, particularly encompassing the psychological aspects of tinnitus.

The Present Study

The SETM study results inspired further questions, such as, is there a strong correlation between a person's level of General Self-Efficacy in life (Bandura,1994) and their level of Self-Efficacy for Tinnitus Management? What other reasons might there be for an individual's SETM score to be low? One possible relationship could exist between a person's desire for control and their level of SETM. If a person has a high desire for control, does that impact (i.e., lower) their perceived sense of self-efficacy for tinnitus management? Such an interaction could then impact a person's level of tinnitus distress. I hypothesize that in combination, the higher an individual's desire for control is and the lower their perceived SETM is, the higher their tinnitus distress level will be. Conversely, the combination of a low desire for control and a high level of self-efficacy in tinnitus management, should produce very little distress.

Ultimately, I believe that a person's level of Self-Efficacy for Tinnitus Management could eventually be increased through a therapy that provides tinnitus education and the ability to mask or distract from the noise (e.g., Tinnitus Retraining Therapy), while their Desire for Control could be moderated by CBT or mindfulness therapy (Cima, 2018; Rademaker et al., 2019, Langguth et al., 2023). Given these factors, I propose that when

addressing tinnitus distress, a patient's level of *desire for control* and their level of *self-efficacy for tinnitus management* should be measured and considered to select the appropriate intervention strategies. This study used the SETMQ developed by Smith & Fagelson (2011), the Desirability of Control Scale by Burger & Cooper (1979), and the Tinnitus Handicap Inventory (THI) developed by Newman et al., (1996), to analyze this interaction.

In summary, the purpose of the current study was to contribute to the existing body of research exploring the individual characteristics of people experiencing tinnitus distress. It had two main objectives: (1) To examine the moderating role of an interaction between Sense of Self-Efficacy in Tinnitus Management and Desire for Control, which are two participant characteristic variables, on level of Tinnitus Distress. (2) To test whether there is a strong correlation between a person's Self-Efficacy for Tinnitus Management score and their General Sense of Self-Efficacy score (Chen et al., 2001), as an extension of the Smith & Fagelson study (2011).

METHODS

The COVID pandemic greatly influenced the decision to conduct a study online. Not only is this type of research resistant to the many lockdowns and restrictions we experienced, but its broad reach capability allows for a large number and diversity of participants across Canada, thereby increasing generalizability and reliability. Since no audiological or physiological assessments could be done consistently without direct access to participants, and due to the inherently subjective nature of tinnitus, the decision was made to do a correlational study using a cross-sectional survey.

Participants

Adults (18 and over), living in Canada, with and without tinnitus, were given the opportunity to participate in an online survey. The main groups of interest, based on their questionnaire answers, were: 1) those with tinnitus and distress, and 2) those with tinnitus and no distress (tinnitus only). Data from participants without tinnitus were used for controls, particularly on questions not related to tinnitus (e.g., desire for control, sense of general self-efficacy).

The decision was made to define Canadians as those currently living in Canada, as opposed to those born in Canada but living abroad, to concentrate on those who currently have access to Canadian healthcare resources and who were impacted by the COVID pandemic in the Canadian context.

Participants were recruited via direct contact (those who reached out to us via email or who were participants in previous tinnitus research at McMaster University), through word-of-mouth and posts on social media (Facebook and LinkedIn), via wide-reaching hearing-related groups found online (e.g., Canadian Hard of Hearing Association, Canadian Hearing Services, Canadian Academy of Audiology), and by reaching out to audiology clinics in major cities across Canada, identified through Google searches, whose website included tinnitus support.

Survey Questionnaires:

Previously validated questionnaires have been published for determining the degree of impact tinnitus has on a person's life (e.g., ability to concentrate, sleep health, quality of life) and for different psychological constructs (e.g., stress, personality). Several of these and other scales and questionnaires were combined for this survey, collecting both qualitative and quantitative data from participants across different domains (e.g., demographics, tinnitus-related, habit-related, general-, auditory-, and psychological health).

This survey consisted of subjective and objective data, collected via 18 scales and questionnaires (see *Table 1.*), with some open-ended questions for added details and clarification. Collectively, these elements can contribute to a relatively comprehensive and intricate exploration of tinnitus, encompassing its associated psychological and emotional aspects, as well as the variations in experiences among individual participants. The decision to include so many (18) questionnaires, was based on three main factors: 1) Due to the heterogeneity of tinnitus symptoms, severity, comorbidities, and patient characteristics, it was important to capture a comprehensive range of information about the participants and their tinnitus experience; 2) Items of interest were spread across multiple questionnaires that, although similar, were not complete on their own; 3) The supplementary data collected from these participants holds potential for future exploratory research on tinnitus, as well as for potential comparisons with specific findings in the literature.

Because the final survey was long (median completion time: one hour; Min: 15 minutes, Max: 4h50m) and there was a high risk for "questionnaire fatigue" and attrition,

the key questionnaires required to answer the study questions were loaded in the first half. The survey was activated November 22, 2022, and advertised to expire Feb 1st, 2023, giving us approximately two full months of data collection. However, it was passively extended (i.e., not advertised) until March 1st for some people as they complained that the survey had expired on them. In hindsight, value would have been added by leaving the survey up until the code for analysis was ready.

	Questionnaire	Rationale for Inclusion	Citation
1.	Audiologic Case	History of hearing-health-related concerns	(Adapted from
	History	including Tinnitus.	collaborative
			work with S.
			Shore lab.)
2.	COVID-19-Related	Possible pandemic-related stress, viral	
	Questions	impacts, medication/ototoxicity, vaccination effects.	
3.	Demographic Questions	Ensure diversity of respondents and facilitate summary by demographics (e.g., age, sex).	
4.	Medical History	Diseases or illnesses that may be relevant or comorbidities.	(Adapted from collaborative work with S. Shore lab.)
5.	Medications	Uncover possible occurrences of ototoxicity.	
6.	Music-Related	Possible music-related noise-induced hearing	
	Questions	loss; Allow for summary by musician	
		subgroup.	
7.	NGSE – New	Standardized. Measures general sense of	(Chen et al.,
	General Self-Efficacy Scale	confidence and self-efficacy.	2001)
8.	NEQ – Noise	Standardized. Used to uncover possible	(Johnson et al.,
	Exposure	noise-induced hearing loss.	2017)
	Questionnaire	Č	,
9.	SETMQ – Self-	Standardized. Measures Self-Efficacy	(Smith &
	Efficacy for Tinnitus	specifically related to management of tinnitus.	Fagelson, 2011)
	Management		
	Questionnaire		

Table 1. Included Scales and Questionnaires. (See Appendix for full questionnaires.)

10.	Social History	Potential tinnitus association with use of	
	Questions	alcohol, tobacco, caffeine, and recreational drugs.	
11.	TFI – Tinnitus	Standardized. Measures impact of tinnitus on	(Henry et al.,
	Functional Index	everyday life covering 8 important aspects of	2016)
		tinnitus handicap. Discriminates between	
		levels of tinnitus distress and is sensitive to	
		changes over time.	
12.	THI – Tinnitus	Standardized. Most popular and reliable scale	(Newman et al.,
	Handicap Inventory	for measuring tinnitus severity and handicap.	1996)
13.	THQ – Tinnitus	Standardized. Measures psychological and	(Kuk et al., 1990)
	Handicap	emotional aspects of tinnitus handicap, with	
	Questionnaire	sensitivity to changes over time	
14.	TRQ – Tinnitus	Standardized. Measures tinnitus-associated	(Wilson et al.,
	Reaction	distress, however there is no recommended	1991)
	Questionnaire	grading system.	
15.	DC – Desirability of	Standardized. Measures the need to feel in	(Burger &
	Control Scale	control of the events in one's life.	Cooper, 1979)
16.	PSS – Perceived	Standardized. Measures the degree to which	(Cohen et al.,
	Stress Scale	situations in one's life are appraised as	1983)
		stressful. Though the scale is nonspecific,	
		many items refer to stress due to the absence	
		of control over different aspects of one's life.	
17.	DASS42 –	Standardized. Measures the severity of	(Lovibond &
	Depression Anxiety	depression, anxiety, and stress; symptoms	Lovibond, 1995)
	Stress Scale	which are often comorbid with Tinnitus	
		Disorder. Sensitive to changes over time.	
18.	IHS – Inventory of	Standardized. Measures symptom severity,	(Greenberg &
	Hyperacusis	treatment outcomes, and diagnostic	Carlos, 2018)
	Symptoms	differentiation of auditory sensitivity disorders	
		which are often tinnitus comorbidities.	

Psychological constructs such as depression, stress, anxiety, self-efficacy, and need-for-control, were captured using widely used scales (e.g., Depression Anxiety Stress Scales (DASS42), Desirability of Control Scale, and Self-efficacy for Tinnitus Management). History of noise exposure, musicianship experience, and questions regarding sensitivity to sound (i.e., hyperacusis) were also collected as they are often correlated with tinnitus (Johnson et al., 2017; Burns-O'Connell et al., 2021). In addition,

demographic, audiological, and medical history were captured, including a separate questionnaire specific to COVID-19 since reports of tinnitus generation due to related environmental stress, the SARS-CoV-2 virus, and adverse effects from SARS-CoV-2 vaccines exist (Schlee et al., 2020; Baig, 2021; Ahmed et al., 2022).

Although this seems like a lot of information to ask of responders, after an initial pilot test of 5 respondents, the whole survey was expected to take only 20-90 minutes to complete depending on the respondent's individual case (i.e., has no tinnitus with very little to report vs. has tinnitus and much to report). Further, the information captured would provide a good base from which to do future data analysis on people living in Canada with tinnitus. A conversation with Nic Wray of Tinnitus UK, formerly known as the British Tinnitus Association (BTA), concluded that based on information from conferences, online forums, surveys, and journal clubs, many tinnitus sufferers would be motivated to help with research. Robert DeVellis (2017), in his book on scale development, remarked that "Completing 'convenient' questionnaires that cannot yield meaningful information is a poorer use of respondents' time and effort than completing a somewhat longer version that produces valid data." So, I traded off risk of attrition due to length, for content validity.

Data Collection

Questionnaires were delivered and stored using the latest McMaster-approved version of LimeSurvey (v5.6.10). To attract serious candidates only, participants were required to register before proceeding. Unique links were then sent to registered candidates by email, giving them access to the online LimeSurvey portal, where they were presented

with a letter of information about the study and with the ability to provide informed consent to participate. Participants were able to pause the survey at will and continue later where they left off. They were also able to quit the survey at any time, whereupon their data was erased. Further consent was requested to enable follow-up contact, and to get permission to share their anonymized data. Participants were assigned random IDs by LimeSurvey and the data was de-identified for analysis to preserve participant privacy. Only summarized data is reported in this thesis.

Measures

Tinnitus and Tinnitus Distress

The first four audiologic questions capture basic tinnitus information and were taken from a simple, 4-question, standardized survey that estimates tinnitus prevalence and severity, as well as help-seeking healthcare visits (Biswas et al., 2019). (Q1. "Over the past year, have you had sounds or noises (such as ringing, chirping or buzzing) in your head or in one or both ears that lasts for more than 5 minutes at a time?"; Q2. Is the sound/noise (tinnitus) constant or intermittent?"; Q3. "Over the past year, how much do these sounds/noises in your head or ears (tinnitus) worry, annoy, or upset you when they are at their worst?"; Q4. "Over the past year, have you seen your family doctor, an audiologist, or a healthcare professional at a clinic or hospital about problems with sound/noises in your head or ears (tinnitus)?")

In the remainder of the study, Q1 was used to indicate which participants had tinnitus, i.e., those who answered "Yes, all of the time" or "Yes, some of the time". Tinnitus

Distress level was measured using Q3. above (Self-Reported), Tinnitus Handicap Inventory (THI), and distress-related subscales (Intrusiveness [#1, 2, 3] and Emotional [#23, 24, 25]) of the Tinnitus Functional Index (TFI). As explained in the Discussion section, ultimately the THI Grade was selected to determine level of distress.

Tinnitus Handicap Inventory

The THI consists of 25 questions such as "Because of your tinnitus, is it difficult for you to concentrate?". Respondent answers are Yes (4 points), Sometimes (2 points), No (0 points). The total score is then divided into five grades indicating varying levels of tinnitus-related handicap:

- Grade 1 (0-16 points): Slight The person experiences minimal tinnitus impact on their daily life, with little interference in their functioning or emotions.
- Grade 2 (18-36 points): Mild Tinnitus has a mild impact on the person's daily life. They may face occasional challenges in specific situations, but generally manage tinnitus well.
- Grade 3 (38-56 points): Moderate Tinnitus has a moderate impact on the person's life. It affects their emotions, concentration, and well-being, making coping in different situations more challenging.
- Grade 4 (58-76 points): Severe Tinnitus poses substantial challenges for the individual. It greatly impacts their emotions, concentration, and daily functioning, causing significant distress and impairment.
Grade 5 (78-100 points): Catastrophic - Tinnitus has a severe and overwhelming impact on the individual's life. It catastrophically affects their emotions, thoughts, and normal activities, causing high distress and handicap.

Tinnitus Functional Index

The TFI consists of 25 questions such as "Over the past week, how STRONG or LOUD was your tinnitus?". Respondents select a number from 0 (never) -10 (always). Items #1 and #3 have answers that range from 0% to 100% and need to be transformed to integers 0 - 10. The maximum possible score is 250 which is then divided by the number of questions answered (25 as they are all mandatory) and multiplied by 10 to get an overall score.

Subscale Name (conceptual content)	Subscale Items				
Intrusive (unpleasantness, intrusiveness, persistence)	#1, 2, 3				
Sense Of Control (reduced sense of control)	#4, 5, 6				
Cognitive (cognitive interference)	#7, 8, 9				
Sleep (sleep disturbance)	#10, 11, 12				
Auditory (auditory difficulties attributed to tinnitus)	#13, 14, 15				
Relaxation (interference with relaxation)	#16, 17, 18				
Quality of Life (QOL) (quality of life reduced)	#19, 20, 21, 22				
Emotional (emotional distress)	#23, 24, 25				

There are eight subscales representing domains of negative tinnitus impacts:

Desire For Control

The Desirability of Control Scale (DCS) developed by Burger & Cooper in 1979, is still the accepted standard tool to measure a person's motivation to control the general events in their life (McCutcheon, 2000). It is not specific to tinnitus. There are 20 statements

written from the responder's perspective about their desire for control in each situation (e.g., "I prefer a job where I have a lot of control over what I do and when I do it."). A Likert-type scale, each item requires a response from 1 - The statement doesn't apply to me at all. to 7 - The statement always applies to me. The total score was used to determine a responder's desire for control, however special attention was paid to the nine (9) items [#1, 3, 5, 8, 9, 11, 12, 15, 18] which the authors suggest may point to a General Desire for Control factor.

Perceived Level of Self-Efficacy in Managing Tinnitus

Although there are two items on the THI that ask about the perceived control over their tinnitus (#8: "Do you feel as though you cannot escape your tinnitus?" and #19: "Do you feel that you have no control over your tinnitus?"), some studies have reported that many people, even with mild tinnitus handicap, have answered "yes" to these questions (Wakabayashi et al., 2020). Therefore, the more thorough and specific 40-item Self-Efficacy for Tinnitus Management Questionnaire (SETMQ) was used to measure this construct (Smith & Fagelson, 2011).

General Sense of Self-Efficacy

The 8-item New General Self-Efficacy Scale (NGSE) is a 5-point Likert-type scale $(1 - strongly \, disagree$ to 5 – strongly agree), that assesses how much one believes that they can successfully achieve their goals, despite difficulties (Chen et al., 2001). A sample

question reads, "I will be able to achieve most of the goals that I have set for myself." The total score was used to represent the respondent's general level of self-efficacy.

Statistical Analysis

Data transformations and statistical analyses were performed in R (version 4.2.2) using RStudio (version 2023.06.1+524). Data preparation included assigning values to answers as per the questionnaire instructions, calculating total scores, and omitting null records where appropriate.

I conducted multiple correlational analyses and linear regression models to identify any main and interaction effects (the different levels) of the two predictors I proposed (Desire for Control and Self Efficacy for Tinnitus Management) on Tinnitus Distress. Where appropriate, I used the Shapiro-Wilk test to verify that the data was normally distributed and the Bartlett test to assess equality of the variances.

Significance level for all statistical analyses was set to alpha < .05.

Ethics

This study was approved by the McMaster University Research Ethics Board (MREB) in June 2022, #5781.

RESULTS

This study aimed primarily to answer the following question: Amongst Canadian adults with tinnitus, is there an association between an individual's Desire for Control and their sense of Self-Efficacy in Tinnitus Management that has an influence on their level of Tinnitus Distress? Specifically, does a high level of Desire for Control combined with a low level of Self-Efficacy for Tinnitus Management predict a high level of Tinnitus Distress? To answer this question, I focused on the results of the following three questionnaires within the overall survey: a) Desirability of Control Scale (DCS), b) Self-Efficacy for Tinnitus Management Questionnaire (SETMQ), and c) the Tinnitus Handicap Inventory (THI). My results did not show evidence of such an association.

To answer the second question of whether Self-Efficacy for Tinnitus Management was strongly correlated with an individual's general *sense of self-efficacy*, I incorporated the results of the New General Self-Efficacy scale (NGSE). Surprisingly, the results disclosed no such correlation.

Finally, I included the Tinnitus Functional Index (TFI) in my analysis to examine the subscales related to Distress and Sense of Control, as explained further below.

Statistics

Summary statistics for the participants (e.g., sex, age, location) and tinnitus distribution were collected. Correlation analysis models were then used to examine the strength and direction of the linear relationships amongst my variables of interest. Significance level for all statistical analyses were set to alpha < .05.

Overview of Statistical Findings

Out of the total 163 respondents exported from LimeSurvey, 130 participants (80%) completed at least the first half of the online survey and were included in the study. Remarkably, 108 of these participants (83%) had completed the entire survey.

As seen in Table 2, participants consisted of slightly more males than females (χ^2 (1, N = 130) = 2.49, p = .11, n.s.). The average age of female participants was slightly higher than that of males, but not significantly so when verified using the Wilcoxon Rank-Sum test (W = 2419.5, p = .10, n.s.). As there was no significant difference between the sexes, total measures were used for data analysis. The overall mean age was 60.5 years (SD = 13.4) ranging from 22 to 85. The majority (65%) of participants fell between the ages of 55 and 75 inclusively (see Figure 1).

Despite efforts made to recruit participants from diverse backgrounds across Canada, the two-month data collection period proved insufficient to effectively target promotion to increase representation in these demographics. Consequently, the study mostly drew respondents from Ontario (the study's originating location), which accounted for the majority (72%) of participants (Figure 2). Likewise, 86% of participants identified as White, while only 6% identified as Mixed (including Latinos), and 5.4% identified as East Asian. While South Asian, Black, Métis, and First Nation groups were also represented, each comprised less than 5% of the total sample. (Figure 3).

		Age					Self-Reported Tinnitus				
C		Malla		M	CD	N	Some-	N	Has		
Sex	Total (%)	Median	Min	Max	SD	No	times	Yes	Tinnitus (%)		
Female	56 (43)	64	23	82	11.7	10	13	32	45 (80)		
Male	74 (57)	61	22	85	14.3	17	13	44	57 (77)		
Missing	0 (0)					1					
Total	130 (100)	63	22	85	13.4	28	26	76	102 (78)		
<i>lote</i> . "Has	Tinnitus" w	vas define	ed as h	aving ans	swered "Sor	netimes	s" or "Y	es" to	the tinnitus		
uestion (s	ee Methods)										
$\sim \% = n / t$	total particip	ants.									

Table 3. Tinnitus Participant Distress

	Self-Reported Tinnitus Distress					THI Distress Grade					
Sex	No	Slightly	Moder-	Severe	Tinnitus and	1	2	3	4	5	Tinnitus and
			ately	ly	Distress (%)	Slight	Mild	Mod.	Severe	Catastrop	Distress (%)
Female	3	19	16	7	23(51)	19	16	4	5	1	10(22)
Male	6	16	25	10	35(61)	21	19	12	2	3	17(30)
No Tinnitus	(28)										
Total	9	35	41	17	58(57)	40	35	16	7	4	27(26)
					\$						\$

Note. Distress was defined as answers of "Moderately" or above for Self-Reported, and Grades 3 and above for THI.

* % = n / "Has Tinnitus" in Table 2.







Those who answered "Yes, most or all of the time." (YES) or "Yes, some of the time." (Sometimes) to the question "Over the past year, have you had sound or noises (such as ringing, chirping or buzzing) in your head or in one or both ears that lasts for more than five minutes at a time?" were considered to have tinnitus. 78% (102) of participants had tinnitus (see Table 2) and all were considered chronic (at least 3 months). When grouped by sex, 44 males answered "YES" to the tinnitus question compared to 32 females, however, a chi-square test showed no statistically significant difference between the self-reported tinnitus groups by sex ($\chi^2(2, N = 130) = 0.93$, p = .63, n.s.).

Of those who had tinnitus, when asked to choose how they would describe the sound that they hear in their heads (e.g., click, crackle, hiss, tone, hum...), the top 3 answers chosen were "tone" (49%), "hiss" (35%), and "hum" (25%) (Figure 4) which is consistent with what has been reported in the literature (Tucker et al., 2005). When provided with the option to include their own descriptors, noteworthy responses from participants included two who wrote "white noise", one who answered "music", and a couple who found it "difficult to describe". As expected, some participants chose more than one answer.

Tinnitus Distress amongst participants with tinnitus (102) was determined in two ways: a) via self-reporting by answering "Moderately" or "Severely" to the question, "How much do these sounds/noises in your head or ears (tinnitus) worry, annoy, or upset you when they are at their worst?"; and b) by obtaining a THI-calculated grade of 3 or above (1 – Slight, 2 – Mild, 3 – Moderate, 4 – Severe, and 5 – Catastrophic). The self-reported measures revealed that 57% of those with tinnitus, considered it at least moderately distressing when their tinnitus was at its worse, while the THI revealed that about 27% of the total handicap score was graded from moderate to catastrophic (see Table 3 and thoughts in the Discussion section).



Analysis

To explore the associations between a tinnitus sufferer's desire for control, their sense of self-efficacy in managing tinnitus, and their level of tinnitus distress (the primary research question), a multiple correlation analysis (included in Figure 5) and a multiple regression model (Table 5) were conducted on the three main variables of interest (for participants who reported having tinnitus): 1) THI Total (THI) to represent Tinnitus Distress level, 2) SETM Mean (SETM) to represent Self-Efficacy for Tinnitus Management, and 3) DCS Total (DCS) to represent Desire for Control.

The first noteworthy observation is the strong negative correlation between THI and SETM (r(100) = -.73, p < .001), even surpassing the moderate correlation

(r(92) = -.49, p = .01) reported by Fagelson and Smith (2011) in their paper. As predicted, the higher a person's confidence in their ability to effectively manage their tinnitus is, the lower their tinnitus distress levels are. A box plot was created to visualize the different THI scores by SETMQ Level (High: ≥ 70 ; Low: < 70) (W = 347, p < .001; see Figure 6).

Surprisingly, the new independent variable under investigation, DCS score (Desire for Control), exhibited no correlation with THI (Tinnitus Distress) (r (100) = .04, p = .67, n.s.), and showed no significant correlation with Self-Efficacy for Tinnitus Management (r (128) = -.17, p = .059, n.s.), although it was trending negatively. A box plot was created to examine the THI scores between those with High DCS scores (\geq 110) and those with Low DCS scores (< 110) (see Figure 7). Fisher's Exact test indicated that there was no significant difference between the two groups (p = .48).

A moderate positive correlation was found between DCS and NGSE (General Self-Efficacy), which will be briefly addressed in the Discussion section (see Figure *5*).

To answer the second question of whether there exists a strong correlation between a person's SETM score and their General Sense of Self-Efficacy, the NGSE total (NGSE) was incorporated into the matrix (see Figure 5). For a summary of the measurements data, see Table 4.

As an exploratory query, the same multi-correlation matrix was generated using the Sense of Control subscale of the TFI in place of the DCS. As shown in Figure 5, this change resulted in a significant increase in correlation with the THI (r (100) = .62, p < .001) and

SETM (*r* (100) = -.66, *p* < .001), while significance with NGSE was lost (*r* (128) = -.08, *p* = .44, n.s.).

Table 4. Measures Summary Table

Measure	м	SD	Min	1st Qu	3rd Qu	Max	n
Desire for Control (DCS) (1 - 140)	101	12.5	61	91.25	110	132	130
General Self-Efficacy (NGSE) (8-40)	32	5.7	8	29	36	40	130
Tinnitus Functional Index (TFI) (0-100)	35.8	24.6	0	15.25	54.75	98	102
TFI Sense of Control subscale %	45.7	27.8	0	24	67	100	102
TFI Distress subscale %	39.7	23.6	0	18	59.5	97	102
Tinnitus Handicap Inventory (THI) (0-100)	28	22.4	0	10	39.5	94	102
Self-Efficacy for Tinnitus Mgmt (SETM) Aggregates (0-4000)	2227	1344.9	0	1428	3345	4000	130
Self-Efficacy for Tinnitus Mgmt (SETM) Means (0%-100%)	70.6	18.7	24	57	85	100	102

Note. Values in parentheses under each Measure represents the possible range of values on the

scale/questionnaire. Values in the table represent mean, standard deviation, range of values,

quartiles, and number of participants represented (102 of 130 participants reported having

tinnitus).



Residuals:	Min	1Q	Median	3Q	Max
	-43.27	-12.06	-4.3	11.77	48.73
		Std.			
Coefficients:	Estimate	Error	t-value	p-value	
(Intercept)	31.65	2.12	14.95	<.001	***
DCS_level1	2.35	2.12	1.11	0.27	
SETMQ_level1	-13.02	2.12	-6.15	<.001	***
DCS_level1:SETMQ_level1	1.74	2.12	0.82	0.41	
Residual standard error: 17.5	1 on 98 degree	es of freedo	om		
Multiple R-squared: 0.41					
Adjusted R-squared: 0.39					
F-statistic: 32.32 on 3 and 98	df, p < .001				

Table 5. Results of Multiple Regression Analysis: DCS and SETM Levels on THI

Note: The second line of the coefficients shows that DCS level does not influence the THI score. The third line reveals that the SETMQ level has a significant negative effect on the THI score, i.e., a Low SETMQ predicts a higher THI score than a High SETMQ does, while holding the DCS level constant. The last line shows that the interaction between DCS and SETMQ levels has no significant effect on the THI score.





DISCUSSION

The impact of personality on resulting distress levels has been a subject of extensive debate in the literature (Husain, 2021). One review seeking evidence of an association between personality traits and tinnitus distress concluded that the search was inconclusive due to methodological limitations in the included studies (van Munster et al., 2020). Nevertheless, that review and others have pointed to evidence suggesting a positive association with certain traits, such as neuroticism (Biehl et al., 2020; van Munster et al., 2020; Husain, 2021). Their ultimate recommendation was to conduct longitudinal studies employing validated questionnaires to evaluate personality dimensions and traits when assessing tinnitus distress (van Munster et al., 2020). As it was not feasible to carry out a longitudinal study within a Master's thesis project, I attempted instead to conduct a large-scale cross-sectional investigation of people with tinnitus in Canada using validated questionnaires.

The initial goal of this study was to see whether the level of a tinnitus sufferer's need for control influenced the level of distress they experienced related to their tinnitus. Because tinnitus is not something that most people can control, the rationale for this line of thinking was that someone who has a high need for control would find the experience more distressing than those who did not have this strong need. Burger and Cooper's 1979 Desirability for Control scale was the closest instrument that could be found to operationalize this measurement; therefore, the terms *need for* control and *desire for* control are used here interchangeably. Subsequently, since prior research conducted by others demonstrated that a strong sense of self-efficacy in managing tinnitus correlated with

decreased tinnitus distress levels, the inquiry became more focused: Does the level of *desire for control* influence this correlation, and if so, what might the underlying dynamics be. The hypothesis was that there would be a negative correlation between *desire for control* and *self-efficacy for tinnitus management* as it pertains to effect on levels of tinnitus distress. Hence, if an individual's desire for control is high, and their sense of self-efficacy for tinnitus management is low, their level of tinnitus distress was predicted to be high. Conversely, if their desire for control were low and their self-efficacy for tinnitus management were high, then their level of tinnitus distress was predicted to be low.

The results of this thesis strengthened support for the previous finding of an existing robust correlation between the level of *self-efficacy in managing tinnitus* and tinnitus distress levels. Surprisingly, however, the results found no correlation to substantiate the hypothesis regarding the role of *desire for control* in mediating this relationship. Nor did they indicate any correlation between *desire for control* and *tinnitus distress*.

Desire for Control

The Desirability of Control Scale (DCS) was designed to measure individual differences in people's motivation to control the general events in their own lives (e.g., interpersonal relationships, decision-making, and coping with uncertainty) (Burger & Cooper, 1979). Due to diverse personal backgrounds and motivations, it would be very difficult to determine an "average" level of Desire for Control that could apply to the general population. However, my DCS results (M = 101, SD = 12.5) are very much in line

with Burger & Cooper's original findings (M = 100.5, SD = 11.8), as well as those found 20 years later (M = 101, SD = 13.3) by McCutcheon (2000), showing some consistency.

In this study, an individual's Desire for Control was measured to see if it could be a predictor of distress-level in those experiencing tinnitus. Like many other chronic conditions, the inability to make tinnitus stop at will can be frustrating and stressful which can lead to anxiety (Pryce & Chilvers, 2018). This would seem to be especially so for those whose desire for control is high (Fritz & Gallagher, 2020). Surprisingly, this factor had no effect on tinnitus distress level, prompting a deeper investigation.

Burger & Cooper's (1979) factor analysis identified five factors (1. General Desire for Control, 2. Decisiveness, 3. Preparation-Prevention Control, 4. Avoidance of Dependence, and 5. Leadership) and, since the other factors seemed less relevant to this study, I decided to focus on only the nine items that contributed to the General Desire for Control to see if it was better correlated to tinnitus distress levels. There was no significant change.

So, my hypothesis that Desire for Control could influence the level of Tinnitus Distress continued to be unsupported. Desire for Control also showed no significant correlation with the level of Self-Efficacy for Tinnitus Management (see Figure 5). However, it did exhibit a moderate positive correlation with General Self-Efficacy (r (128) = .38, p < 0.001). This finding is discussed further below.

The role of Desire for Control, however, remains inconclusive, as this concept proved to be more elusive than initially anticipated. I very recently found research that offered some clarification: to effectively measure traits pertaining to control, such as *desire* for control, it may be necessary to frame the questions in a context-specific manner (Folkman, 1984; Logan et al., 1991, Sirois et al., 2006). To understand the role of control within a situation, it is important to clarify, "Control over what?" (Folkman, 1984). Consequently, the standard generalized Desirability for Control scale (DCS) may not be suitable for gauging the extent to which individuals with tinnitus, desire to control their tinnitus or tinnitus-related symptoms and experiences. A new, contextualized scale could therefore be necessary to effectively measure this construct. When considering the assessment of a dental patient's desire for control and its connection to their level of *perceived* control as predictors of stress during dental visits, Logan et al. (1991) introduced an explicit 4-item index. Using this index, which gauged both the *desire for control* (a 2item subscale) and the sense of control (a 2-item subscale) within a dental context, they revealed that dental patients scoring high on *desire for* control and low on *feeling in* control, experienced elevated levels of distress related to getting dental treatment. They also employed Burger and Cooper's DCS, for comparison, but unlike the context-specific scale, it did not produce a significant correlation with distress.

Another factor that may explain the underwhelming results is the low statistical power due to low sample size for the "high Desire for Control and low Self-Efficacy for Tinnitus Management" sub-group (n = 11, df = 9). In fact, the total count of participants with tinnitus who scored high on *desire for control* (n = 22) was much lower than those who scored low (n = 80). A potential explanation for this imbalance could be that individuals with a strong desire for control might be more likely to quit participating in the study upon realizing the time commitment needed to complete the survey.

A final perspective to consider is that tinnitus distress may be attributed more to abnormal brain activity rather than to the individual's personality traits. In addition to auditory brain networks, brain-imaging studies have also implicated various non-auditory systems, such as attentional, emotional, and memory networks, in the generation, maintenance, and exacerbation of tinnitus (Haider et al., 2018; Husain, 2021). A notable example of this interaction is the involvement of the prefrontal cortex (PFC), the dysregulated limbic system, and the auditory system, particularly in the amplification of negative emotions related to one's tinnitus and the tendency to catastrophize its potential consequences (Leaver et al., 2011; Husain, 2021).

Similarly, in the literature focused on control-centered research, the PFC and the limbic system have been associated with the ability to modulate stress responses when confronted with uncontrollable stressors (Leotti et al., 2010). An inverse relationship has been observed between PFC activity and limbic system activity when managing or reducing related negative emotions. Therefore, it is recognized that other neurological and cognitive factors are at play in tinnitus and potentially in tinnitus distress. While these factors are intriguing for further investigation, they fall beyond the scope of this study.

After finding no correlation between the total DCS score and either the level of tinnitus distress or Self-Efficacy for Tinnitus Management scores, the investigation turned to the Sense of Control subscale of the TFI (items #04, 05, 06). A correlation matrix was generated which revealed it had a strong association with both the THI score (distress level) and Self-Efficacy for Tinnitus Management. This result made sense upon further inspection

of the individual items however, as they are very similar to the types of questions asked in the SETMQ (#04: "Did you feel IN CONTROL in regard to your tinnitus?"; #05: "How easy was it for you to COPE with your tinnitus?"; #06: "How easy was it for you to IGNORE your tinnitus?") It therefore proved unenlightening, other than providing some cross-validation of these measures across the two questionnaires.

General Self-Efficacy vs. Self-efficacy for Tinnitus Management

Unexpectedly, there was no correlation between the NGSE and SETM scores (r (128) = .01, p = .92 (n.s.)). My expectation was that a person's tendency to feel that they were generally capable of achieving goals in their lives, would positively correlate to their sense of ability to manage their tinnitus. However, upon closer inspection of the individual items on the two questionnaires, it is understandable that they are not as related as one might presume. The NGSE scale asks about how effective one feels they can be when tasks need to be performed, i.e., success depends on the ability to put effort, energy and focus on the right things to be successful. The SETMQ, on the other hand, asks questions regarding the individual's mental and emotional capacities to deal with their tinnitus specifically. Some examples are: the ability to ignore their tinnitus, their ability to control their feelings about their tinnitus (e.g., anger, frustration, fear), their ability to be effective despite their tinnitus, their understanding of what they are experiencing (e.g., hearing loss vs. tinnitus) and any options they may have in managing it (e.g., get hearing aids and/or counseling). Apart from seeking help and educating oneself about tinnitus, the answers to these questions are less task- or effort-related and are very domain-specific. Therefore, after further reflection, it becomes evident that these two questionnaires are markedly different. This distinction then, sheds light on the moderate correlation found between the Desirability of Control and the General Self-Efficacy scores, as well as the apparent lack of correlation between Desirability of Control and SETMQ scores given that a) both the DCS and the NGSE encompass action-oriented elements, and b) they are both generalized and not tinnitus-specific.

Self-reported Level of Distress vs. THI Grade vs. TFI Distress subscale

While at first glance, the difference between THI Grade (27%) and the self-reported measures of tinnitus distress (57%) may seem to be due to some people overstating their negative feelings, I believe that it's due to the extra answer option that the THI had between "Moderate" and "Slight": "Mild". The inclusion of this extra option in the THI, or its absence in the self-report question, begs the question, what is the difference between "Mild" and "Slight"? Also, is "Mild" closer to "Moderate" or "Slight"? Since 34% of participants fell into this "Mild" grade category in the THI, how one answers those questions, changes the perceived gap between the two measures.

In light of this discrepancy, a correlation analysis was conducted to assess the level of association (convergent validity) between three different measures of distress: 1) Selfreported Distress as indicated by respondents (severely, moderately, slightly, not at all); 2) the total score of the THI (as opposed to calculated Grade); and 3) the combined distressrelated subscales of the TFI. The results, depicted in Figure *8*, revealed very strong positive correlations throughout. These robust associations confirm the comparability of reported distress levels and further support the validity and use of self-reporting questionnaires. Based on these findings, the THI total score was selected as the primary operational measure of tinnitus distress, aligning with the THI's original purpose.

Although interesting to report, it is important to remember that proportions of study participants with tinnitus only, versus those who also experience tinnitus distress, cannot be used to make statements about the general population since these participants selfselected to respond to my survey.



Handicap Inventory total score (THI), and the Tinnitus Functional Index (TFI) Distress subscale.

Limitations

The COVID-19 pandemic placed many limitations on the ability to gather in-person data. For this reason, the entire study was moved online where only self-reported data could be captured. Given the extended length of the survey, there is a risk for response bias, where agreement to participate in the study or motivation to complete the study may be impacted by the degree of discomfort experienced from tinnitus. In anticipation of this, and to reduce any negative impacts, the most relevant questions to this study were included in the first half of the survey. All respondents who at least reached the halfway point were then included in the analysis.

Because this is a cross-sectional correlational study, the data gathered is a snapshot at one point in time and no causal inference can be made; only remarks about possibly existing relationships can be made (Lau, 2017). In addition, the retrospective self-report nature of the survey makes it vulnerable to recall bias, where questions rely on the participant's ability to remember events, approximate dates, and length of time (e.g., when tinnitus started, COVID impacts or experience, duration of noise exposure). Consequently, because some tinnitus symptoms (e.g., loudness) and distress levels can fluctuate (Schlee, 2016), answers received from the respondent may be heavily dependent on how they feel or what they can recall at the time of filling out the survey. Furthermore, there is evidence that an individual's desire for control can change over time (Burger & Solano, 1994) and under varying conditions (Suls & Mullen, 1981; Logan et al., 1991). In health-related chronically stressful situations like tinnitus, where control over the situation or outcome is improbable, it becomes a beneficial adaptive response to eventually stop striving for control and to relinquish it (Heckhausen et al., 2013; Fritz & Gallagher, 2020). To investigate if the data in this study could be affected by this phenomenon, I ran a t-test between DCS scores of those who had tinnitus vs. those who did not have tinnitus (Figure 9). The results of this t-test showed a significant difference in the means (t(47) = 2.5, p = .016) indicating that those without tinnitus had a higher desire for control (M = 105.89) than those who had tinnitus (M = 99.81). Hence, it is possible that some *desire for control* levels amongst those with tinnitus were previously higher; however, no pre- and post-values were collected for comparison in this cross-sectional study.



Although many efforts were made to gather Canada-wide data, because this was a master's thesis, data gathering time-constraints limited the number of contacts that could be initiated in each province, as well as time for information to reach potential participants. As a result, there is a large proportion of the data coming from participants in Ontario, where this study originated. Similarly, though efforts were made to include data from a diverse set of the population, the bulk of respondents self-identified as white. Given this experience, it is my belief that with enough time and support from relevant organizations (i.e., Canadian Armed Forces, hospitals and/or audiology clinics), better diversity of respondents could be achieved. With the benefit of hindsight, I would have extended the data collection time to six months, instead of two. Finally, because the survey was accessible via an internet link, it is possible that some participants accessed the study from other countries (such as the U.S.A) and claimed to live in Canada.

A significant limitation for tinnitus research is the inability to capture some key pieces of objective auditory data via an online survey. No consistent, valid, and reliable way to capture the psychoacoustic properties of tinnitus through sound matching (e.g., pitch, loudness, sound characteristics, ability to mask, presence of any residual inhibition) could be found that would not be impacted by the diversity of technology available to respondents (e.g., phones, desktops, headphones, earbuds). Similarly, audiological assessments and comorbidities (e.g., degree of hearing loss, any damage to the auditory system) could not be reliably captured by the respondent without the assistance of an audiologist and/or ENT. Nonetheless, the research questions asked in this study could be answered without having these details, and self-reported descriptive data sufficed. Because

no audiological tests were included with this data, any findings reported were limited to the tinnitus percept, to avoid potential confounding issues related to factors such as the degree of hearing loss. Self-reported impacts of hearing loss captured, however, were considered if they showed an influence on results, such as on levels of tinnitus distress.

CONCLUSION

This study found that the degree to which a person believes in their capacity to handle their tinnitus correlates with the level of distress they experience due to it. The results also suggest that the general DCS scale might not be suitable for predicting distress specifically related to tinnitus, aligning with findings from other studies on medical-related distress.

Future directions

In tinnitus research then, while the Self-Efficacy for Tinnitus Management Questionnaire (SETMQ) and the TFI Sense of Control subscale remain suitable for evaluating levels of self-efficacy and the *sense* of control, the development of a succinct scale specifically targeting the *desire for* control within a tinnitus context is recommended.

Using this new scale, it would be beneficial to retest the hypothesis in this study. To enhance participation among those with a strong desire for control, it may be advisable to present this questionnaire, along with the THI and the SETMQ independently, rather than integrating them with other questionnaires.

Finally, it would be interesting to run further exploratory analysis on the additional data collected in this study.

Postscript

As I write the finishing touches on my thesis and think about how much I've learned about tinnitus and research, I would like to complete the circle and attempt to answer the two questions I had before embarking on this journey.

Why the differences in tinnitus experience, levels of distress, and therapy effectiveness?

The heterogeneous nature of tinnitus seems to be the answer to this question. This encompasses characteristics and etiology, neural and cognitive mechanisms, as well as the psychological, emotional, and behavioural diversity of patients (De Ridder et al., 2021; Husain, 2021).

Why does mindfulness therapy work for so many people with tinnitus distress?

The effectiveness of mindfulness therapy may come from its ability to help patients to accept their tinnitus, relinquish their desire to control it, and thereby improve coping and facilitate habituation (Heckhausen et al., 2013; Fritz & Gallagher, 2020; Husain, 2021).

Considering the practical use of these questionnaires in a clinical setting, when a patient scores low on Self-Efficacy for Tinnitus Management, they could be provided with education on tinnitus and guided towards CBT counseling. Further, if a patient scores high on Desirability for Tinnitus Control, they could be directed towards mindfulness-based cognitive therapy.

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APPENDIX A

Table A1. List of Question Groups in Study

Section A	Introduction and Consent Form
Section B	Screening Questions
Section C	Demographics
Section D	Audiological and Otological (Hearing Health) History
Section E	TFI - Tinnitus Functional Index
Section F	NEQ - Noise Exposure Questionnaire
Section G	THI - Tinnitus Handicap Inventory
Section H	DCS - Desirability of Control Scale
Section I	Music
Section J	NGSE - New General Self-Efficacy Scale
Section K	SETMQ - Self-Efficacy for Tinnitus Management Questionnaire
Section L	HALFWAY POINT!
Section M	COVID-19 Pandemic
Section N	THQ - Tinnitus Handicap Questionnaire
Section O	DASS42 - Depression Anxiety Stress Scales
Section P	PSS - Perceived Stress Scale
Section Q	SUQ - Substance Use Questionnaire
Section R	IHS - Inventory of Hyperacusis Symptoms
Section S	TRQ - Tinnitus Reaction Questionnaire

Section T	MHQ - Medical History Questionnaire
Section U	Medications
Section V	Consent for Communication

APPENDIX B

LimeSurvey Full Questionnaires





Yes

No

Welcome to McMaster University's Tinnitus Survey 2022.

You will be asked a series of questions about you and your tinnitus experience. Some answers may need to rely on your memory.

Please answer the following questions as honestly as possible and to the best of your abilities.

As this is a long survey, please feel free to take breaks. ??

Section A: Introduction and Consent Form

Below is what you should know about this study before you agree to participate.

For more details, click on the highlighted Letter of Information below.

Introduction

Tinnitus is a persistent ringing or hissing sound that is heard in one's head when no external sound is present. There is currently not much data on Canadians who suffer from tinnitus. The purpose of this study is to collect extensive data about Canadians who experience tinnitus, and to use that data for immediate and future tinnitus-related study and analysis. Canadians over the age of 18 who experience tinnitus are eligible to participate in this study. Adults who do not experience tinnitus may also participate for comparison purposes. You are invited to take part in this study. This research is being done by Keiko Gutierrez for a master's thesis project under the supervision of Dr. Ian C. Bruce. To learn more about this survey and the research study, particularly in terms of any associated risks or harms associated with the survey, how confidentiality and anonymity will be handled, withdrawal procedures, and how to obtain information about the survey's results, please read the accompanying Letter of Information. This online survey should take approximately 1 to 2 hours to complete (depending on your individual circumstances). Your participation in this study is voluntary and appreciated. If you decide to be part of the study, you can stop (withdraw) from the survey at any time, even after giving consent. You may quit participating in the study at any time by selecting the "Exit and clear survey" button. Doing so, will delete all the data you have entered up to that point. You may also Pause the survey at any time and continue later. This survey is part of a study that has been reviewed and cleared by the McMaster Research Ethics Board (MREB). The MREB protocol number associated with this survey is MREB 5781. You are free to complete this survey or not. If you have any concerns or questions about your rights as a participant or about the way the study is being conducted, please contact: McMaster Research Ethics Secretariat Telephone 1-(905) 525-9140 ext. 23142 c/o Research Office for Administration, Development and Support (ROADS) E-mail: ethicsoffice@mcmaster.ca

A1. Consent to Participate Having read the above, I understand that by selecting the "Yes" option below, I agree to take part in this study under the terms and conditions outlined in the accompanied Letter of Information.



Section B: Screening Questions

Before we begin, we need to make sure that you are part of our target audience.

B1. In which Canadian province/territory do you live?

D1.	in which Canadian province/territory do you nve?		
	Alberta		
	British Columbia		
	Manitoba		
	New Brunswick		
	Newfoundland & Labrador		
	Northwest Territories		
	Nova Scotia		
	Nunavut		
	Ontario		
	Prince Edward Island		
	Quebec		
	Saskatchewan		
	Yukon		
	I don't live in Canada		
B2.	Are you 18 years of age or older?		
	Yes		
	No		
Section C: Demographics			
First, we	will ask you some basic questions about you.		
Your ans	Your answers will allow us to view the data through various demographic lenses and make sure we have diversity in respondents.		

C1. Please enter your age:

Age is an important considerat	tion fo	r tinni	tus.
]			

C2. What is your Race/Ethnicity?

(Check all that apply)

We ask this to monitor our respondent diversity and for another demographic lens.

Black, Afro-Descendent



Yes.	L
No.	
I prefer not to answer.	



Section D: Audiological and Otological (Hearing Health) History Here we will ask specific questions regarding your hearing and auditory system.			
D1.	Over the past year, have you had sound or noises (such as ringing, chirping or buzzing) in your head or in one or both ears that lasts for more than five minutes at a time?		
	(E.g. buzzing, chirping, clicking, hissing, pulsating, ringing, st	atic, tone)	
	Yes, most or all of the time.		
	Yes, some of the time.		
	No, not in the past year.		
	No, never.		
	I don't know or prefer not to answer.		
D2.	Is the sound/noise (tinnitus) constant or intermittent? Is the sound always there, or is it sometime	s not there?	
	Constant		
	Intermittent		
	I prefer not to answer.		
D3.	Over the past year, how much do these sounds/noises in your head or ears (tinnitus) worry, annoy, or upset you when they are at their worst?		
	Severely		
	Moderately	\square	
	Slightly		
	Not at all.		
	I don't know/Prefer not to answer.		
D4.	Over the past year, have you seen your family doctor, an audiologist, or a healthcare professional at a clinic or hospital about problems with sound/noises in your head or ears (tinnitus)?		
	Yes, 5 or more visits.		
	Yes, from 2 to 4 visits.		
	Yes, just one visit.	Ļ	
	Not at all.		
	I don't know/Prefer not to answer.		
D5.	Approximately how long have you had tinnitus?		
	(Approximately how long have you heard the sound/noise in	your head.)	
	Years		
	Months		

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5.	Are you able to change your tinnitus (volume, tone, etc.) by clenching your teeth, moving your head, neck, jaw, or eyes, or by flexing your facial muscles?	
	Yes	
	No	
	I don't know/Prefer not to answer.	
7.	In which ear do you hear the sound/noise?	
	Right	
	Left	
	Both or Centre	
	I prefer not to answer.	
8.	If both, in which ear is the tinnitus louder?	
	Right	
	Left	
	Same/Centre	
	I don't know/Prefer not to answer.	
).	Sound Quality: What does your tinnitus sound like?	
	Click	
	Crackle/Crunch	
	Crickets/Cicadas	
	Hiss	
	Hum	
	Multi-tonal	
	Tone/Ring	
	Pulse	
	Static	
	Other	
	Other	•

D10.	Does your tinnitus fluctuate in volume (increase and/or decrease) over the course of one or more days?	
	Yes	
	No	
	I don't know/Prefer not to answer.	
D11.	Does your tinnitus fluctuate in pitch (increase and/or decrease) over the course of one or more days?	
	Yes	
	No	
	I don't know/Prefer not to answer.	

D12.

Please indicate which, if any, of the Tinnitus treatments listed below you have tried in the past.

For those you have tried, please further indicate whether you found them helpful or not.

DID YOU TRY?

	I prefer
	Yes No toanswer
Acupuncture	······
Chiropractor	······
Cognitive Behavioural Therapy (CBT)	
Ear drops	
Fractal Music/Tones (Zen Hearing Devices)	
Hearing Aids	······
Hearing Aids + Tinnitus Masker	······
Herbal Medications	······
Mindfulness Meditation	······
Neuromonics	······
Noise maker/White noise	······
Sound Machine	
TENS Treatment (Trans-Electrical Nerve Stimulation)	
Vagus Nerve Stimulation	



D13.

D14.

Please indicate which, if any, of the Tinnitus treatments listed below you have tried in the past.

For those you have tried, please further indicate whether you found them helpful or not.

IF SO, DID IT HELP?

	Yes, it Yes, it I don't No, it No, it helpeda helpeda I don't didn't made in lot. little know. help. worse.		
Acupuncture			
Chiropractor			
Cognitive Behavioural Therapy (CBT)			
Ear drops			
Fractal Music/Tones (Zen Hearing Devices)			
Hearing Aids			
Hearing Aids + Tinnitus Masker			
Herbal Medications			
Mindfulness Meditation			
Neuromonics			
Noise maker/White noise			
Sound Machine			
TENS Treatment (Trans-Electrical Nerve Stimulation)			
Vagus Nerve Stimulation			
Please briefly describe the situation in which you think you may have			

developed tinnitus. If you have no idea, leave this blank.

D15. Do you tend to get excessive cerumen (ear wax)?

Yes	
No	
	Г

I don't know/prefer not to answer.

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D16.	Do you currently have any difficulty with your hearing, such as listening to speech in a noisy situation?	
	Yes, cannot hear at all	
-	Yes, severe difficulty	
	Yes, moderate difficulty	
	Yes, slight difficulty	
	No difficulty	
	I prefer not to answer.	
D17.	Are you Right- or Left-handed?	
	Right	
	Left	
	Ambidextrous (both)	
	I prefer not to answer.	
D18.	Do any of your immediate family members have a history of tinnitus? Tinnitus is the perception of a sound/noise in your head, usually that nobody else	se can hear.
	Father	
	Mother	
	Sibling(s)	
	No.	
	I don't know/Prefer not to answer.	
D19.	Do any of your immediate family members have a history of hearing loss?	
	Father	
	Mother	
	Sibling(s)	
	No.	
	I don't know/Prefer not to answer.	
D20.	Do you have a history of Head/Neck Injury?	
	Yes	
	No	
	I don't know/Prefer not to answer.	
D21.	Please specify which type of Head/Neck Injury. (Select all that apply.)	
	Car accident	

Concussion	
Fall	
Motorcycle accident	
Traumatic Brain Injury (TBI)	
Whiplash	
I don't know/prefer not to answer.	
Other	

Other

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D22. Please indicate the severity of your concussion.

If you've had more than one, please select the most severe one.

	Mild	
	Moderate	
	Severe	
	I don't know/Prefer not to answer.	
D23.	Approximately how long ago was your concussion?	
	Years	
	Months	
D24.	Please indicate the severity of your TBI.	
	If you've had more than one, please select the most	severe one.
	Mild	
	Moderate	
	Severe	
	I don't know/Prefer not to answer.	
D25.	Approximately how long ago was your TBI?	
	Years	
	Months	

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D26.	Do you have, or have you had, any of the following otol	ogic cor	ndition	s:	
		Current ly	In the Past	No	I prefer not to answer
	Dizziness	·····			
	Ear Infections	·····			
	Ear Pain	·····			
	Ear Drainage				
	Ear Surgery				
	Hearing Loss				
	Ménière's Disease				
	Vestibular Schwannoma/ Acoustic Neuroma				
	Other				
027.	Please specify the "OTHER" otological condition(s) here	re.			
		Y	es, in my	y left ear.	
		Ye	es, in my	right ear. ooth ears.	
	I don't		es, in my Yes, in t	right ear. both ears. No.	
129		Ye know/Pre	es, in my Yes, in t	right ear. both ears. No.	
29.	I don't Have you ever had Mastoidectomy Surgery?	know/Pre	es, in my Yes, in t efer not to	right ear. ooth ears. No. o answer.	
029.		know/Pre Ye	es, in my Yes, in t efer not to es, on my	right ear. ooth ears. No. o answer. left side.	
29.		know/Pre Ye Yes	es, in my Yes, in t efer not to es, on my , on my r	right ear. ooth ears. No. o answer. left side. ight side.	
29.		know/Pre Ye Yes	es, in my Yes, in t efer not to es, on my , on my r	right ear. both ears. No. o answer. left side. ight side. oth sides.	
29.		know/Pre Ye Yes	es, in my Yes, in t efer not to es, on my , on my r	right ear. ooth ears. No. o answer. left side. ight side.	
929.	Have you ever had Mastoidectomy Surgery?	know/Pre Ye Yes	es, in my Yes, in t efer not to es, on my , on my r Yes, on bo	right ear. poth ears. No. o answer. left side. ight side. oth sides. No.	
	Have you ever had Mastoidectomy Surgery?	know/Pre Ye Yes	es, in my Yes, in t efer not to es, on my , on my r Yes, on bo	right ear. poth ears. No. o answer. left side. ight side. oth sides. No.	
	Have you ever had Mastoidectomy Surgery? I don't	know/Pre Yes Yes N know/Pre	es, in my Yes, in t efer not to es, on my , on my r Yes, on bo	right ear. poth ears. No. o answer. left side. ight side. oth sides. No.	
	Have you ever had Mastoidectomy Surgery? I don't	know/Pre Ye Yes Y know/Pre	es, in my Yes, in t efer not to es, on my , on my r Yes, on bo efer not to Yes, in my	right ear. poth ears. No. o answer. left side. ight side. oth sides. No. o answer.	
	Have you ever had Mastoidectomy Surgery? I don't	know/Pre Ye Yes Y know/Pre	es, in my Yes, in t efer not to es, on my , on my r Yes, on bo efer not to Yes, in my	right ear. poth ears. No. o answer. left side. ight sides. oth sides. No. o answer. y left ear.	
	Have you ever had Mastoidectomy Surgery? I don't	know/Pre Ye Yes Y know/Pre	es, in my Yes, in t efer not to es, on my , on my r Yes, on bo efer not to Yes, in my	right ear. poth ears. No. o answer. left side. ight side. oth sides. No. o answer. y left ear. right ear. poth ears.	
029.	Have you ever had Mastoidectomy Surgery? I don't Have you ever had Tympanoplasty/ Ear Drum Repair?	know/Pre Ye Yes Y know/Pre	es, in my Yes, in t efer not to es, on my r des, on bo efer not to Ves, in my Yes, in my	right ear. poth ears. No. o answer. left side. ight side. oth sides. No. o answer. y left ear. right ear. poth ears. No.	

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D32.



D31. Have you ever had Other Ear Surgery not mentioned above?

Yes, in my left ear.	
Yes, in my right ear.	
Yes, in both ears.	
No.	
I don't know/Prefer not to answer.	
Please specify your OTHER surgery here.	

Section E: TFI - Tinnitus Functional Index

These questions are specifically about how tinnitus affects your daily life.

Please read each question carefully and pay attention to timelines being asked about.

Also note what each end of the scale (0 - 10) means for each question.

E1. Over the PAST WEEK ...

0 1 2 3 4 5 7 8 9 10 6 What percentage of your time awake were you consciously AWARE OF your How STRONG or LOUD was your What percentage of your time awake were you ANNOYED by your tinnitus?None of the E2. **Over the PAST WEEK...** Think of the last approximately 7 days when answering these questions. 0 9 1 2 3 4 5 6 7 8 10 Did you feel IN CONTROL in regard to your tinnitus?Very much in control | Never in How easy was it for you to COPE with your tinnitus?Very easy to cope | Impossible How easy was it for you to IGNORE your tinnitus?Very easy to ignore | Impossible to E3. Over the PAST WEEK, how much did your tinnitus interfere with... 0 1 10 Your ability to CONCENTRATE?Did not

Think of the last approximately 7 days when answering these questions.

	0 1 2 3 4 5 6 7 8 9 10
Your ability to THINK CLEARLY?Did not	
Your ability to FOCUS ATTENTION on other things besides your tinnitus?Did not	
E4. Over the PAST WEEK	
	0 1 2 3 4 5 6 7 8 9 10
How often did your tinnitus make it difficult to FALL ASLEEP or STAY ASLEEP?Never	
How often did your tinnitus cause you difficulty in getting AS MUCH SLEEP as you needed?Never had difficulty Always had	
How much of the time did your tinnitus keep you from SLEEPING as DEEPLY or as PEACEFULLY as you would have	
E5. Over the PAST WEEK, how	much has your tinnitus interfered with
Your ability to HEAR CLEARLY?Did not	0 1 2 3 4 5 6 7 8 9 10
Your ability to UNDERSTAND PEOPLE who are talking?Did not	
Your ability to FOLLOW CONVERSATIONS in a group or at meetings?Did not interfere Completely	
E6. Over the PAST WEEK, how	much has your tinnitus interfered with
	0 1 2 3 4 5 6 7 8 9 10
Your QUIET RESTING ACTIVITIES?Did	
Your ability to RELAX?Did not	
Your ability to enjoy "PEACE AND QUIET"?Did not interfere lCompletely	
E7. Over the PAST WEEK, how a	much has your tinnitus interfered with
	0 1 2 3 4 5 6 7 8 9 10
Your enjoyment of SOCIAL ACTIVITIES?Did not interfere Completely	
Your ENJOYMENT OF LIFE?Did not	
Your RELATIONSHIPS with family,	
friends and other people?Did not interfere	
How often did your tinnitus cause you to have difficulty performing your WORK OR OTHER TASKS, such as home maintenance, school work, or caring for children or	
,	

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E8. Over the PAST WEEK		
	0 1 2 3 4 5 6 7 8 9 10	
How ANXIOUS or WORRIED has your tinnitus made you feel?Not at all anxious or		
How BOTHERED or UPSET have you been because of your tinnitus?Not at all bothered or		
How DEPRESSED were you because of your tinnitus?Not at all depressed Extremely		

Section F: NEQ - Noise Exposure Questionnaire

Please answer the following questions about yourself, your hearing, and any noise you may have been around *during a typical year*.

F1. Outside of a paid job, how often did you use power tools, chainsaws, or other shop tools?

	Never	
	Every few months	
	Monthly	
	Weekly	
	Daily	
	I prefer not to answer.	
F2.	If you used power tools, on average, how many hours did each time/session last?	
	8 hours or more	
	4 hours up to 8 hours	
	1 hour up to 4 hours	
	Less than 1 hour	
	I prefer not to answer	
F3.	If you used power tools, how often did you wear earplugs or earmuffs during this activity?	

I.e., Hearing protection	
Never.	
Sometimes.	
Always.	
I prefer not to answer.	

E.g., For a hobby or recreationally.

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F4.	Outside of a paid job, how often did you drive heavy equipment or use loud machinery (such as tractors, trucks, or farming or lawn equipment like mowers/leaf blowers)?	
	Never	
	Every few months	
	Monthly	
	Weekly	
	Daily	
	I prefer not to answer.	
F5.	If you drove/used loud machinery, on average, how many hours did each time/session last?	
	8 hours or more	
	4 hours up to 8 hours	
	1 hour up to 4 hours	
	Less than 1 hour	
	I prefer not to answer.	
F6.	If you drove / used machinery, how often did you wear earplugs or earmuffs during this activity?	
	Never	
	Sometimes	
	Always	
	I prefer not to answer.	
F7.	How often did you attend car / truck races, commercial / highschool sporting events, music concerts / dances or any other events with amplified public announcement (PA) / music systems?	
	Never	
	Every few months	
	Monthly	
	Weekly	
	Daily	
	I prefer not to answer.	

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F8.	If you attended these events, on average, how many hours did each time/session last?	
	8 hours or more	
1	4 hours up to 8 hours	
	1 hour up to 4 hours	
	Less than 1 hour	
	I prefer not to answer.	
F9.	If you attended these events, how often did you wear earplugs or earmuffs during this activity?	
	Never	
	Sometimes	
	Always	
	I prefer not to answer.	
F10.	How often did you ride / operate motorized vehicles such as motorcycles, jet skis, speed boats, snowmobiles, or four-wheelers?	
	Never	
	Every few months	
	Monthly	
	Weekly	
	Daily	
	I prefer not to answer.	
F11.	If you rode motorized vehicles, on average, how many hours did each time/session last?	
	8 hours or more	
	4 hours up to 8 hours	
	1 hour up to 4 hours	
	Less than 1 hour	
	I prefer not to answer.	
F12.	If you rode motorized vehicles, how often did you wear earplugs or earmuffs during this activity?	
	Never	
I	Sometimes	
	Always	
	I prefer not to answer.	
•	76	

Č Lime	eSurvey			
F13. How often did you ride in or pilot small aircraft / private airplanes?				
	Never			
	Every few months			
	Monthly			
	Weekly			
	Daily			
	I prefer not to answer.			
F14.	If you flew airplanes, on average, how many hours did each time/session last?			
	8 hours or more			
	4 hours up to 8 hours			
	1 hour up to 4 hours			
	Less than 1 hour			
	I prefer not to answer.			
F15.	If you flew airplanes, how often did you wear earplugs or earmuffs during this activity?			
	Never			
	Sometimes			
	Always			
	I prefer not to answer.			
F16.	How often were you around or did you shoot firearms such as rifles, pistols, shotguns, etc.?			
	Never			
	Every few months			
	Monthly			
	Weekly			
	Daily			
	I prefer not to answer.			
F17.	If you were around / shot firearms, on average, how many shots did you fire each time/session?			
	Shotgun/rifle shots per session			
	Pistol shots per session			

F18.	18. If you were around / shot firearms, how often did you wear earplugs or earmuffs while shooting?				
		Never			
1		Sometimes			
		Always			
		I prefer not to answer.			
F19.	How often did you play a musical instrument?				
		Never			
		Every few months			
		Monthly			
		Weekly			
		Daily			
		I prefer not to answer.			
F20.	If you played a musical instrument, on average, ho each time/session last?	w many hours did			
		8 hours or more			
		4 hours up to 8 hours			
		1 hour up to 4 hours			
		Less than 1 hour			
		I prefer not to answer.			
F21.	If you played an instrument, how often did you we earmuffs while playing?	ar earplugs or			
		Never			
		Sometimes			
		Always			
		I prefer not to answer.			
F22.	Please tell us what musical instrument(s) you playe	ed (up to 3): you referring to, when answering the previou	s questions?		
	Instrument 1				
	Instrument 2				
I	Instrument 3				

		IIIIIIIIII	
F23.	F23. How often did you listen to music, radio programs, etc. using personal headsets, earbuds, or headphones?		
	Never		
•	Every few months		
	Monthly		
	Weekly		
	Daily		
	I prefer not to answer.		
F24.	On average, how many hours did each time/session last?		
	8 hours or more		
	4 hours up to 8 hours		
	1 hour up to 4 hours		
	Less than 1 hour		
	I prefer not to answer.		
F25.	Other than music concerts and headphone use, how often did you listen to music, radio programs, etc. from audio speakers in a car or at home?		
	Never		
	Every few months		
	Monthly		
	Weekly		
	Daily		
	I prefer not to answer.		
F26.	On average, how many hours did each time/session last?		
	8 hours or more		
	4 hours up to 8 hours		
	1 hour up to 4 hours		
	Less than 1 hour		
	I prefer not to answer.		



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F33.	If yes, please describe the noisy job(s):	
F34.	If you worked a noisy job, please estimate the number of hours you worked in a typical non-summer week:	
F35.	If you worked a noisy job during the school year, did your employer give you earplugs or earmuffs to wear at work?	
	Yes No I prefer not to answer.	
F36.	How often did you wear earplugs or earmuffs when around loud noise at this noisy job?	
	Never	
	Always I prefer not to answer.	
F37.	How often do you use a hair dryer to dry your hair?	reationally.
	Never Every few months	
	Monthly	
	Weekly Daily	

I prefer not to answer.



F38. How often do you use an electric hand dryer to dry your hands (e.g. at school or at work)?



Section G: THI - Tinnitus Handicap Inventory

The purpose of this questionnaire is to identify difficulties that you may be experiencing because of your tinnitus.

Please read the questions carefully. While some questions may seem familiar, the nuances are different.

G1. Please answer every question as best as you can and do not skip any questions.

	Yes mes
Because of your tinnitus, is it difficult for you to concentrate?	
Does the loudness of your tinnitus make it difficult for you to hear people?	·····
Does your tinnitus make you angry?	
Does your tinnitus make you feel confused?	
Because of your tinnitus, do you feel desperate?	
Do you complain a great deal about your tinnitus?	
Because of your tinnitus, do you have trouble falling asleep at night?	
Do you feel as though you cannot escape your tinnitus?	
Does your tinnitus interfere with your ability to enjoy your social activities (such as going	
Because of your tinnitus, do you feel frustrated?	
Because of your tinnitus, do you feel that you have a terrible disease?	·····
Does your tinnitus make it difficult for you to enjoy life?	
Does your tinnitus interfere with your job or household responsibilities?	
Because of your tinnitus, do you find that you are often irritable?	
Because of your tinnitus, is it difficult for you to read?	
Does your tinnitus make you upset?	
Do you feel that your tinnitus problem has placed stress on your relationships with	

er not to answer.

Someti

No





Do you find it difficult to focus your attention away from your tinnitus and on other

Do you feel that you have no control over your tinnitus?

Because of your tinnitus, do you often feel tired?

Because of your tinnitus, do you feel depressed?

Does your tinnitus make you feel anxious?

Do you feel that you can no longer cope with your tinnitus?

Does your tinnitus get worse when you are under stress?

Does your tinnitus make you feel insecure?

	Someti	
Yes	mes	No
·····		
·····		
·····		
·····		

Section H: DCS - Desirability of Control Scale

Next you will find a series of statements. Please read each statement carefully and respond to it by expressing the extent to which you believe the statement applies to you. For all items, a response from 1 to 7 is required. Use the number that best reflects your belief when the scale is defined as follows:

- 1 = The statement does not apply to me at all
- 2 = The statement usually does not apply to me
- 3 = Most often, the statement does not apply
- 4 = I am unsure about whether or not the statement applies to me, or it applies to me about half the time
- 5 = The statement applies more often than not
- 6 = The statement usually applies to me
- 7 = The statement always applies to me

H1. As honestly as possible, for all items below, please reply from 1 to 7.

	Not at Unsure			Alw				
	all1	2	3	50/504	5		6	7
I prefer a job where I have a lot of control over what][
I enjoy political participation because I want to have][
I try to avoid situations where someone else tells me][
I would prefer to be a leader than a follower.][
I enjoy being able to influence the actions of others.	·][·····	
I am careful to check everything on an automobile][
Others usually know what is best for me.][
I enjoy making my own decisions.][
I enjoy having control over my own destiny.][



	Not at	Unsure	Always
	all1 2	3 50/504 5	6 7
I would rather someone else take over the leadership	·····		
I consider myself to be generally more capable of	·····		
I'd rather run my own business and make my own	·····		
I like to get a good idea of what a job is all about	·····		
When I see a problem, I prefer to do something	·····		
When it comes to orders, I would rather give them			
I wish I could push many of life's daily decisions off			
When driving, I try to avoid putting myself in a situation where I could be hurt by another person's			
I prefer to avoid situations where someone else has	·····		
There are many situations in which I would prefer only one choice, rather than having to make a	·····		
I like to wait and see if someone else is going to solve a problem so that I don't have to be bothered	·····		

Section I: Music

LimeSurvey

These next series of questions are related to your experience listening/hearing music.

I1. How often do you listen to music?

	Not often at all.	
	Sometimes.	
	Very often.	
	I prefer not to answer.	
I2. What kind of music do you generally list	en to?	
	Calming, soothing or relaxing.	
	Both calming and energizing.	
	Energizing.	
	Very energizing.	
	Whatever is playing. I do not select.	
	I prefer not to answer.	

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I3.	I3. Have you ever attended, or performed in, live music concerts?		
	No, never.		
	Yes, less than 5 times.		
	Yes, 5-10 times.		
	Yes, more than 10 times.		
	I prefer not to answer.		
I4.	Do you sing and/or play a musical instrument?		
	No, never.		
	Not recently, but I have in the past.		
	Yes, currently.		
	I prefer not to answer.		
15.	Approximate years of musical playing experience (either formal lessons, regular practice, or performance):		
	Less than 1 year.		
	1 to 3 years.		
	3 to 6 years.		
	6 to 10 years.		
	10 to 20 years.		
	Over 20 years.		
	I prefer not to answer.		
I6.	Please select all instruments that you play or have played:		
	Voice - medium-to-high register (e.g., alto, mezzo-soprano, soprano)		
	Voice - medium-to-low register (e.g., bass, baritone, tenor)		
	Bowed Strings - High (e.g. violin, viola)		
	Bowed Strings - Low (e.g., cello, double/upright bass)		
	Brass (e.g., trumpet, trombone)		
	Drums		
	Electric Bass		
	Electric Guitar		
	Electronic		
	Guitar (Acoustic)		
	Harp (strings)		

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Harmonica	
Percussion	
Piano / Keyboards	
Woodwind (e.g., flute, clarinet, saxophone)	
I prefer not to answer.	
Other	

Other	

LimeSurvey

I7. Do you or have you played music with others (i.e., band, orchestra, choir)?

	No, never.	
	Yes, in the past.	
	Yes, currently.	
	I prefer not to answer.	
I8.	Please specify which types of musical groups you have participated in:	
	Band (e.g., jazz, pop, rock, country)	
	Choir	
	Orchestra	
	I prefer not to answer.	
	Other	
	Other	•

19. Are you, or have you ever been, a professional Disc Jockey (D.J.)?

	٦
Yes, in the past.	
Yes, currently.]
I prefer not to answer.]

Č Lin	neSurvey	
I10.	Do you <i>listen</i> to music professionally (e.g., sound engineer, producer, sound tech, choir director, conductor)?	
	No.	
1	Yes. (Currently or in the past.)	
	I prefer not to answer.	
I11.	Please specify the professional listening job(s) you are referring to:	
	Choir Director	
	Conductor (Orchestral)	
	Instrument Technician	
	Radio Broadcaster	
	Record Producer	
	Sound/Audio Engineer	
	Sound/Audio Technician	
	Other	
	Other	•

I12. For how many total years have you been professionally listening to music?

	music:	
	Less than 1 year.	
	1 to 5 years	
	5 to 10 years	
	10 to 20 years	
	Over 20 years.	
	I prefer not to answer.	
I13.	Do you, or have you, worked elsewhere in the live music industry, not previously mentioned here? (E.g., bouncer, security, stage crew, road crew, lights specialist, instrument tech.)	
	No.	
	Yes, in the past. (Please specify in the comment box.)	Ļ
	Yes, currently. (Please specify in the comment box.)	
	I prefer not to answer.	

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I14. How long did you do this kind of work for?

	Less than 1 year.	[-]
	1 to 5 years.	
	5 to 10 years.	
	Over 10 years.	
	I prefer not to answer.	
I15.	What platform or device do you use to listen to music?	
	Online video channels (e.g., YouTube, Vimeo)	
	Streaming music service (e.g., Spotify, AppleMusic, etc.)	
	Physical personal music collection (e.g. CDs, Vinyl)	
	Radio, TV	
	Live (e.g., amplifiers, PA system)	
	I prefer not to answer.	
	Other	

Other

I16. Does your tinnitus negatively affect your ability to do your music-related work well?

N/A - Not applicable.	
No.	
Yes, to a small degree.	
Yes, to a large degree.	
I prefer not to answer this question.	

Č Lim	eSurvey	
I17.	Do you think that music may have played a role in your tinnitus experience?	
	(If so, please select Yes, and provide your comments in the space provided.)	
	No	
	Yes	
	I prefer not to answer this question.	

I18. Are there any instruments that, when you play or hear them, cause you to perceive your tinnitus more?

If so, please select Yes, and list them in the space provided.

No.	Ļ
Yes. (Please list them in the space provided.)	
I prefer not to answer this question.	

Section J: NGSE - New General Self-Efficacy Scale

Self-efficacy is defined by the APA Dictionary of Psychology as, "an individual's subjective perception of their capability to perform in a given setting or to attain desired results."

This questionnaire will ask you about your sense of general Self-Efficacy.

J1. Please read the statements below and indicate your level of agreement. 1: strongly *disagree* to 5: strongly *agree*.

	Strongly				Strongly	
	disagree1	2	3	4	agree5	
I will be able to achieve most of the goals that I have set for myself.	·····					





When facing difficult tasks, I am certain that I will accomplish them. In general, I think that I can obtain outcomes that are important to me. I believe I can succeed at most any endeavor to which I set my mind. I will be able to successfully overcome many challenges. I am confident that I can perform effectively on many different tasks.

> Compared to other people, I can do most tasks very well. Even when things are tough, I can perform quite well.



Section K: SETMQ - Self-Efficacy for Tinnitus Management Questionnaire

These questions ask about your perceived ability to manage your *tinnitus* in various situations.

If you have never been in these situations, then make your best guess about how well you would do.

Given what you know right now, indicate how confident you are that you could do the things described below.

K1. For the questions below, please indicate how certain you are that you can do this *right now*.

0%: I cannot do this at all - 100%: I am certain I can do this

100

	0% 10% 20% 30% 40% 50% 60% 70% 80% 90% %
I can think of my tinnitus as a sound I do not	
I can ignore my tinnitus when reading in a	
I can ignore my tinnitus when performing quiet chores such as straightening up a room in	
I can ignore my tinnitus when I work on a	
I can ignore my tinnitus when listening to	
I can ignore my tinnitus when watching TV.	
I can ignore my tinnitus when shopping.	
I can ignore my tinnitus when working on my	
I can ignore my tinnitus when driving in light	
I can ignore my tinnitus when driving in heavy	
I can ignore my tinnitus when I am working.	
I can ignore my tinnitus when I try to go to	
I can ignore my tinnitus when I try to go take a	
I can ignore my tinnitus if I wake up in the	
I can perform relaxation exercise to help me	
I can manage my tinnitus.	



														100
I can manage my anger when I hear my	0%	10%	20%	30	% 4	10%	50%	60%	67 гг	0%	80%	5 90	% 7 [%
				·····	[·····	}[] [····	}····∟ ı	[
I can manage my frustration when I hear my												·····	[
I can manage becoming irritated when I hear	·····][·····][
I can manage my stress level when I hear my					····-[][·][
I can manage feelings of fear when I hear my][][·][
I can manage feelings of anxiety when I hear][][·][
I can manage feelings of nervousness when I][][·][
I can manage negative thoughts when I hear][][·][
I can think of my tinnitus as a neutral sound][][][][
I can help people in my workplace despite][][][][
I can manage to have a positive self-image	<u> </u>][][}[][
I can feel that my senses are reliable even					[][}F	7[
I can be a contributing member of society][}][
I can carry out conversations with one other][][·][
I can carry out conversations with a small][][·][
I can have a conversation on the telephone][][·][
I can communicate in order to complete my][·][
typical work responsibilities even when I hear														
I can understand the difference between my				·····									[
I can understand the results of my hearing test.												·····	{	
I can understand the changes to my hearing][][·][
I can understand that my hearing loss is not][][][][
I can use hearing aids or other assistive devices to help reduce communication problems][][][][
I can use a masking device to help reduce my tinnitus without reducing my ability to][][]][
I can use a sound generating device such as a fan or noise machine to help me sleep when I][][][][





Section L: Yay! You have reached the HALFWAY POINT!

Do you need a BREAK or can you KEEP GOING?

UPON COMPLETION of the survey, you will receive a confirmation email with some Canadian support resources which may assist you.

You may now KEEP GOING by hitting NEXT

OR

you can choose to TAKE A BREAK by hitting Resume Later on the top right of your screen. You can then sign back in later to continue. Remember that you may do this at any point in the survey.

If you wish to quit the study altogether, select Exit and clear survey and all your answers will be deleted.

Thanks again for helping me to complete my thesis, and for contributing to Tinnitus Research in Canada!

-- Keiko

Section M: COVID-19 Pandemic

This series of questions gathers information about your experience with the COVID-19 Pandemic.

M1. Did you notice a change in your tinnitus during the pandemic?



M2. Please comment on any changes to your tinnitus perception during the pandemic.

Enter up to 300 characters.

M3. Have you had COVID-19?



M4. If yes, please list the variant(s) that you have had.

If you said "more than once" in the previous question, please specify the variants for the first 3 times.



Lin	neSurvey	
M5.	After having COVID-19, did you notice a	change in your tinnitus?
		No
		Yes, I noticed it less.
		Yes, I noticed it more.
		I prefer not to answer.
МС	Have you been versionated against COVID	
M6.	Have you been vaccinated against COVID	
		No.
		Yes.
		I prefer not to answer.
M7.	Please select the number of doses for each	ı vaccine that you have received.
		No 0 1 2 3 4 Answer
	AstraZeneca	
	Janssen Johnson & Johnson	
	Medicago Covifenz	
	Moderna Spikevax	
	Novavax Nuvaxovid	
	Pfizer-BioNTech	
	Other	
M8.	Did you notice a change in your tinnitus a vaccine?	fter having a COVID-19
		No.
		Yes, I noticed it LESS.
		Yes, I noticed it MORE.
		I prefer not to answer.
M9.	Feel free to comment on any changes you	perceived to your Tinnitus

after vaccination here.

Enter up to 300 characters.


M10. During the COVID-19 pandemic, were you responsible for the care of another person?

No.	
Yes, sole care provider of a child/children.	Ļ
Yes, joint care provider of a child/children.	\square
Yes, sole care provider of an adult(s).	Ļ
Yes, joint care provider of an adult(s).	
I prefer not to answer.	

M11. Please indicate any changes that you've experienced DURING THE **PANDEMIC:**

	Increas	Decrea
	e Sa	me se
Did your STRESS level change?]
Did your level of WORRY change?		
Did your level of FEAR change?]
Did your feelings of CONNECTEDNESS with other people change?		
Has your sense of CONTROL over your life changed?		
Have your episodes of LONELINESS changed?]
Have your feelings of OPTIMISM changed?	·····]
Has your FINANCIAL SECURITY changed?	······]

Section N: THQ - Tinnitus Handicap Questionnaire

This standard questionnaire assess the physical, emotional, and social consequences of tinnitus.

Please read the questions carefully. While some questions may seem familiar, the nuances are different.

N1. This questionnaire has 27 questions.

> For each statement below, use the slider to indicate agreement from 0 (Strongly disagree) to 100 (Strongly agree).

Please do not skip any questions.

0: Strongly disagree - 100: Strongly agree



My tinnitus has gotten worse over the years.

Tinnitus creates family problems.

I have support from my friends regarding my tinnitus.

I do not enjoy life because of tinnitus.







The general public does not know about the devastating nature of tinnitus.	
I am unable to follow conversation during meetings because of tinnitus.	
Tinnitus affects the quality of my relationships.	
I think I have a healthy outlook on tinnitus.	
I cannot concentrate because of tinnitus.	
Tinnitus causes me to avoid noisy situations.	
Tinnitus contributes to a feeling of general ill health.	
Tinnitus interferes with my ability to tell where sounds are coming from.	
Tinnitus makes me feel annoyed.	
I am unable to relax because of tinnitus.	
Tinnitus makes me feel insecure.	
Tinnitus makes me feel anxious.	
I feel frustrated frequently because of tinnitus.	
Tinnitus makes me feel tired.	
Tinnitus causes me to feel depressed.	
Tinnitus interferes with my speech understanding when listening to the television.	
Tinnitus has caused a reduction in my speech understanding ability.	
Tinnitus interferes with my speech understanding when talking with someone in a noisy room.	
I find it difficult to explain what tinnitus is to others.	
I complain more because of tinnitus.	
I have trouble falling asleep at night because of tinnitus.	
I feel uneasy in social situations because of tinnitus.	
Tinnitus causes stress.	



Section O: DASS42 - Depression Anxiety Stress Scales

A 42 question standardized scale to measure Depression, Anxiety and Stress as these can have an impact on tinnitus perception.

O1. Please read each statement and select a number 0, 1, 2, or 3, which indicates how much the statement applied to you *over the past week*.

There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all.
- 1 Applied to me to some degree, or some of the time.
- 2 Applied to me to a considerable degree, or a good part of time.
- **3** Applied to me very much, or most of the time.

	Not at Consid Very
	all0 Some1 erable2 much3
I found myself getting upset by quite trivial things.	
I was aware of dryness of my mouth.	
I couldn't seem to experience any positive feeling at all.	
I experienced breathing difficulty (e.g., excessively rapid breathing,	
I just couldn't seem to get going.	
I tended to overreact to situations.	
I had a feeling of shakiness (e.g., legs going to give way).	
I found it difficult to relax.	
I found myself in situations that made me so anxious I was most relieved when	
I felt that I had nothing to look forward to.	
I found myself getting upset rather easily.	
I felt that I was using a lot of nervous energy.	
I felt sad and depressed.	
I found myself getting impatient when I was delayed in any way (e.g., elevators,	
I had a feeling of faintness.	
I felt that I had lost interest in just about everything.	
I felt I wasn't worth much as a person.	
I felt that I was rather touchy.	
I perspired noticeably (e.g., hands sweaty) in the absence of high temperatures	



	Not at all0	Some1	Consid erable2	Very much3
I felt scared without any good reason.	····			
I felt that life wasn't worthwhile.				
I found it hard to wind down.				
I had difficulty swallowing.				
I couldn't seem to get any enjoyment out of the things I did.				
I was aware of the action of my heart in the absence of physical exertion (e.g.,	····			
I felt downhearted and blue.				
I found that I was very irritable.	····			
I felt that I was close to panic.	····			
I found it hard to calm down after something upset me.				
I feared that I would be "thrown" by some trivial but unfamiliar task.				
I was unable to become enthusiastic about anything.				
I found it difficult to tolerate interruptions to what I was doing.				
I was in a state of nervous tension.				
I felt I was pretty worthless.				
I was intolerant of anything that kept me from getting on with what I was doing.				
I felt terrified.				
I could see nothing in the future to be hopeful about.				
I felt that life was meaningless.				
I found myself getting agitated.				
I was worried about situations in which I might panic and make a fool of myself.				
I experienced trembling (e.g., in the hands).				
I found it difficult to work up the initiative to do things.				

LimeSurvey

Section P: PSS - Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month.

In each case, you will be asked to indicate how often you felt or thought a certain way.

Although some of the questions are similar, there are differences between them and you should treat each one as a separate question.

The best approach is to answer each question fairly quickly.

P1. For each question, choose from the given alternatives.

Never In the last month, how often have you been upset because of something In the last month, how often have you felt that you were unable to In the last month, how often have you felt nervous and "stressed"? In the last month, how often have you dealt successfully with irritating In the last month, how often have you felt that you were effectively In the last month, how often have you felt confident about your ability In the last month, how often have you felt that things were going your In the last month, how often have you felt that things were going your In the last month, how often have you found that you could not cope In the last month, how often have you been able to control irritations in In the last month, how often have you been angered because of things In the last month, how often have you found yourself thinking about In the last month, how often have you been able to control the way you In the last month, how often have you found yourself thinking about In the last month, how often have you been able to control the way you In the last month, how often have you felt difficulties were piling up so

I	Almost S		Fairly	
Never0 1	never1	mes2	often3	often4

Section Q: SUQ - Substance Use Questionnaire

Some substances have been found to contribute to or exacerbate tinnitus. We would like to identify any such correlations in this study.

Q1. Do you drink alcohol, or have you in the past?

No, never.	Ļ
Not currently, but I have in the past.	
Yes, I do.	
I prefer not to answer.	

Q2. Please indicate how much of the following drinks you have consumed within the *past 6 months*.

		1 to 5	6 to 15	16 to 25	Over 25	I prefer
		drinks/we	drinks/we	drinks/we	drinks/we	not to
	None	ek	ek	ek	ek	answer
Beer (1 drink = 12 oz.)	·····					
Liquor (1 drink = 1.5 oz.)	·····					
Wine $(1 \text{ drink} = 5 \text{ oz.})$	·····					
Caffeine (coffee, tea, energy drinks)						

Q3. Please indicate whether you use, have used, or have been exposed to tobacco/nicotine (including e-cigarettes).

No, never.
I do not consume, but am (or have been) regularly exposed (e.g., partner, roommates, or job).
Not currently, but I have in the past.
Yes, currently.
I prefer not to answer.

Q4. Please indicate which of the following products you consume or have consumed.



Č Lin	neSurvey				
Q5.	Q5. Please indicate the approximate number of cigarettes <i>per day</i> .				
	Less than 1 cigarette per day.				
	1 to 5 cigarettes.				
	More than 5 cigarettes but less than 20 (a pack).				
	20 cigarettes or 1 pack.				
	More than 20 cigarettes or 1 pack.				
	I prefer not to answer.				
Q6.	Please indicate the length of time that you have been smoking (or have smoked in the past).				
	Less than 1 year.				
	1 to 5 years.				
	5 to 10 years.				
	10 to 20 years.				
	Over 20 years.				
	I prefer not to answer.				
Q7.	How long has it been since you quit smoking?				
	Less than 1 year.				
	1 to 5 years.				
	5 to 10 years.				
	10 to 20 years.				
	Over 20 years.				
	I prefer not to answer.				
Q8.	Do you consume marijuana/cannabis?				
	No.				
	Not currently, but I have in the past.				
	Yes.				
	I prefer not to answer.				
Q9.	Please select which method(s) you use to consume cannabis.				
	Inhalation Smoking.				
	Inhalation Vaping.				
1	Oral Edibles, oils, tinctures, capsules				
	I prefer not to answer.				
1					

L

LimeSurvey	
Other	Other
0. Do you consume Psilocybin (Magi the past?	ic Mushrooms), or have you done so in
	No. No. Yes, I do.
1. Are there any other recreational d the past?	I prefer not to answer.
	No. No. Yes.
12. Please list up to 4 other recreation used.	I prefer not to answer.
	Drug 1: Drug 2:
	Drug 3: Drug 4:
	or recreational drug use may have akes it worse), please select ''Yes'' t box.
	No, I don't think so.
	Maybe.
	I prefer not to answer.



Section R: IHS - Inventory of Hyperacusis Symptoms

Hyperacusis, or increased sound sensitivity, is a condition that often coexists with tinnitus. This inventory of symptoms is used to measure hyperacusis.

R1. For each statement below, please select the answer that applies most to you.

There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Not at all.
- 1 A little.
- 2 Somewhat.
- 3 Very much so.

Compared to most people, common everyday sounds seem excessively loud to Sound can cause me pain and/or physical discomfort. Hearing sounds can make me feel stressed out. Hearing sounds can make me feel tense. Hearing sounds can make me feel angry. Hearing sounds can make me feel irritated. My sensitivity to sounds can make it difficult to cope. My sensitivity to sounds can make it difficult to concentrate. My sensitivity to sounds can make it difficult to relax. My sensitivity to sounds can make it difficult to relax. My sensitivity to sounds can make it difficult to sleep. My sensitivity to sounds can make it difficult to sleep. My sensitivity to sounds can make it difficult to sleep. My sensitivity to sounds can make it difficult to sleep. My sensitivity to sounds can make it difficult to maintain important work, My sensitivity to sounds can make it difficult to have the social life I wish to My sensitivity to sounds can make it difficult to take part in meaningful My increased sound sensitivity can make me feel hopeless.

	Somew hat2	
·	 	
······	 	
·····	 	
<u> </u>	 	
·····	 	
·····	 	
······	 	
······	 	
······	 	





My increased sound sensitivity can make me feel alone or isolated. My increased sound sensitivity can make me feel afraid. My increased sound sensitivity can make me feel frustrated. My increased sound sensitivity can make me feel tired or fatigued. I find the challenges of being exposed to loud sounds difficult to explain to my I find the challenges of being exposed to loud sounds difficult to explain to I find the challenges of being exposed to loud sounds can make it difficult to be I find the challenges of being exposed to loud sounds can make it harder to use I find the challenges of being exposed to loud sounds can make it harder to use I find the challenges of being exposed to loud sounds can make it more of a I find the challenges of being exposed to loud sounds can make it more of a

Section S: TRQ - Tinnitus Reaction Questionnaire

This questionnaire is designed to find out what sort of effects tinnitus has had on your lifestyle, general well-being, etc.

Some of the effects below may apply to you, some may not.

Please read the questions carefully. While some questions may seem familiar, the nuances are different.

S1. Select the number that best reflects how your tinnitus has affected you over the past week.

0 = Not at all

- 1 = A little of the time
- **2** = Some of the time
- 3 = A good deal of the time
- **4** = Almost all of the time

My tinnitus has made me unhappy. My tinnitus has made me feel tense. My tinnitus has made me feel irritable. My tinnitus has made me feel angry. My tinnitus has led me to cry.





	0	1	2	3	4
My tinnitus has led me to avoid quiet situations.	·····				
My tinnitus has made me feel less interested in going out.	·····				
My tinnitus has made me feel depressed.					
My tinnitus has made me feel annoyed.	·····				
My tinnitus has made me feel confused.	·····				
My tinnitus has "driven me crazy".					
My tinnitus has interfered with my enjoyment of life.					
My tinnitus has made it hard for me to concentrate.					
My tinnitus has made it hard for me to relax.					
My tinnitus has made me feel distressed.					
My tinnitus has made me feel helpless.					
My tinnitus has made me feel frustrated with things.					
My tinnitus has interfered with my ability to work.					
My tinnitus has led me to despair.					
My tinnitus has led me to avoid noisy situations.					
My tinnitus has led me to avoid social situations.					
My tinnitus has made me feel hopeless about the future.					
My tinnitus has interfered with my sleep.					
My tinnitus has led me to think about suicide.					
My tinnitus has made me feel panicky.					
My tinnitus has made me feel tormented.	·····				

Section T: MHQ - Medical History Questionnaire

Though not consistent, some medical conditions have been associated with tinnitus in the past.

This could be related to the condition itself, the symptoms of the condition, the medication used to treat the condition, or other treatment.

Therefore, would now like to capture some information about your medical history.

T1. Do you have a history of, or currently have, any of the following Ear, Eye, Nose or Throat disorders?







T2. Do you have a history of, or currently have, any of the following Respiratory disorders?

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	Current In the I prefer not
	ly Past Never toanswer
Asthma	
Bronchitis	
Chronic Cough	
Chronic Obstructive Pulmonary Disease (COPD)	······
Lung Cancer	
Pneumonia	······
Pulmonary Embolus	······
Shortness of Breath	
Sleep Apnea	······
Tuberculosis	······

T3. Do you have a history of, or currently have, any of the following Gastrointestinal disorders?

	Current In the I prefer not to ly Past Never answer
Bowel Cancer	r
Constipation	1
Chronic Diarrhea	ì
Gallstones	s
GERD (Gastroesophageal Reflux Disease))
Hepatitis	s
Hiatal Hernia	ì
Liver Cancer	r
Liver Disease	·
Pancreatic Cancer	r

105

	Current In the I prefer not to ly Past Never answer
Pancreatitis	
Stomach Cancer	
Stomach Ulcer	
Ulcerative Colitis	

T4. Do you have a history of, or currently have, any of the following Urological or Kidney disorders?

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T5. MALES: Do you have a history of, or currently have, any of the following Urological or Kidney disorders?



T6. Do you have a history of, or currently have, any of the following Dermatology disorders?

	Current ly	In the Past	Never	I prefer not to answer
Eczema in ear	·····			
Rash in ear				
Skin Cancer				
Skin Ulcers in or near ears				
a history of, or currently have, any of the				

T7. Do you have a history of, or currently have, any of the following Musculoskeletal disorders?



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	Current ly	In the Past	I prefer not to Never answer	
Gout (Inflammatory Arthritis)	·			
Rheumatoid Arthritis	·			
Sarcoma				
Unhealed Wounds	·			

T8. Do you have a history of, or currently have, any of the following Neurological disorders?

	Current ly	In the Past	Nev	I prefer not to
Alzheimer's Disease				er answer
Brain Cancer]
Dementia	·]
Headache	······]
Migraines]
Multiple Sclerosis	······]
Neuropathy				·····
Parkinson's Disease	·····]
Seizure Disorder	······]
Stroke/TIA]
Syncope/Fainting				

Т9. Do you have a history of, or currently have, any of the following Hematology/Oncology disorders?

Abnormal Bleeding to Bruising

Anemia

Leukemia

Lymphoma



I prefer

Do you have a history of, or currently have, any of the **T10.** following Infectious Diseases?





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Do you have a history of, or currently have, any of the following T11. **Endocrinology disorders?**

	Current ly	In the Past	Never	I prefer not to answer
Diabetes	····-			
Lupus				
Obesity				
Thyroid Abnormalities				

Do you have a history of, or currently have, any of the following T12. **Cardiac disorders?**

	Current In the ly Past Nev	I prefer not to er answer
Arrhythmia/Abnormal Heartbeat/Atrial Fibrillation]
Chest Pain	······]
Congestive Heart Failure	······]
Coronary Artery Disease	······]
Deep Vein Thrombosis]
Heart Murmur]
High Blood Pressure	······]
Pacemaker]
Varicose Veins]

Do you have a history of, or currently have, any of the following T13. **Psychological or Substance Abuse disorders?**

	Current In the I prefer not to
	ly Past Never answer
Alcoholism	
Anorexia or Bulimia Nervosa	
Anxiety	
Bipolar Disorder	
Depression	
Drug Dependence	
Obsessive-Compulsive Disorder	
Post-Traumatic Stress Disorder (PTSD)	
Schizophrenia or Schizoaffective Disorder	
ve a history of, or currently have, any of the	

T14. Do you have a history of, or currently have, any of the following Allergies?

Allergic Rhinitis (Hay fever)



Food Allergies Environmental Allergies		In the Past	Never	I prefer not to answer	
gies here:					
w that you are allerg		Hydr Local Ana M	rocodone aesthesia Aorphine		
	Environmental Allergies gies here:	Iv Food Allergies Environmental Allergies gies here: w that you are allergic to:	Current In the Iv Past Food Allergies	Current In the Iv Past Food Allergies Iv Environmental Allergies Iv gies here: Iv v that you are allergic to: v that you are allergic to: v that you are allergic to: Aspirin Codeine Hydrocotone Local Anaesthesia Morphine Penicillin Sulfa Vicodin	v that you are allergic to: v that you are allergic to: Aspirin Codeine Hydrocodone Local Anaesthesia Morphine Penicillin Sulfa Vicodin

Other





T18.	Please list any other allergies that you have that were not already
	mentioned above:

Section U: Medications

Some medications may affect some people's hearing, depending on dosage and frequency.

If you are unsure about medication you have been prescribed, please check with your doctor or pharmacist.

U1. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Allergy medication

Name					
Indication					
Dose					
Frequency					
Current / Past					

U2. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Anti-anxiety

Name					
Indication					
Dose					
Frequency					
Current / Past					



U3. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Antibiotics

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Name					
Indication					
Dose					
Frequency					
Current / Past					

U4. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Anti-depressants

,					
Name					
Indication					
Dose					
Frequency					
Current / Past					

U5. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Blood Pressure

Name					
Indication					
Dose					
Frequency					
Current / Past			 		

U6. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Chemotherapy

Name					
Indication					
Dose					

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	Frequency	
	Current / Past	

U7. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Diuretics/water pills

Name					
Indication					
Dose					
Frequency					
Current / Past					

U8. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Painkillers, anti-inflammatory (Aspirin/Tylenol/Ibuprofen...)

Name					
Indication					
Dose					
Frequency					
Current / Past					

U9. Please enter the names of any medication you are taking or have taken, in their appropriate categories. If you know the dosage and frequency, please enter it as well.Other or Over the counter

c counter					
Name					
Indication					
Dose					
Frequency					
Current / Past					

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U10. If you are taking, or have taken, other medication that did not fit in the section above, please list them below.

(But please do not stress if you don't remember.)

Section V: Consent for Communication

You've reached the last page! Please make sure to hit SUBMIT at the bottom of the screen.

Please read the following requests for permission to use the data you have provided for future studies and any follow-ups to this one.

V1.	I agree to allow my data, linked to my ID, to be stored indefinitely and used for future tinnitus-related research by Keiko Gutierrez, Dr. Ian C. Bruce, and/or McMaster University. (This will allow us to re-analyze data or add to existing data in the future.)		
		Yes	
		No	
V2.	I agree to allow my anonymized data (not linked to me), to be stored indefinitely and to be used for future tinnitus-related research. (E.g. Many publication journals ask to see the data that was used for the reported results in order to validate them. In the name of Open Science, we may also share anonymized data for other tinnitus research teams to access.)		
	·	Yes	
		No	
V3.	I agree to be contacted for a follow-up interview or a study related to this one (to gather more data, for example).		
		Yes	
		No	
V4.	I agree to be added to a recruitment database to be contacted for future tinnitus research (a completely different study, for example).		
		Yes	
		No	

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V5.	I would like a copy of the study results.												
									Yes				
									No				
V6.	For contact that I've agreed to above, my preferred <u>contact is:</u>									_			
	Email address:												
	Phone number:												

Thank you very much for completing McMaster's Tinnitus Survey 2022.