

1 **Coping with tinnitus during the COVID-19 pandemic**

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25

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30

31 **Key Words**

32 Tinnitus, Coping, Support, Self-management, Automated content analysis, COVID-19,
33 Support Groups, Social support, Tinnitus management, Audiologist

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35 **Abbreviations**

36 **ACA:** Automated Content Analysis

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39 **Abstract**

40 **Purpose:** The COVID-19 pandemic disrupted normal operations of healthcare services,
41 broad sectors of the economy, and the ability to socialize freely. For those with tinnitus, such
42 changes can be factors in exacerbating tinnitus. The purpose of this study was to determine
43 tinnitus help-seeking behavior, which resources individuals utilized to cope during the
44 pandemic, and what additional support is desired.

45 **Method:** An exploratory cross-sectional study design including 1,522 adults with tinnitus
46 living in North America (Canada and the U.S.) was used. Data was collected through an
47 online survey distributed by the American Tinnitus Association via email. Free text from
48 open-ended questions was analyzed using the Automated Content Analysis (ACA). The
49 responses to the structured questionnaire were analyzed using descriptive and non-parametric
50 statistics.

51 **Results:** Significantly less tinnitus support was sought during the pandemic and very few
52 respondents utilized tinnitus support networks during the pandemic at the time the survey was
53 conducted. Nonetheless, seeking support during the pandemic was significantly associated
54 with significantly less tinnitus distress. The most frequently utilized resources for coping
55 during the pandemic were contacting family and friends, spending time outdoors or in nature,
56 relaxation, and exercise. Such tools for coping were associated with significantly less tinnitus
57 distress. The support requested and advice provided by participants to healthcare services had
58 overlap. The main support needs related to managing tinnitus included addressing hearing
59 loss, providing peer support, finding cures, accessing trained and understanding healthcare
60 providers to help. The advice for professionals related to tinnitus management included the
61 need for cures, personalized support, addressing hearing loss, targeting the tinnitus percept,
62 and providing more information about the condition.

63 **Conclusions:** These findings provide suggestions on how to better support those with tinnitus
64 at a time when healthcare is undergoing rapid changes. Findings can be used by stakeholders,
65 clinical practitioners, and tinnitus support services to devise ways to work more effectively
66 together to improve access to patient-driven, suitable, accessible, and evidence-based
67 support.

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76 **Introduction**

77 The rapid spread of the COVID-19 infection resulted in the outbreak of a global pandemic
78 (World Health Organization, 2020). To break the chain of transmission in this human-to-
79 human virus, numerous regional lockdowns were enforced. People were asked to stay at
80 home, maintain social distance guidelines, and many venues, such as schools, offices, and
81 recreational venues, were closed, particularly in hotspot regions with higher points of contact
82 between people (Roy & Ghosh, 2020). These measures also disrupted the normal operation of
83 healthcare services, and support was not always available, particularly for medical concerns
84 that were not critical. Such service included care for hearing healthcare such as addressing
85 hearing loss with the fitting or maintenance of hearing aids and managing tinnitus, which is
86 the perception of sound/s when no external sound is present.

87

88 Since there is a bidirectional relationship between tinnitus and stress (Mazurek, Szczepek, &
89 Hebert, 2015), the additional stress associated with the pandemic may be a contributing factor
90 to the reports of increased tinnitus severity during the pandemic (Anzivino, Sciancalepore,
91 Petrone, D’Ella & Quaranta, 2020). Life-style changes during the pandemic may have
92 furthermore impacted on tinnitus experiences, as found in a global tinnitus study, including
93 3,103 adults (Beukes et al., 2020a). Almost a third (32%) reported their pre-existing tinnitus
94 was exacerbated. Tinnitus was worse for those who were self-isolating, experiencing
95 loneliness, sleeping poorly, and exercising less than before the pandemic. Increased levels of
96 depression, anxiety, irritability, and financial worries further contributed to tinnitus being
97 more bothersome. As tinnitus is often associated with anxiety and depression (Salazar, et al.,
98 2019; Trevis, McLachlan, & Wilson, 2018), identifying ways to support such individuals
99 should be prioritized especially considering affects around 10% of the U.S. population (Bhatt,
100 et al., 2016; Shargorodsky, Curhan, & Farwell, 2010). Moreover, help should be readily

101 available for those who developed tinnitus and/or hearing loss following COVID-19
102 infection, since this might be an unknown and a possible consequence of the infection
103 (Munro, Uus, Almufarrij, Chaudhuri, & Yioe, 2020, Vlola et al., 2020).

104

105 Although tinnitus was exacerbated during the pandemic for some, Beukes et al. (2020a)
106 found 67% of the respondents reported their tinnitus was not affected, and 1% indicated their
107 tinnitus improved. It may be assumed that such individuals had effective coping skills to
108 manage stress, which thereby minimized the impact on their tinnitus, Understanding their
109 coping techniques is important to aid future intervention and support planning, and should be
110 investigated. The aim of the present study was to (1) investigate tinnitus help-seeking
111 behavior during the pandemic, (2) identify what resources were utilized to cope with tinnitus,
112 and (3) what additional support is needed by those with tinnitus.

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114 **Method**

115 **Study Design**

116 An exploratory cross-sectional survey study design was used to investigate tinnitus
117 experiences (see Beukes et al., 2020a) and examine how those with tinnitus coped during the
118 COVID-19 pandemic. Ethical approval was granted by Lamar University, Beaumont, Texas,
119 United States (IRB-FY20-215). The STROBE reporting guidelines (von Elm, et al., 2007)
120 were used to report the methods and results of the study.

121

122 **Data Collection**

123 Eligibility to complete the survey included being 18 years or older, reporting the presence of
124 tinnitus, and living in North America (Canada and the U.S.). The American Tinnitus
125 Association (ATA) distributed the survey via email in May 2020. The survey was available
126 for 6 weeks. Online informed consent was required before taking the survey and only one
127 submission from each IP address was permitted by the survey software. The survey was
128 distributed online via Qualtrics (Qualtrics, 2005). No randomization of items was used, and
129 respondents were unable to change their responses once submitted. No identifiable data were
130 collected.

131

132 To investigate the research questions, the following information was gathered using closed-
133 ended questions where relevant answers could be selected and free text could be added if
134 required: (a) Demographic information including age, gender, nationality, ethnicity, tinnitus
135 duration, use of hearing aids; (b) Help-seeking prior to and during the pandemic; (c)
136 Resources utilized to cope during the pandemic; and (d) Support required to better manage
137 tinnitus by asking the following open-ended questions:

- 138 ▪ Support question: What type of support would help you better manage your tinnitus or
139 hearing related issues during these uncertain times?
- 140 ▪ Advice question: What advice/suggestions for healthcare professionals and/or
141 researchers can you offer so that we might provide/develop more effective care for the
142 future?

143

144 In addition, tinnitus severity was measured using the Tinnitus Handicap Inventory-Screening
145 version (THI-S; Newman, Sandridge, & Bolek, 2008) consisting of 10 questions, with
146 scoring between 0–40, with higher scores indicating more severe tinnitus. Scores less than six
147 indicate no difficulty, while scores above six indicate some degree of difficulty and that

148 benefit may be obtained from audiological and/or psychological support. The survey
149 questions used in this study can be found in the supplementary materials.

150

151 **Data Analysis**

152 **Statistical Analysis:** The Statistical Package for Social Sciences version 26.0 was used to
153 perform the descriptive and non-parametric tests on the responses to structured questions.
154 Descriptive statistics, including frequencies, means, and standard deviations were computed.
155 Linear regression was used to look at the association between variables. Statements from the
156 free text responses were used as examples to support the descriptive analysis of the results.

157

158 **Automated Content Analysis (ACA):** The ACA was used to analyze the free-text responses
159 to two open-ended questions using the Leximancer software (edition 4.0). ACA is a type of
160 “topic modelling” approach for analyzing qualitative data using quantitative technique to
161 identify patterns within the data (Nunez-Mir et al., 2016). ACA is underpinned by Bayesian
162 theory and uses advanced statistical methods to examine the semantic and linguistic
163 complexity of the text to produce concepts and themes related to the text. ACA is found to
164 have equivalent and/or higher semantic coherence than human inter-rater correlations in
165 qualitative analysis (Newman et al., 2020). ACA provides a bird’s-eye view of the data,
166 showing primary themes, concepts, frequencies, and examples of meaning units by mapping
167 the text to theme/concept. The terms “theme” and “concept” in ACA refer to “category” and
168 “sub-category,” respectively in qualitative content analysis. After the initial review of the
169 themes, redundant words, which included “COVID,” “none,” “sure,” and “told”, were
170 removed and the analysis was done again. The themes are presented in a concept map
171 showing the main concepts, their frequency, and inter-connectedness (or co-occurrence). The

172 bubbles represent the themes, while the dots within the bubbles represent the concepts
173 included within the theme. A detailed description of concept mapping by Leximancer
174 software was provided by Smith and Humphreys (2006).

175

176 **Results**

177 **Characteristics of the Individuals with Tinnitus**

178 There were 1,522 eligible respondents who completed the survey. Of these, 896 provided free
179 text responses for open-ended questions. The mean tinnitus severity was 23.85 (SD: 10.10)
180 out of 40, indicating tinnitus levels in which such persons might benefit from information
181 counselling and management strategies from healthcare professionals in audiology and/or
182 psychology. The mean tinnitus duration was 15 (SD: 15) years. The average age was 64.05
183 (SD: 11.58) years among an age range of 18-97 years. There were more males (n = 856;
184 56%) than females (n = 651; 43%), with 15 (1%) being gender diverse and/or preferring not
185 to state their gender.

186 **Tinnitus Support Sought Prior to and During the Pandemic**

187 To ascertain support sought during the pandemic, comparisons were made between the
188 support sought prior to and during the pandemic. Analysis of the responses to structured
189 questions indicated that significantly less support was sought during the pandemic, as shown
190 in Figure 1.

191 Linear regression indicated that help seeking was related to tinnitus severity [$F(4) = 5.31, p <$
192 $.001$] and how bothersome tinnitus was (scale of 1-5) [$F(4) = 3.41, p = .009$] in a model
193 excluding help seeking via the internet or helplines. Tinnitus distress was significantly less
194 for those who sought help via their usual clinics ($B = -2.77, SE 1.19; t = -2.33, p = 0.02$), had

195 ongoing support ($B = -1.89$, $SE .73$; $t = 2.60$, $p = 0.01$) or had remote support ($B = -1.51$, SE
196 $.59$; $t = -2.54$, $p = 0.01$).

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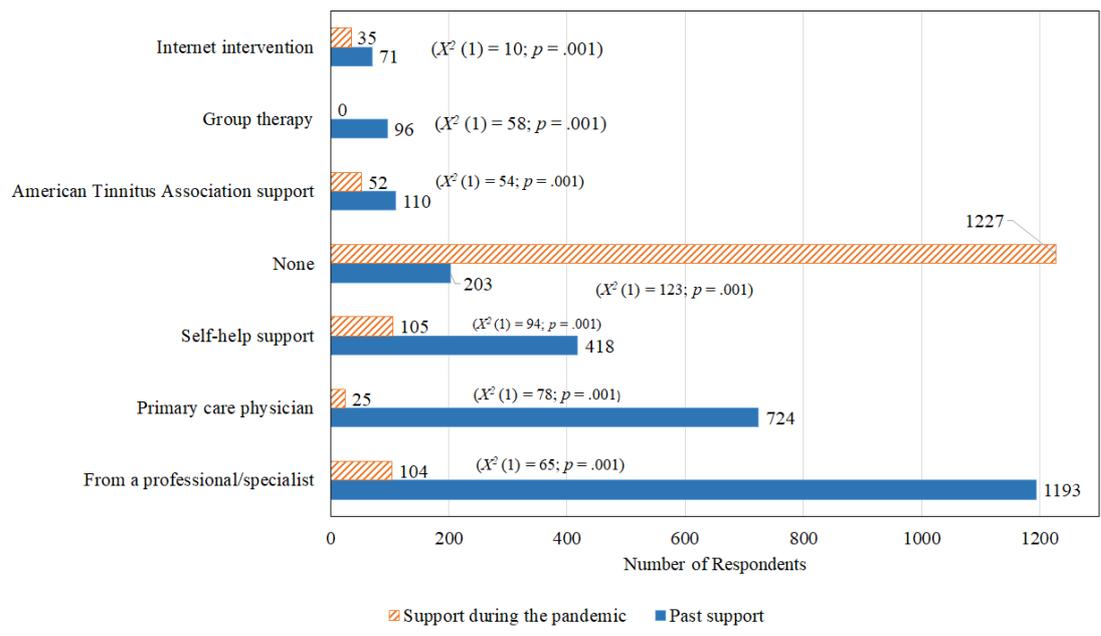
198 Those providing additional free-text responses indicated that less support was sought due to
199 concerns regarding the risks of going out as supported by such statements as, “*My general*
200 *practitioner has referred me to an Ear Nose Throat doctor but I am hesitant to make an*
201 *appointment due to the risks[of infection] involved*” (Male, 60 years, California). Some
202 participants also indicated in free-text responses that they sought help but were unsure where
203 to access it, as noted by such statements as, “*I don’t know what I can do about my tinnitus*
204 *and wish there was information on where to access online help at a time like this*” (Male, 67
205 years, Oklahoma).

206

207 The majority of those who sought additional help rated the support as generally helpful ($n =$
208 $49/74$; 66%) or very helpful ($n = 18/74$; 24%) with 9% ($n = 7/74$) indicating that the support
209 was not helpful. Concerns were raised by 9% ($n = 141$) that they would not be able to access
210 professional help for their tinnitus during the pandemic, as noted by the following statement:
211 “*I hope to see a doctor later as the offices are closed now due to the virus*” (Female, 80 years,
212 Florida).

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217 Figure 1. Comparison of support prior to and during the pandemic. (Chi square analysis
 218 provided in brackets indicating significant differences)

219

220 Prior to the pandemic, 83% (n = 1247/1490) reported not attending a tinnitus support group,
 221 7% reported attending an in-person tinnitus support group (n = 105/1490), 6% (n = 83)
 222 received online support or information from a support group, and 4% (n = 55/1490) from an
 223 online discussion forum. Some indicated a desire to be part of a group and have more
 224 information about tinnitus, as noted by the following statement: *“I would not mind being part
 225 of a tinnitus help group, even if it is online. [I’m] already part of an online hearing support
 226 group that I enjoy very much”* (Female, 79 years, Arizona).

227

228 During the pandemic and at the time of the survey, only 3 individuals (0.2% of the sample)
 229 reported attending an online tinnitus support group as these may not have been readily
 230 available as noted by such statements as *“I think it would be great if Zoom meetings were
 231 available for support groups”* (Female, 77 years, Minnesota). Twenty individuals (2% of the

232 sample) reported being negatively affected by not being able to attend support group
233 meetings during the pandemic, explained as *“I miss my in-person group support. Since the*
234 *pandemic, everything closed down. I am missing support, which leaves me feeling less*
235 *confident in dealing with the ups and downs of everyday tinnitus, and each day I struggle*
236 *with who is stronger, me or tinnitus, as it is on constant[and is a] relentless tyrant at times.”*
237 (Female, 66 years, Massachusetts).

238

239 **Support for Tinnitus-Related Comorbidities**

240 Support may also have been needed for other tinnitus-related comorbidities. In addition to
241 tinnitus, 702 (46%) reported hearing loss, 346 (23%) reported hyperacusis, and 96 (6%) also
242 experienced misophonia (severe annoyance caused by such sounds as chewing and throat
243 clearing). There were 899 (57%) respondents not wearing any devices and 488 (31%) using
244 unilateral or bilateral hearing aids. Other devices used were wearable sound generator/s (n =
245 137, 9%), hearable/s (n = 35; 2%), cochlear implant/s (n = 15; 0.7%) and bone anchored
246 hearing aids (0.3%). Some reported needing devices but being unable to afford them, as noted
247 by the following comment: *“It costs \$4,000 for me to get wearable sound generators to assist*
248 *with my tinnitus. Our family budget cannot afford that. I would like to get financial assistance*
249 *to pay for sound generator treatments”* (Female, 42 years, North Carolina). Concerns were
250 raised by 7% (n = 114) of respondents that they were unable to get support for their hearing-
251 related needs, including hearing aids, during the pandemic. This was supported by such
252 statements as *“My hearing aids were such an expensive investment and I can’t go for my*
253 *check. If something should happen to one or both of them, I am concerned I would not be*
254 *able to get them repaired”* (Female, 67 years, New York) and *“My left hearing aid squeals. I*

255 *am in a retirement home and we are in lockdown, so I am unable to have the aid repaired'*
256 (Female, 85 years, Texas).

257

258 In addition to tinnitus, 70% of respondents reported experiencing additional health
259 problems, including hypertension (n = 455; 30%), back/neck pain (n = 326; 21%),
260 osteoarthritis (n = 273; 18%), chronic allergies (n = 220; 14%), thyroid disease (n = 174;
261 11%), and cancer (n = 134; 9%). For this sample, linear regression indicated that the presence
262 of additional health problems were not associated with tinnitus severity [$F(13) = 1.62, p =$
263 $.07]$ or the degree of bothersome tinnitus (scale of 1-5) was [$F(13) = 1.16, p = .30]$.

264 Obtaining support for additional health problems during the pandemic was a concern raised
265 by 26% (n = 394). This was supported by such statements as *"They need to understand that*
266 *other health problems didn't stop because the coronavirus arrived. People still need*
267 *healthcare"* (Male, 68 years, Oregon).

268

269 In addition to tinnitus, anxiety (n = 503/1840, 27%), depression (n = 424/1840, 23%) and
270 other psychiatric disorders (n = 51/1840, 3%) were reported to have been diagnosed in the
271 past. These conditions were managed through use of medication (n = 373/724; 51%),
272 professional support (n = 178/724, 25%), and online tools (42/724; 6%). For this sample,
273 linear regression indicated that the reporting past diagnosis of a mental health issue was not
274 associated with tinnitus severity [$F(3) = 1.68, p = .17]$ or the degree of bothersome tinnitus
275 (scale of 1-5) was [$F(3) = .71, p = .55]$. No help for mental health concerns was noted by
276 18% (n = 132/724). Seeking support for mental health issues during the pandemic was a
277 concern raised by 4% (n = 56), supported by statements such as *"My anxiety has worsened*
278 *during the pandemic because of my tinnitus, which causes more stress and anxiety—[it's] a*
279 *vicious circle"* (Female, 50 years, Georgia).

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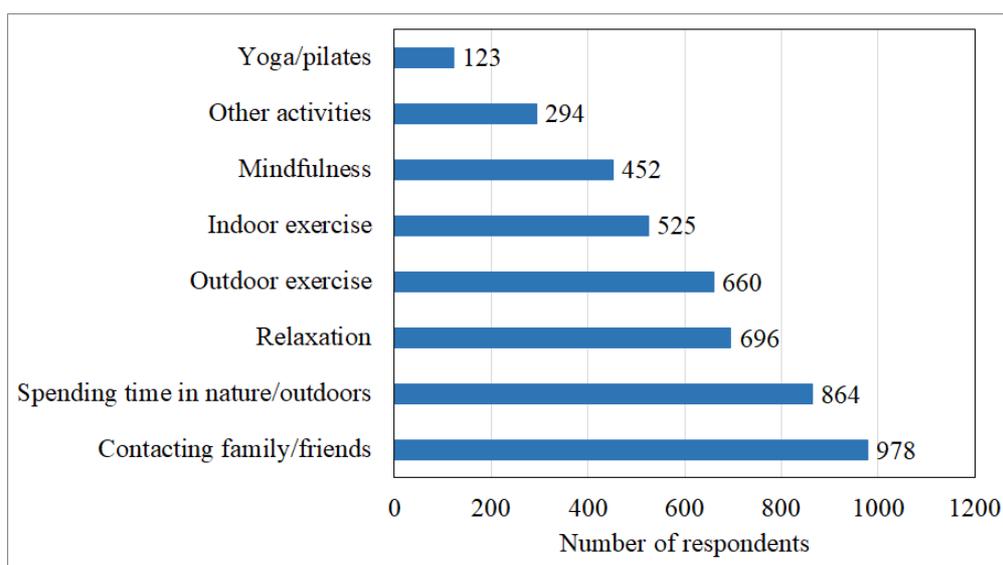
281 **Resources to Cope with the Present Situation**

282 Participants indicated the most frequently utilized resource for coping during the pandemic
283 was family and friends (reported by 65%), followed by spending time outdoors or in nature
284 (reported by 57%), as shown in Figure 2.

285

286 Free-text responses indicated that other support activities for coping included arts and crafts,
287 woodwork, cooking, reading, online courses, pet therapy, music, prayer, movies, gardening,
288 house/yard maintenance, or other projects. Linear regression indicated that using additional
289 resources to cope was related to tinnitus severity [$F(7) = 3.83, p < .001$] and the degree of
290 how bothersome tinnitus (scale of 1-5) [$F(7) = 2.37, p = .02$]. Tinnitus distress was less for
291 those who used relaxation ($B = -2.65, SE 1.13; t = -2.34, p = 0.02$), outdoor exercise ($B = -$
292 $1.51, SE .60; t = 2.53, p = 0.01$) and/or spent time outdoors to cope ($B = -.63, SE .19; t = -$
293 $3.31, p < 0.001$).

294



295

296 Figure 2: Resources used to cope during the pandemic

297

298 For respondents who consume alcohol, 34% (n = 486) reported similar consumption levels
299 during the pandemic, with 16% (n = 218) reporting lower levels due to such things as
300 decreased restaurant visits and social gatherings. However, a smaller percentage (n = 160,
301 11%) reported higher consumption due to more home dining. More substance and drug usage
302 (e.g., marijuana) was reported by 0.5% (n = 8/1393), as noted by the following comment: “[I
303 am] *smoking more marijuana to help me cope with the present stress and to sleep*” (Male, 42
304 year, Canada). Some reported using medication to cope, particularly for sleep, including the
305 use of valium, doxepin, antidepressants, as well as alternative homeopathic remedies.

306

307 Respondents living with others indicated that such individuals were moderately (n = 479,
308 31%) or very (n = 646, 43%) understanding and/or supportive of issues related to their
309 tinnitus, with only 7% (n = 84) feeling that they were not supportive. An example statement
310 was “*I want to discuss my problems with someone who has experienced the debilitating*
311 *events that occur with tinnitus and understand without them rolling their eyes*” (Female, 71
312 years, Colorado). During the pandemic, respondents indicated that the people living with
313 them generally provided similar support (n = 1,074; 92%) compared with prior to the
314 pandemic, and in some cases provided more support (n = 64; 6%), with a few respondents
315 reporting less support (n = 27; 2%).

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317 **Type of Support Required During the Pandemic**

318 Table 1 and Figure 3 present the ACA results for the open-text data to examine the *support*
319 *question* that identified five support themes related to tinnitus, including hearing loss,

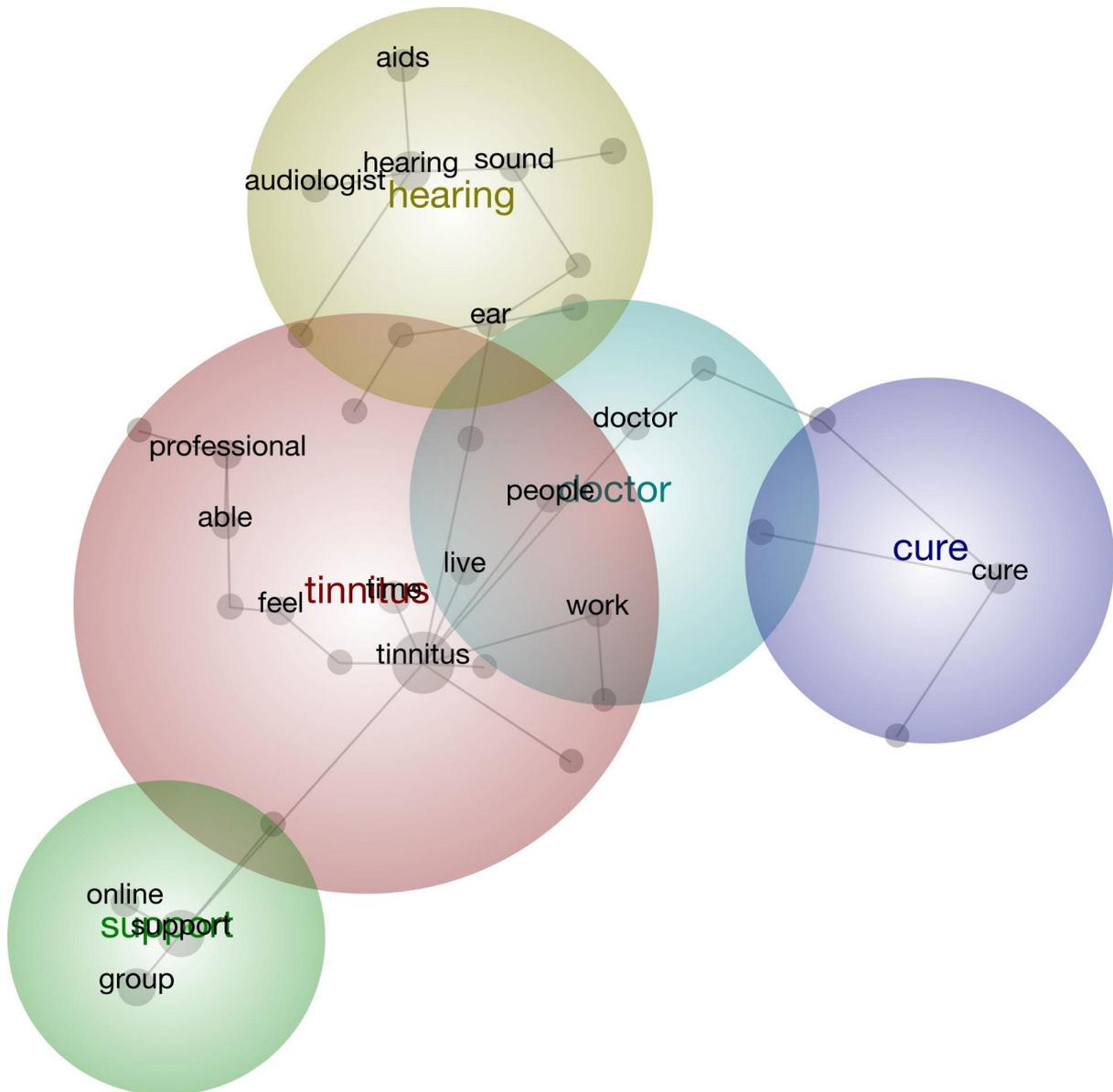
320 providing peer-support, finding a cure for tinnitus, and ensuring access to trained and
 321 understanding doctors to help.

322 **Table 1: Themes and concepts regarding the type of support desired**
 323

Themes	Concepts	Hits	Concepts within the theme	Examples
Tinnitus	tinnitus, time, professional, feel, live, able	304	This theme mainly covered statements that expressed respondent's sentiment that there is no additional support needed and that learning to live with tinnitus is what is needed.	<p>"I do not feel I could do anything better to manage my tinnitus. It was very difficult in the beginning but over the course of time it has gotten easier to live with."</p> <p>"I have learned to live with it and most times, even though it is like having a jet engine in my head, I am able for the most part to tune it out. The worst thing for me to do is dwell on it, discuss it, join groups to discuss it."</p>
Hearing	hearing, aids, ear, sound, audiologist, need	148	This theme covered statements related to respondents' hearing needs (e.g., get hearing checked, hearing aid adjusted) either met or not met during the pandemic lockdown.	<p>"<i>Prior</i> to the coronavirus crisis, I had an appointment to see an audiologist and ENT. I think I probably need hearing aids."</p> <p>"I am unable to see my out-of-state audiologist and my sound generators need adjustment."</p>
Support	support, group, online	146	This theme identified the need for group online support for tinnitus.	<p>"[I'd like a] therapy group online to assist with dealing with the buzzing noise."</p> <p>"[I'd like a] <i>Support</i> group.....online, Zoom, etc."</p>
Cure	cure	92	This theme identifies that some respondents are still looking for a cure and/or have understood that since there is no current cure, they rely on	<p>"<i>Someone</i> discovering a cure!"</p> <p>"Since there is no cure, I cannot expect any management. I take CBD to help me fall asleep."</p>

			symptom management using alternative therapies.	
Doctor	doctor, people, work	81	This theme included statements concerning need to consult with healthcare professionals for tinnitus and/or other general health issues.	<p>“Talking with a doctor that is trained in working with <i>tinnitus</i> issues.”</p> <p>“Busy working and going to doctors. May have walking pneumonia, or permanent scarring on lungs from <i>Covid</i>, takes all [my] time.”</p>

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327 Figure 3: Concept map regarding the type of support desired. The bubbles represent the
 328 themes while the dots within the bubble represent the concepts included within the theme,
 329 and the lines indicate their interconnectedness.

330

331 **Suggestions for Healthcare Professionals and Researchers**

332 Table 2 and Figure 4 present the ACA results for the open-text data to examine the *advice*
 333 *question* that identified six suggestion themes related to tinnitus, finding a cure, personalized
 334 support, addressing hearing loss, addressing the tinnitus percept, and need for more
 335 information.

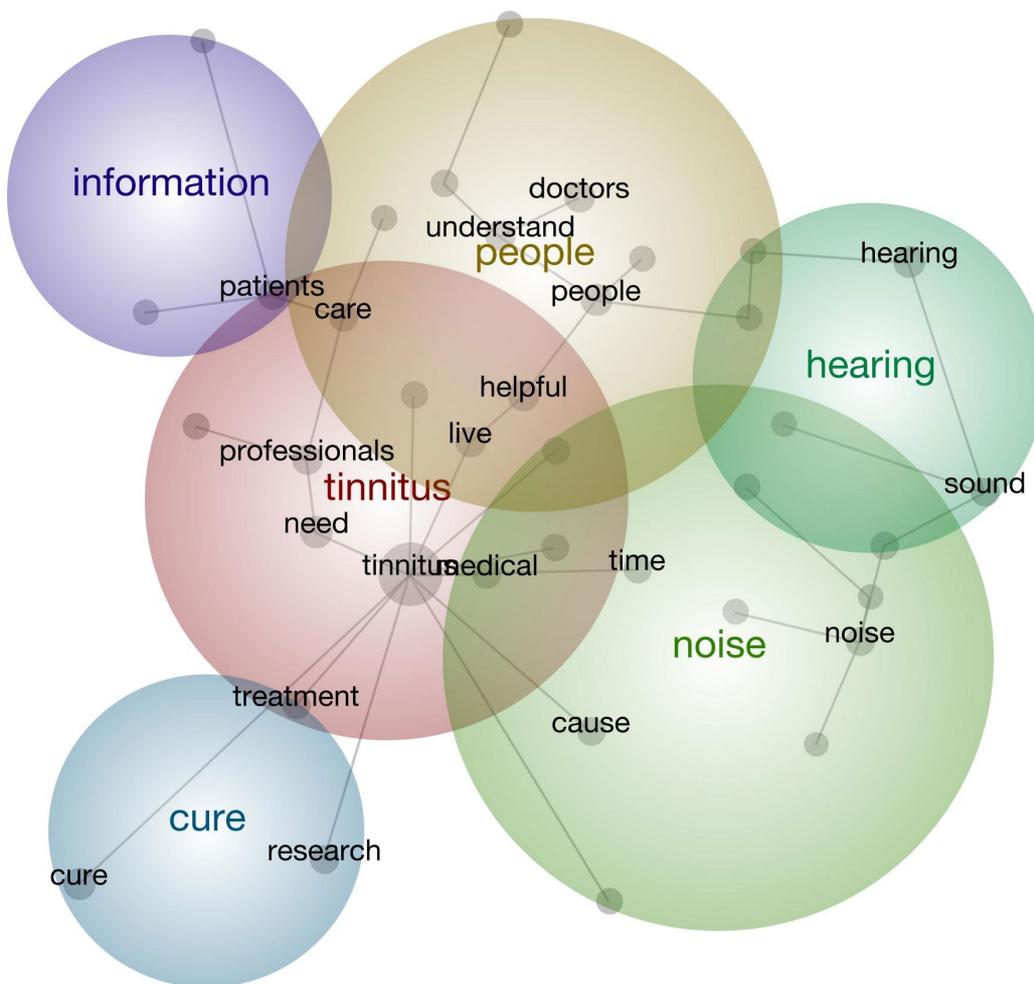
336 **Table 2: Themes and concepts regarding advice/suggestions for healthcare professionals**
 337

Themes	Concepts	Hits	Concepts within the theme	Example
Tinnitus	tinnitus, need, live, professionals, patients, medical, care	468	This theme covered respondents’ suggestions in terms of tinnitus management by improving training for healthcare professionals and also developing evidence-based treatments for tinnitus. Some statements also included suggestions for healthcare professionals to be hopeful when talking to individuals with tinnitus because it is likely to	<p>“Healthcare professionals have to STOP telling tinnitus patients that nothing can be done...go home and live it, there is no cure.”</p> <p>“<i>Healthcare</i> professionals need to be trained to answer questions related to tinnitus and be able to steer us in the right direction as far as what CAN be done to make it less bothersome and [easier] to live with.”</p> <p>“I would like to see a better connection between traditional medical healthcare (“learn to live with it”) and alternative healing methods (several modalities have proven successful).</p>

			help the patient cope.	
Cure	cure, research, treatment	218	This theme recognizes that many individuals with tinnitus are hoping for cures, although they are aware there are no cures currently available.	<p>“<i>Healthcare</i> professionals and researchers must be more vocal in their advocacy for treatment and ultimately cures for tinnitus. Many millions of people have this condition and suffer in silence.”</p> <p>“Find a cure or a truly effective treatment. Be honest but not cruel.”</p>
People	people, helpful, doctors, understand	198	This theme identifies that it is necessary to understand individual needs and experiences related to tinnitus, which may aid in providing personalized support.	<p>“Not a ‘common’ malady. Don't lump people together or make assumptions about [tinnitus] based on limited understanding of what in fact [tinnitus] sufferers individually experience.</p> <p>“Be more understanding of <i>tinnitus</i>. Some doctors think I’m faking it.”</p>
Hearing	hearing, sound, ear	138	This theme covered statements related to respondents’ hearing needs.	<p>“The cross hearing aids are amazing; they can only get better with technology. Adding that extra sound in my good ear seemed to help my tinnitus.”</p> <p>“I was told I had hearing loss, but I couldn't hear all sounds because of the noise in my ear.”</p>
Noise	noise, cause, time	124	This theme specifically covered statements that focused on the need for addressing the tinnitus sound perception rather than its effects.	<p>“I had been using CBD oil 2 to 3 times a day (have not been consistent [recently] since I’m almost out). It seems to help distract/manage/dissipate the noise.”</p> <p>“Find the mechanism in the brain that’s causing all this noise. I know this is being studied and I feel someday it will be found.”</p>

Information	information	26	This theme identified user statements requesting more information and advice, especially through electronic media.	<p>“More communication (i.e. emails, articles, etc.) providing information on coping options.”</p> <p>“Provide ongoing information on promising studies and studies that are available to participate in. It is very hard to find clinical trials for this disease.”</p> <p>“Develop an information program and an actual treatment program.”</p>
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343 Figure 4: Concept map regarding advice/suggestions for healthcare professionals and
344 researchers. The bubbles represent the themes while the dots within the bubble represent the
345 concepts included within the theme, and the lines indicate their interconnectedness.

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347 **Discussion**

348 This study investigated which coping resources people with tinnitus utilized, as well as the
349 support needed (medical and nonmedical) for tinnitus, during the COVID-19 pandemic.

350 When comparing help-seeking, the level of support sought for tinnitus during the pandemic

351 was significantly less than prior to the pandemic. Help sought during the pandemic included

352 both medical and nonmedical help from professional healthcare providers (8%), self-help

353 resources (7%), the American Tinnitus Association (ATA) (3%), and internet interventions

354 (2%). This decrease in help-seeking behavior during the pandemic appeared to be partly

355 attributable to people being unable to access support or not realizing support was available. It

356 could also be that people were afraid to seek care during the pandemic. It was found that

357 tinnitus distress was significantly lower for those that had sought support during the

358 pandemic, either from their usual healthcare or support networks, including online support.

359 .The COVID-19 pandemic undoubtedly disrupted and transformed usual healthcare services,

360 however, these findings demonstrate the need to make services more readily and safely

361 available to people who might benefit from them (Rosenbaum, 2020).

362

363 As tinnitus seldom occurs as an isolated hearing disorder, 46% of the participants reported

364 hearing and/or hyperacusis (23%), and misophonia (6%). Accessing support for these

365 hearing-related difficulties and associated treatment devices, such as hearing aids, was also

366 reported to be problematic. This may be partly attributed to the fact that many audiology

367 clinics had reduced access during the pandemic. A UK-based survey indicated that although
368 the use of tele-audiology is increasing, this was not the case at the start of the pandemic
369 (Saunders & Roughley, 2020). Further development of tele-audiology should be prioritized to
370 ensure continued hearing healthcare support (Beukes et al., 2019; Manchaiah & Beukes,
371 2020; Manchaiah et al., 2020; Swanepoel & Hall, 2020). It was also noted that hearing aids
372 were recommended to help with tinnitus and hearing loss, but respondents were not always
373 able to purchase them because of cost. Due to the detrimental effects of untreated hearing
374 loss, such as increased risk of dementia (Loughrey, Kelly, Kelley, et al., 2018), ensuring
375 access to affordable hearing aids/assistive listening devices should be prioritized (Sinha et al.,
376 2020).

377

378 Seeking help for mental health issues during the pandemic was raised as a concern by 26%,
379 in contrast to only 4% raising concerns about support for other health problems. This may
380 reflect that although most in-person healthcare was disrupted, telehealth was available in
381 some instances and provided a continuation of general healthcare services (Hollander & Carr,
382 2020; Zhou, Snoswell, Harding, Bambling et al., 2020).

383

384 The use of self-guided coping techniques, such as relaxation, exercising outdoors, and
385 spending time outdoors were reported strategies to reduce tinnitus distress during the
386 pandemic. The most frequently used resource for coping with tinnitus during the pandemic
387 was contact with family and friends. The importance of living with supportive people was
388 also highlighted, which underscores the importance of educating significant others on the
389 impact of tinnitus. Other resources that enhanced coping included spending time outdoors
390 and in nature. Relaxation, exercise, and mindfulness were also cited as useful for coping
391 during the pandemic. Tinnitus interventions that incorporate relaxation and mindfulness have

392 been shown repeatedly to reduce tinnitus severity (Beukes et al., 2018a; McKenna, Marks,
393 Hallsworth, & Schaette, 2017). Overall, this survey population appeared to draw on active
394 methods of coping behaviors and to rely less on unhelpful behaviors. Using such coping
395 techniques for managing tinnitus has been found to lower tinnitus severity (Beukes et al.
396 2018b; Fludra et al., 2019), which might have contributed to the overall degree of tinnitus
397 being less severe in this population.

398

399 Tinnitus support groups are often a valuable resource for those with tinnitus because they
400 provide social connectedness and shared social identity (Pryce, Moutela, Bunker, Shaw,
401 2019). Considering this, it was interesting that the majority of respondents (82%) reported not
402 attending a support group prior to the pandemic and very few attended the limited online
403 tinnitus support groups that formed because of the pandemic. Many respondents, even those
404 wanting to join a support group, did not appear to be aware of the existence of support
405 groups, such as those associated with the ATA. The need for peer-support and more
406 information about tinnitus were prominent themes in the analysis of responses related to
407 desired support. As such, more should be done by healthcare professionals and tinnitus
408 patient advocacy associations to actively promote support groups, particularly the cultivation
409 of online groups, which can be accessed by anyone via the internet. This is key since access
410 in-person support groups are generally limited to larger metropolitan areas. Support groups
411 could also share information about current tinnitus research and management strategies,
412 which were other areas of desired support that respondents identified.

413

414 When planning tinnitus support and management services, it is important to include input
415 from those actually experiencing tinnitus (Pryce et al., 2018). Thus, respondents were given
416 the opportunity to make suggestions regarding the help they desired and advice they would

417 give to healthcare professionals. The identified themes for the suggestions and advice were
418 very similar, indicating these are prominent needs within the population. The identified
419 themes included hope for cures, need to understand why they had tinnitus, and what caused
420 the tinnitus. Similar themes have been reported when identifying patient preferences in
421 tinnitus treatments in a UK population (Pryce et al., 2018).

422

423 An additional identified theme was the availability of qualified professionals who understood
424 the impact of tinnitus and could provide management guidance. This indicated a clear need
425 for improvement in tinnitus training for all professionals who might see tinnitus patients (El-
426 Shunnar et al., 2011). A need for accessible internet-based tinnitus interventions, such as
427 those currently being developed for the U.S. (Beukes et al. 2020b; Manchaiah et al., 2020)
428 was also mentioned.

429

430 Another prominent theme was addressing hearing loss. Those with tinnitus often experience
431 hearing difficulties and/or report that tinnitus makes it hard to hear. Addressing hearing loss
432 when present is an important aspect of tinnitus management. During the pandemic this was
433 not always possible. Providers need to ensure that hearing difficulties are appropriately
434 managed using suitable tele-audiology solutions. Respondents also indicated a need for
435 people to be more aware of tinnitus and understand its negative impact. Tinnitus is often
436 reported to be exacerbated in noisy situations, which results in some people limiting social
437 outings. Access to quieter recreational spaces (e.g., restaurants) was also suggested. Overall,
438 these results point to a range of support needed by individuals with tinnitus to effectively
439 manage their tinnitus and its negative effects.

440

441

442 **Limitations and Future Directions**

443 There are numerous limitations in the interpretation of the present study that should be
444 considered. Although this study attempted to capture a wide range of responses from those
445 living with tinnitus in the U.S., it is more biased toward those within the ATA tinnitus
446 community. It could be the case that this population is better informed about managing
447 tinnitus and available support services. Comparisons of these desired support findings to that
448 in other countries should be made.

449 **Clinical Implications**

450 Although it has been many months since the COVID-19 pandemic was declared, many of the
451 social distancing restrictions remain. Healthcare services, especially non-urgent care, have
452 not fully resumed and social interactions remain limited for many people. The impact of this
453 is far reaching for those with tinnitus (Beukes et al., 2020a) and additional support should be
454 provided. It is noteworthy that these findings are patient-driven and are not those of
455 stakeholders or professionals. The findings can therefore guide stakeholders, clinical services,
456 tinnitus organizations, clinical training facilities, and tinnitus support groups. Common
457 themes were the desire for peer support, and more information about research into tinnitus
458 cures and treatments. Participants suggested that more online information, such as talks by
459 professionals and online support groups, would be valued. There was a clear need for
460 effective treatments. Individual and group-based guided cognitive behavioral therapy and/or
461 internet-based interventions may be a means of providing such support (Beukes et al., 2019);
462 at present, few such interventions exist. The pandemic may have a positive impact if the
463 outcome is greater coordination and cooperation among professionals in providing accessible,
464 evidence-based care for individuals with tinnitus.

465

466

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622

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626

627