

Loss, Meaning Making, and Reconstruction of Narratives in Adults Enduring Tinnitus
Exacerbated by Exposure to Sound

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Abstract

Tinnitus is an auditory processing disorder involving frequently distressing levels of sound perception without corresponding external stimuli. In many cases, a complicating factor is the exacerbation of tinnitus intensity and pain following exposure to even moderate sounds, which can profoundly impact mental health and quality of life. Although more detrimental to patient suffering and more challenging to treat clinically, the experience of tinnitus exacerbated by sound is still poorly understood, as are implications for clinical practice and counseling. Considering that millions of people worldwide suffer from tinnitus and heightened auditory sensitivity to the point of disability, this qualitative study sought to identify relevant factors in encountering this complex disorder in clinical and counseling work. Thematic analysis of 418 unique open-ended question responses revealed themes of loss, psychological impact, inadequate understanding, crises of meaning, and solutions. Psychological interventions and the evidence basis of various theoretical methodologies are discussed.

Keywords: tinnitus, hyperacusis, sound-sensitive tinnitus, mental health, quality of life, counseling, clinical psychology, psychotherapy

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Tinnitus Exacerbated by Exposure to Sound**

Tinnitus and hyperacusis are auditory disorders that impact approximately 50,000,000 people in the U.S. alone, with roughly 3,000,000 enduring symptoms so severe that available interventions do not successfully treat them (Baguley, McFerran, & Hall, 2013; Jastreboff & Jastreboff, 2000; Shargorodsky, Curhan, & Farwell, 2010). Tinnitus is the perception of sound without corresponding auditory stimuli, and is currently the most predominant disability for U.S. veterans of recent foreign wars (Møller, Salvi, De Ridder, Kleinjung, & Vanneste, 2015; Yankaskas, 2013). Hyperacusis is generally defined as an abnormally heightened auditory sensitivity marked by decreased sound tolerance (Baguley, 2003). These disorders frequently occur in tandem, can manifest in varied subtype presentations (Møller, 2016; Tyler et al., 2014) and are of

increasing prevalence among youth and young adult populations around the world (Daniel, 2007; Gilles, Van Hal, De Ridder, Wouters, & Van de Heyning, 2013; Sliwinska-Kowalska & Davis, 2012). Common comorbid challenges with both tinnitus and hyperacusis include anxiety, depression, sleep difficulty, psychosocial issues, and increased suicide risk (Langguth, Salvi, & Elgoyhen, 2009; Pace & Zhang, 2013).

It has been estimated that approximately 85% of individuals who report hyperacusis also experience tinnitus, while 40% of individuals with tinnitus also have symptoms of hyperacusis (Baguley, 2003). Tinnitus and hyperacusis may be caused by a variety of triggers, including acoustic trauma caused by excessive noise exposure, Meniere's disease, acoustic neuroma, and ototoxic medications (Chan, 2009; Crummer & Hassan, 2004; Paulin, Andersson, & Nordin, 2016), and are frequently accompanied by profound distress and psychological disorders including anxiety and depression (Falkenberg & Wie, 2012; Langguth, Landgrebe, Kleinjung, Sand, & Hajak, 2011). Both tinnitus and hyperacusis range from non-bothersome to debilitating (Baguley, 2002, 2003) and in some cases may mirror aspects of a posttraumatic stress response (Fagelson, 2007). Increased risk of psychological distress including anxiety, depression, sleep issues, and heightened suicidal ideation have all been indicated in cases where tinnitus is perceived as bothersome and intrusive (P. J. Jastreboff & Hazell, 1993; Pace & Zhang, 2013; Yankaskas, 2013). Similar challenges have been observed in individuals with hyperacusis (Baguley, 2003).

Strains on psychosocial wellbeing are also regularly associated with tinnitus and hyperacusis, including impaired daily functioning, decreased quality of life, work-related and academic challenges, and social isolation (Holmes & Padgham, 2011; Valente, Goebel, Duddy, Sinks, & Peterin, 2000). When tinnitus and hyperacusis occur together, increased risk of depression and reduced quality of life has been observed, compared to the presence of tinnitus or hyperacusis alone (Schecklmann, Landgrebe, & Langguth, 2014). In cases of anxiety and depression in which tinnitus and/or hyperacusis is a comorbid secondary issue, the audiological distress caused by either or both conditions may also further exacerbate mood symptoms, causing an increase in depression and anxiety levels in what has been called a 'negative feedback loop' (Andersson, 2002; Jastreboff, 1999; Paulin et al., 2016).

Psychological interventions including cognitive behavioral therapy (CBT) have demonstrated some efficacy in reducing adverse psychological symptoms associated with tinnitus and hyperacusis (Jüris, Andersson, Larsen, & Ekselius, 2014). In a controlled trial, participants who underwent CBT demonstrated overall improvements in areas of tinnitus loudness, severity, and annoyance (Zenner et al. 2012). While CBT for hyperacusis demonstrated a reduction in noise intolerance and depression symptoms that was maintained over a period of 12 months, it has not shown similar efficacy in addressing anxiety and quality of life concerns (Jüris et al., 2014).

Other cognitive-based treatments specifically developed for tinnitus that have demonstrated some efficacy in preliminary clinical trials include acceptance and commitment therapy (ACT; Westin et al., 2011); mindfulness-based tinnitus stress

reduction (MBTSR; Gans, Cole, & Greenberg, 2015); and meditation-based CBT (Sadlier, Stephens, & Kennedy, 2008). However, results from most studies on CBT and other cognitive interventions have not indicated which is the greater problem among research participants: mental health symptoms such as anxiety and depression or the severity of tinnitus and hyperacusis symptoms. Thus, the efficacy of such interventions in treating severe symptom presentations and subtypes including manifestations of comorbid tinnitus and hyperacusis still need further clarification.

While psychodynamic psychotherapy has not been subject to randomized clinical trial in treating tinnitus and hyperacusis, there have been reports of its effectiveness in the treatment of audiological processing disorders (Dauman & Erlandsson, 2012; Schaaf & Gieler, 2010). Psychodynamic therapy has demonstrated efficacy in supporting positive changes in functional neuroplasticity among brain regions including the amygdala, hippocampus, thalamus, insula, dorsolateral prefrontal cortex, anterior cingulate cortex, and orbitofrontal cortex (Abbass, Nowowieski, Bernier, Tarzwell, & Beutel, 2013; Buchheim et al., 2012; Lane, Ryan, Nadel, & Greenberg, 2015). These areas are associated with levels of stress, anxiety, depression, perception, emotion regulation, mood, self-concept, cognition, and social functioning (Dauman & Erlandsson, 2012), all of which are impacted in tinnitus and hyperacusis (Chen, et al., 2017). Psychodynamic psychotherapy has also been proposed as effective for addressing issues of heightened emotional arousal, relational challenges, and internal psychological conflicts associated with tinnitus and hyperacusis distress (Lane, Ryan, Nadel, & Greenberg, 2015; Schaaf, Eichenberg, Kastellis, & Hesse, 2010).

Audiological interventions for tinnitus and hyperacusis delivered by audiologists are among the most common treatments for tinnitus and hyperacusis (Hobson, Chisholm, & El Refaie, 2012; Vernon & Schleuning, 1978), and include Tinnitus Retraining Therapy (TRT; Jastreboff & Jastreboff, 2000). Combining elements of sound therapy and behavioral counseling, TRT addresses tinnitus and hyperacusis perception using a model of neurophysiological arousal (Jastreboff & Hazell, 1993). Nevertheless, partly due to the complexity of limbic system activation factors in conjunction with inconclusive neurological models, there is still a dearth of empirically validated treatments that can help severe presentations where both disorders interact (Henry, Trune, Robb, & Jastreboff, 2007; Schecklmann et al., 2014).

Pharmacological treatments for tinnitus and hyperacusis are controversial, as differing opinions exist in the literature regarding potential risks and benefits of antidepressants and other medications (Baldwin et al., 2013). Accordingly, some have suggested that no available pharmacological treatment is suitable for clinical use in tinnitus and hyperacusis (Tunkel et al., 2014). Still, despite risks including addiction, withdrawal, seizures, and several other potential health concerns, various studies have indicated efficacy of the benzodiazepines clonazepam and alprazolam for the reduction of tinnitus symptoms and hyperacusis-related anxiety (Han et al., 2012; Jalali, Kousha, Naghavi, Soleimani, & Banan, 2009; & Shaikh, 2012). Furthermore, intravenous lidocaine has demonstrated capacity to reduce or even eliminate tinnitus symptoms, but

has failed to alleviate symptoms once the intravenous drip is removed (Henry, Dennis, & Schechter, 2005; Israel, Connelly, McTigue, Brummett, & Brown, 1982).

Concerning the interplay of auditory processing disorders, there is no consensus as to whether tinnitus and hyperacusis have overlapping or divergent pathophysiological mechanisms (Chen et al., 2015; Noreña, 2011; Zeng, 2013). In existing descriptions of tinnitus severity categories, patients with comorbid hyperacusis in which sound sensitivity leads to prolonged instances of worsened tinnitus have been referred to as the most severe and hardest to treat clinically (Henry et al., 2007; Jastreboff, 1999). We have recently proposed the term sound-sensitive tinnitus, so as to differentiate this subtype from phantom auditory perception that is not impacted negatively by sound exposure (Greenberg, 2017). Considering the high prevalence of tinnitus in cases of hyperacusis, along with the challenging clinical implications unique to the sound-sensitive tinnitus subtype, there is a clear need to better understand the experiences of individuals whose tinnitus is adversely impacted by exposure to sound (Knipper et al., 2013; Schecklmann et al., 2014). Thus, the purpose of this study was to elucidate key aspects of the lived experience of having sound-sensitive tinnitus, so as to inform future research and clinical practice guidelines for the treatment of individuals suffering from this challenging condition that still has no cure.

Methods

Procedures

In seeking to elucidate the subjective experience of sound-sensitive tinnitus through qualitative data analysis, three open-ended questions were formulated based on a thorough review of the literature. These questions were structured with the intention of capturing fundamental aspects to the lived experience of having tinnitus exacerbated by exposure to sound. The small number of questions reflects the aim of striving to construct a broad understanding and context to participants' lived experience, and a large amount of study participants was sought to obtain ample data for a thorough qualitative analysis. Study participants were asked the following questions: to articulate any specific ways their lives have been impacted by having sound-sensitive tinnitus, what has been most helpful in coping with having sound-sensitive tinnitus, and if there is anything else regarding their experience of having sound sensitive tinnitus they feel it would be important to add.

Due to the pervasiveness of tinnitus and sound sensitivity issues across cultures and ethnicities, obtaining a sample large enough to represent a broad scope of individuals afflicted worldwide by these conditions was a major consideration in designing this study. Ethics review board approval from Argosy University was granted in November 2015, and participants were sought entirely online. Internet data collection was chosen to support the research goals of accessing a wide range of participants across vast geographic domains, which have been suggested benefits of internet research (Clarke, 2000; Fricker & Schonlau, 2002; Salmons, 2015). While still not as established as in-person and phone interviews, online formats for conducting qualitative research have been utilized and explored for close to two decades, with increasingly established

guidelines and protocols (Im & Chee, 2012; Hunsinger, Klastrop, & Allen, 2010; Mann & Stewart, 2000).

Information about study participation along with a web link to the study protocol was originally posted in various international online support groups via the website tinnitustalk.com, and in various support groups on Facebook. Participants were also sought through collaboration with audiologists in the San Francisco Bay Area and through the national network of support groups affiliated with the American Tinnitus Association (ATA), which supported this study through a student research grant award. Notification about recruitment was also posted on the ATA's website and on the websites of counterpart international tinnitus organizations in primarily English-speaking countries including the United Kingdom, Canada, and Australia.

Participants were initially asked if they consented to participate in the study, and were informed of the minimal risk of emotional discomfort due to the mood and anxiety symptoms known to be common with tinnitus and hyperacusis. Upon agreeing, participants were then linked to a set of questions related to study inclusion delimitations of having tinnitus, and that their tinnitus was at least occasionally exacerbated by noise exposure. If participants answered yes to both of these delimitations, they were then guided to the complete set of questionnaires. To protect participant confidentiality, no data contained any information that could identify the participants. Participation was completely voluntary, and 418 responses to the three open-ended questions were collected in sum.

Participants

Total participants who provided at least demographic information amounted to 335 individuals from 32 countries. An additional 85 individuals accessed the website to participate in the study, but two did not consent to the terms of participation, six did not meet the criteria of having tinnitus, and 65 individuals were excluded from participation by falling outside of the study delimitation that hearing loud sounds can make their tinnitus worse. Another 58 individuals stopped participating voluntarily at various points of the study. The total number of participants who completed demographic information and provided at least one qualitative response was 277.

Demographic factors included that study participants were 56% female, and reported being 92% White or of European descent. Regarding their geographic location at time of taking the study, the greatest representations included the United States (42%), the United Kingdom (20%), Continental Europe (14%), Australia (9%), and Canada (7.2%). Ages of participants were measured in ranges including 18-21 (2.2% of participants), 22-29 (8.3% of participants), 30-39 (20.5% of participants), 40-49 (21.2% of participants), 50-59 (26.6% of participants), 60-64 (13.7% of participants), and 65+ (7.2% of participants). See Table 1 for more detail on participant demographics.

Table 1
Participant Demographics (N = 277)

Characteristic	<i>n</i>	%
Age range (in years)		
18–21	6	2.2
22–29	23	8.3
30–39	57	20.5
40–49	59	21.2
50–59	74	26.6
60–64	38	13.7
65+	20	7.2
Gender		
Male	121	44.0
Female	155	56.0
No response	1	0.4
Armed Services veteran		
Yes	11	4.0
No	266	96.0
Ethnicity		
White/European	255	92.0
Hispanic/Latino	11	4.0
Black/African American	1	0.4
Asian/Pacific Islander	8	3.0
Native American/Indigenous	3	1.1
Location		
United States	118	42.4
United Kingdom	55	20.0
Australia	25	9.0
Canada	20	7.2
Ireland	5	1.8
New Zealand	1	0.4
Continental Europe	40	14.4
Africa	3	1.1
South America	6	2.2
Asia	4	1.4

Note. Totals of percentages are not 100 for every characteristic because of rounding.

Qualitative Analysis

The qualitative methodology utilized in constructing this study and for analyzing collected data was thematic analysis. Thematic analysis is an established and standard qualitative methodology for determining patterns arising from interview text (Aronson, 1995; Creswell, 2012), and has been noted as beneficial for exploratory studies that may be used as eventual foundations to theory construction (Nowell et al, 2017; Vaismoradi, Turunen, & Bondas, 2013). This method was selected due to the experimental nature of this study, with consideration that thematic analysis has been portrayed as a flexible and expedient research method due to its theoretical freedom, and as such is compatible with

essentialist, realist, and constructionist psychological paradigms (Braun & Clarke, 2006). In contrast to other formalized qualitative methods, thematic analysis limits the amount of subjective narrative interpretation by virtue of its descriptive and interpretive process, leading to the creation of mapped thematic structures through integrating manifest and latent contents from participants' lived experience (Vaismoradi et al, 2013).

Following established qualitative methodology procedures, answers to open-ended questions were compiled and arranged sequentially. Then, each answer was reviewed in three rounds of coding and subsequently divided into themes with the aim of providing deepened understanding into the subjective experience of individuals with sound-sensitive tinnitus. Important clusters of information from transcripts were identified and organized as codes, and groups were then created and further refined to clarify categorical themes in the data set (Fossey, Harvey, McDermott, & Davidson, 2002). Additionally, a second reader was utilized in order to ensure inter-reader reliability. Relevant excerpts from participant statements were then structured into narrative format corresponding with each theme, in seeking to provide coherence and interpretability to the analyzed results.

Due to the narrative structure of thematic analysis studies, emergent themes were elaborated to provide context to overall responses. However, in favor of seeking rich subjective descriptions within an essentialist, constructionist lens in accordance with established qualitative guidelines and protocols, results were not organized through statistics, percentages, and other quantitative means of data portrayal (Cresswell, 2012; Firestone, 1987; Ponterotto, 2005).

Results

Analysis of data from participant responses yielded five themes: loss, psychological impact, inadequate understanding, crisis of meaning, and solutions. Three themes also had subthemes, as reconstruction of narratives was a subtheme of loss; inadequate understanding was given the subthemes of medical professionals, work, and general lack of understanding; and the theme solutions had three subthemes, which were labeled active solutions, passive solutions, and nothing. Descriptions of each theme and subtheme along with examples from obtained participant data follows below, and all themes and subthemes are listed in Table 2.

Table 2

Themes derived from thematic analysis of qualitative data

Theme/Subtheme
1. Loss
1a. <i>Reconstruction of Narratives</i>
2. Psychological Impact
3. Inadequate Understanding
3a. <i>Medical Professionals</i>
3b. <i>Work</i>
3c. <i>General lack of Understanding</i>
4. Crisis of Meaning
5. Solutions
5a. <i>Active Solutions</i>
5b. <i>Passive Solutions</i>
5c. <i>Nothing</i>

Qualitative Theme 1—Loss

The theme of loss entailed several impacted areas of participants' lives and livelihoods, and in some cases was reported to convey a sense of destruction or devastation wrought by their auditory conditions. Common areas of loss included employment, social gatherings, relationships, music, community, dreams, public spaces, television, and movies. Regarding these losses, examples of participant statements included "I feel that it's a big part of my life gone," "No relationships, no more joy," and "loss of interest to live." Encapsulating the many areas of impact, one participant offered that "sound sensitivity and tinnitus destroyed my life quality and ability to pursue my dreams." Another mentioned, "I had to quit my job, my dream, my ambition because the sounds . . . were unbearable." Yet another stated, "My life has fallen apart." One participant lamented the loss of enjoying "drugs such as caffeine or weed, since they cause an increase in tinnitus problems," and another shared, "I quit drinking. It's what I miss the most." Some of the losses were ambiguous, in that the extent of the loss was still unclear. One respondent questioned, "Will this ever stop? Am I going to lose my hearing?"

However, the theme of loss also yielded a subtheme that was titled reconstruction of narratives, entailing various areas in which participants struggled to make new meaning out of their loss and suffering. This subtheme encompassed areas of seeking coherence and experiencing posttraumatic growth, which has been characterized as positive psychological changes occurring after devastating life circumstances (Tedeschi & Calhoun, 2004). For example, one participant shared that "Even the sound of loud laughter can spike my tinnitus; so much of the joy of life is lost but I try to cope by finding happiness elsewhere." Other responses representing this subtheme included a spiritual perspective in that "It has increased my prayer life and brought me close to God", and shifting perceptions inward, such as "Now I'm trying to understand more what my body is trying to tell me what it needs."

Qualitative Theme 2—Psychological Impact

This theme comprises areas of impact relating to psychological symptoms including depression and anxiety, and also includes experiences of fear, avoidance, isolation, sadness, and other similar challenges. As one participant simply stated, “It is frightening and depressing,” others added that their experience is “totally isolating from the rest of the world,” and on a more extreme note that it is “a torture that may lead to suicide.” Another participant described specific challenges along with the negative impact and hopelessness endured:

Even with earplugs, my tinnitus is so reactive it gets worse every single time. I have permanent spikes that never go back down. It makes me very depressed and not look forward to the future because without a cure, I cannot see myself ever getting used to it. Suicidal thoughts are very common with me, and this is coming from a person that never used to be suicidal. It is the most horrible thing that I have ever experienced. I just want my silence back.

The frequent discussion of suicide in the tinnitus community was cited as particularly stressful to one participant, who indicated, “Hearing people who kill themselves with tinnitus is very upsetting and sad. It makes my tinnitus worse.”

Participants described anxiety symptoms including that “The constant worrying about loud sounds, the hypervigilance, has created an anxiety disorder” and “It has made me afraid of sounds I would never be afraid of.” Others commented “Sound sensitivity reminds me I have tinnitus, and my anxiety increases,” “I am much more tense than I used to be before having tinnitus,” and “More panic and anxiety attacks afterwards loud whooshing tinnitus. It’s a vicious cycle!” Some participants shared strategies of avoidance, with statements including: “I avoid certain work and social interactions when I know that there will be loud noise,” “I avoid restaurants and noisy places,” “I no longer go to parties and social gatherings or live music events,” and that concern relating to sound-sensitive tinnitus “makes me want to stay out of noisy places I used to enjoy.”

Struggles with depressive symptoms were described in various ways, including “Life has no pleasure, the world is so loud,” “My life has fallen apart. I struggle to get out of bed every day. I have no quality of life at the moment,” and “I am isolated with this constant noise, that no one else can hear.” Other responses involving depressive symptoms included the simple reply of “Loneliness.” Self-esteem was also identified as an area of impact, as participants shared “It makes you feel worthless and inadequate,” “It has destroyed my hope of ever feeling truly happy or fulfilled,” and “My confidence in myself to accomplish tasks have been shaken.” One participant reported, “I get very frustrated at the feelings of uselessness and not being able to be proactive in making this better.” Adverse somatic experiences were also portrayed, including “I have tension and pain in my body due to feeling on edge all the time.”

Qualitative Theme 3—Inadequate Understanding

This theme addresses various experiences in which participants shared feeling misunderstood that have prevented them from receiving the care, support, or accommodations they need. One participant pondered if inadequate understanding is possibly related to sound-sensitive tinnitus being “a weird condition and very difficult to explain.” Regardless, inadequate understanding also yielded three subthemes: medical professionals, work, and general lack of understanding. This theme also entails some of the external and internal stigma that participants have faced, including that “For the longest time I didn’t tell anybody about my symptoms because I thought they would think I was crazy.” Others offered, “A lot of people in the church, they don’t believe me” and “I feel alienated from others believing that they cannot understand and would think I imagine or exaggerate my symptoms.”

Inadequate understanding by medical professionals was the most prominent and pressing category in this theme. One participant cited “frustration with dental and medical people, not being understood,” while others indicated, “I am bothered by the lack of knowledge by doctors and hearing aid technicians about this topic,” “No ENT doctors, four different ones, seem to quite understand tinnitus,” and “Doctors do not know how to provide resources for managing this condition.” One participant highlighted some of the challenges faced in being understood by a doctor and seeking appropriate medical advice: “I don’t think doctors understand the social isolation this condition generates. They tell us to not overprotect or something like that, but it’s impossible not to in some situations.”

Another participant detailed some difficulties encountered when seeking support from an audiologist and the subsequent experience of stigma:

I went to an audiologist to discuss tinnitus and what I could do to prevent it from getting worse . . . I was told he could do nothing for me . . . It discourages me from going to the doctors in the future. They feel my health issues are not legitimate.

Challenges to being understood at work were described in ways that included “Staff at work don’t understand, manager thinks I am making it up, not taking it seriously” and “When fire alarms go off . . . people at work do not understand why I need to plug my ears.” General lack of understanding was highlighted through statements such as “We need a lot more support and understanding for people with invisible disabilities” and simply, “Most people don’t understand.”

Qualitative Theme 4—Crisis of Meaning

Distinct from themes of loss and psychological impact are ways in which participants reported sound-sensitive tinnitus as devastating, all encompassing, and life shattering. Therefore, the theme crisis of meaning entails various existential challenges that have been transfigured by enduring sound-sensitive tinnitus. Some participants shared, “It is the worst thing in the world, I wouldn’t wish it on my worst enemy,” and “Life changing, horrific, and wouldn’t wish this condition on anyone.” Other perspectives on the crisis of meaning due to sound-sensitive tinnitus included “It never stops,” “It’s

the most awful thing, just takes over your life,” and “It’s hell . . . after being in noisy situations, I pay for days with louder T [tinnitus].”

While one participant mentioned “I have a lot of other health issues but T [tinnitus] & H [hyperacusis] are the hardest to deal with,” another lamented that “It is heartbreaking and hard to find a partner that can understand so it has made my world much smaller.” Regarding some of the negative and all-encompassing changes participants have undergone, statements reflected that “It has ruined my life so far, it only gets worse year after year, and I need a cure” and “My life has changed completely since I got hyperacusis and tinnitus.” Another participant added, “You do not appreciate how precious your hearing is until your auditory system is messed up.”

Qualitative Theme 5—Solutions

This theme consists of diverse ways in which study participants attempt to alleviate their symptoms and cope with the challenges that accompany sound-sensitive tinnitus. Many responses in this category evoked descriptions of shifts occurring in participants’ internal states and preferences regarding sound qualities in the environment. Other statements reflected externally sought manners of solution and alleviation. Accordingly, passive solutions and active solutions were two subthemes applied within this category. For many participants, however, the absence of effective solutions was a subtheme in itself as evidenced by responses including “Nothing,” “There is nothing,” “Nothing, don’t cope,” and “Nothing, my tinnitus reacts to everything.”

When recounting passive solutions, some statements alluded to patience and shifts in attitude, such as one participant who deferred to “Time, acceptance, waiting for habituation,” and another who shared that “Making peace with the ringing is helping a lot.” Others cited the inclusion of hope and positive thinking as helpful, providing statements such as “Patience, positivity, and hope” and “Positive thinking and trying not to let it get me down.” A frequently mentioned solution related to sound qualities in the environment, such as maintaining “sound enrichment of right kind,” and being in a “quiet environment, but not completely silent.” More passively, one participant simply stated “Trying to forget that I have it,” while another suggested “Trying to ignore it, getting used to it, and accepting that it’s there no matter what.” Some participants indicated a multiplicity of strategies including both passive and active solutions such as “Time, perspective, focus on helping others, staying busy.”

Active solutions that involved seeking out a specific change or intervention included several categories of actions taken. For one participant, this meant “becoming self-employed to be able to control my noise exposure, and then retiring.” Others found shared community through “reading other people’s testimonies” and “contact with other people with T and H.” Many referred to proactivity regarding hearing protection, evidenced by statements including “using earplugs in all situations where unforeseen louder sounds may occur,” wearing “noise cancelling headphones,” and “having earplugs with me all the time.” Other participants sought relief through audiological means including “sound therapy and masking with earphones for relief” and “when loud, using a sound masker.” One participant offered, “Now I have found sound therapy that helps to

calm the tinnitus to some degree,” and another shared, “I went for TRT which really helped with my ability to cope with tinnitus.” One participant affirmed that “Calming sounds are definitely the right path.”

Additional active solutions among collected responses included using relaxation techniques, learning tai chi and principles of Chinese medicine, and mindfulness meditation. Medication was also a frequently cited solution, and several participants shared taking “low dosage anxiety tablets,” “antidepressants and benzos,” and “trying out anti-seizure meds.” Others mentioned medication in combination with other strategies, including “Xanax, Indian flute music, hot baths, massages, not going to work,” “hearing aids, white noise, medications,” and “ambient sounds and unfortunately, prescription medications to help sleep.” Various other intervention modalities that participants cited as useful included psychological therapy, hypnotherapy, and joining support groups.

Discussion

This study sought to elucidate the subjective experience of adults with sound-sensitive tinnitus, which was portrayed by respondents as being marked by significant areas of loss, stigma and misunderstanding, applying independent solutions, and confronting overwhelming crises of meaning. Accordingly, results from this study may offer a clearer conception for practitioners and family members alike through having compiled and organized narratives of the lived experience of individuals with this complex manifestation of auditory symptoms. Specifically, these narratives may assist clinicians who are working with this population in their capacity to understand unique needs and concerns associated with the sound-sensitive tinnitus subtype. Themes highlighted in this study emphasized the magnitude of loss and disenfranchisement endured by participants, as well as the unfortunate failure of medical professionals to understand the nature of their challenges and subjective experience.

The prominence of existential and mental health concerns underscores the challenging task of reconfiguring meaning, as individuals suffering from sound-sensitive tinnitus seek to create coherent narratives while enduring a poorly understood condition that currently has no cure. At that, the level of creativity and diversity within the active and passive solutions utilized by participants speaks to the individual, idiosyncratic nature of sound-sensitive tinnitus. Successful interventions may highlight and elaborate upon these strategies in providing a wide array of tools and options that can help individuals endure the level of distress that they described. Regardless, the fundamentally important mental health component of sound-sensitive tinnitus makes clear the need to better understand how commonly reported symptoms such as depression and anxiety both influence and are mediated by this subtype.

Taking into account the complexity of mental health and psychosocial concerns presented in this study, it seems important to consider adaptations to existing audiological, psychological, and counseling approaches in addressing challenges specific to the subjective experience of living with sound-sensitive tinnitus. Specifically, it may not be useful to suggest that individuals with sound sensitive tinnitus seek out increasing

decibel levels of sound exposure, as is currently a common suggestion in hyperacusis and tinnitus treatments including TRT (Jastreboff & Jastreboff, 2000) and CBT (Jüris et al., 2014). While CBT has shown promise in the treatment of tinnitus and hyperacusis symptomology (Andersson, 2002), further consideration of the interplay of auditory sensitivity, increased tinnitus, psychosocial limitations, and psychological distress is warranted, as well.

Considering the existential nature of data shared by participants that fell within the themes of crisis of meaning and loss, therapy modalities with a subjectively-oriented focus may also be useful to investigate. For example, psychodynamic psychotherapy may be helpful in the treatment of sound-sensitive tinnitus due to its capacity to promote narrative reconstruction and meaning making through processing and containing unresolved aspects of challenging emotional experience (Schoore, 2011). In all, considering the absence of a cure, it is likely that multiple areas of support including individualized audiological and psychological interventions will be crucial in assisting adaptation to the specific circumstances and idiosyncratic manifestations of sound-sensitive tinnitus.

Results presented here corroborate with findings by Jastreboff (1999), Henry et al (2007), and Schecklmann et al (2014) that tinnitus exacerbated by exposure to sound is a unique, severe phenomenon that is poorly understood and thus warrants further clarification and awareness in research and guidelines for clinical practice. Building upon prior studies, this research provides a novel addition in being the first qualitative exploration of the experience of sound-sensitive tinnitus, and can thus potentially enhance understanding regarding the subjective experience of individuals who endure this condition. These findings may be particularly helpful for practitioners attending to the stresses, challenges, and mental health concerns of these individuals in clinical and counseling practices.

The lack of prior elaboration and contextualization of the lived experience of sound-sensitive tinnitus may help explain why participants reported difficulty receiving empathy and understanding from healthcare providers, family, and in other social and occupational settings. Thus, this study may hopefully contribute to increased context and clarity in helping to translate the lived experience and unique concerns that this population faces. In turn, this may enhance levels of support and understanding between individuals with sound-sensitive tinnitus and the necessary and available support systems within their sociocultural environments.

Strengths of this study include that it contributed to the understanding of a marginalized manifestation of complex auditory processing disorders through substantial qualitative data collection and analysis regarding the subjective experience of individuals with sound-sensitive tinnitus. Thematic analysis revealed codes and themes highlighting stigma and significant challenges in being understood by healthcare providers, along with the devastation, loss, fear, and life-altering crisis of meaning that can befall those who experience sound-sensitive tinnitus. Furthermore, active and passive solutions to coping with sound-sensitive tinnitus were identified, as well as areas of narrative reconstruction.

Accordingly, these qualitative results offer clinical health service providers and researchers a preliminary framework to better understand potential areas of vulnerability and resilience that will enhance their capacity to communicate with and effectively address the needs of this population.

Study limitations include that participant demographics were overwhelmingly White, and that qualitative data was obtained with answers from only three questions. While there were ample responses contributing to a robust set of data yielding codes and themes that may offer increased insight into the subjective experience of sound-sensitive tinnitus, it cannot in any way be said that this was a comprehensive inquiry into relevant factors faced by this population. Therefore, future researchers should seek to compile longer, more substantial sets of open-ended questions and seek more diverse participants, so as to gain a better understanding of various components to the subjective experience of sound-sensitive tinnitus that were not encapsulated here. Another limitation is that while internet qualitative data collection has been associated with increased access to geographically diverse participants, as well as reduced inhibition and thus potentially more honest responses (Im & Chee, 2017; Salmons, 2015), it has also been suggested to provide less contextual richness and descriptive content that can assist in the creation of more complete narratives as compared with more traditional means of data collection (Dimond, Fiesler, DiSalvo, Pelc, & Bruckman, 2012). Thus, future studies will benefit from comparing the results of this study to subsequent endeavors that utilize in-person, video, or phone interview data.

Concluding Remarks

It is hoped that clinicians and counselors may benefit from awareness of the themes and mental health factors clarified in this study, and may consequently more effectively attend to the needs of their patients who endure sound-sensitive tinnitus. Furthermore, awareness of these themes may assist in more appropriately identifying and addressing challenging psychological components among individuals in this clinical population in audiological and counseling practices. In this regard, interdisciplinary collaborations among practitioners may lead to greater capacity to identify important areas of loss and potential crises of meaning, and support the reconstruction of narratives through allowing their patients to feel understood despite their frequently challenging emotional experience. Clinicians may also seek to reinforce areas of strength and resiliency in helping to reconstruct shattered narratives, and gain greater familiarity with useful solutions that participants shared in this study to impart in their own clinical work. Guided by this research, clinicians who gain improved understanding of some principal areas of impact as experienced by this population may be able to offer patients increased capacity to mourn their losses, reconfigure their lives, make meaning of their experience, and continue to grow despite the devastating challenges and limiting factors of enduring sound-sensitive tinnitus.

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