

Shaping Tinnitus Service Provision in Europe: Lessons From the COVID-19 Pandemic

Eldré W. Beukes,^{1,2} Matheus P.C.G. Lourenco,^{3,4} Lana Biot,⁵ Gerhard Andersson,^{6,7} Viktor Kaldo,^{8,9} Vinaya Manchaiah,^{1,9} & Laure Jacquemin^{10, 11}

1. Department of Speech and Hearing Sciences, Lamar University, Beaumont, Texas, USA
2. Vision and Hearing Sciences Research Group, Anglia Ruskin University, Cambridge, United Kingdom
3. Experimental Health Psychology, Maastricht University, Maastricht, The Netherlands
4. Research Group Health Psychology, KU Leuven University, Leuven, Belgium
5. Faculty of Biomedical, Pharmaceuticals and Veterinary sciences, University of Antwerp, Antwerp, Belgium
6. Department of Behavioral Sciences and Learning, Department of Biomedical and Clinical Sciences, Linköping University, Linköping, Sweden
7. Department of Clinical Neuroscience, Karolinska Institutet, Sweden
8. Department of Psychology, Faculty of Health and Life Sciences, Linnaeus University, Växjö, Sweden.
9. Department of Speech and Hearing, School of Allied Health Sciences, Manipal University, Karnataka, India
10. Department of Translational Neurosciences, Faculty of Medicine and Health Sciences, University of Antwerp, Wilrijk, Belgium
11. Department of Otorhinolaryngology and Head and Neck Surgery, Antwerp University Hospital, Edegem, Belgium

Corresponding author: Dr. Eldré Beukes
Postal address: Department of Speech and Hearing Sciences,
Lamar University, Beaumont, Texas 77710, USA
Email: eldre.beukes@aru.ac.uk
Tel: +1 (409) 880 8927
Fax: +1 (409) 880 2265

Abstract

Background: Tinnitus severity has been exacerbated due to the COVID-19 pandemic and those with tinnitus require additional support. Such support should be informed by patient preferences and needs. The objective of this study was to gather information from individuals with tinnitus living in Europe to inform stakeholders of the (i) support they needed in relation to changes associated with the COVID-19 pandemic, and (ii) suggestions regarding tinnitus care for the future.

Methods: A cross-sectional mixed methods study design was used using closed and open-ended questions via an online survey. Data was gathered from 710 adults experiencing tinnitus in Western Europe, with the majority living in The Netherlands, Belgium, and Sweden. Data were analysed using qualitative content analysis and descriptive statistics.

Results: Those with tinnitus indicated the following support needs during the pandemic (a) support for tinnitus, (b) support for hearing-related difficulties, (c) social support, and (d) pandemic-related support. Five directions for future tinnitus care were provided, namely (a) need for understanding professional support and access to multidisciplinary experts, (b) greater range of therapies and resources, (c) access to more information about tinnitus, (d) prioritizing tinnitus research, and (e) more support for hearing protection and hearing loss prevention

Conclusions: The findings point to the need for accessible (remote), patient-centred, suitable and evidence-based tinnitus care. Insights from the current study can be used by various stakeholders including clinical practitioners and tinnitus support services to ensure those with tinnitus have access to the help and support required in order to reduce service provision insufficiencies.

What's known: Tinnitus severity has been exacerbated due to the COVID-19 pandemic. For some tinnitus has started during the pandemic or as a result of contracting COVID-19. These individuals reported that they require additional support during the pandemic to manage the associated stress and impact on their tinnitus. Such support should be informed by patient preferences and needs, and should hence be investigated.

What's new: Individuals with tinnitus indicated four main support needs during the pandemic, namely support for tinnitus, hearing-related difficulties, social support and pandemic related support. They also indicated directions for future tinnitus care should focus on support from understanding professionals from multidisciplinary teams, a greater range of therapies and resources, access to more tinnitus information, prioritizing tinnitus research and more support for hearing protection and hearing loss prevention.

Key Words

Tinnitus, COVID-19, Service provision, Coping, Self-management, Social support, Tinnitus management, support groups

Introduction

The COVID-19 pandemic has imposed many restrictions and regulations which has disrupted the normal operation of healthcare services in an effort to break the transmission chain and spread of the virus. Restrictive lockdown measures resulted in more than a medical pandemic, they also affected the social and mental health of individuals due to the separation from loved ones, loss of freedom of mobility and choices, uncertainty, and increased stress (Yao, Chen, & Xu, 2020). Moreover, there were cutbacks in healthcare services for many chronic conditions including cancer and orthopedic diseases (e.g., Liebensteiner et al., 2020; Salako et al., 2020) as the healthcare efforts were mainly targeted towards containing the virus and providing immediate support for those who were affected by the virus. In addition, those with health and/or mental health problems may be left with insufficient support to address their difficulties and fears, thus causing their difficulties to escalate (Vindegaard & Benros, 2020).

Populations already at risk for increased anxiety and depression should be monitored to ensure mental health difficulties are not escalated (Beukes et al., 2020a). One population who may be at higher risk are those with tinnitus. Those with tinnitus hear meaningless noises in their head and/or ears when there is no corresponding sound in the surroundings. Tinnitus is a condition that is often associated with emotional distress, anxiety and depression (Salazar, et al., 2019; Trevis, McLachlan, & Wlison, 2018). It can also lead to insomnia, concentration problems and occupational stress (Hall et al 2018). Due to the bidirectional relationship between tinnitus and stress (Mazurek, Szczepek, & Hebert, 2015), the additional stress associated with the pandemic may be a contributing factor to complaints of increased severity of tinnitus noted by some tinnitus clinics (Anzivino, Sciancalepore, Petrone, D'Ella & Quaranta, 2020). Due to the high prevalence of tinnitus, affecting at least 10% of the adult population (Biwas and Hall, 2020; McCormack, Edmondson-Jones, Somerset, and Hall, 2016), prioritizing tinnitus healthcare is needed.

Some studies are emerging looking at the impact of the pandemic on those with tinnitus. For example, 122 tinnitus patients from a clinic in Germany indicated increased levels of stress during the pandemic (Schlee et al., 2020). A global study investigating the impact of the pandemic on 3,103 adults with tinnitus found that during the pandemic pre-existing tinnitus was significantly exacerbated for 32% of the respondents (Beukes et al. 2020a). Contributing factors included the emotional consequences and lifestyle changes such as experiencing loneliness, self-isolating, and sleeping poorly due to increased levels of stress. Increased levels of depression, anxiety and irritability were reported due to financial worries, work changes and health-related concerns. To ensure these difficulties don't escalate, ways to effectively support these individuals should be sought and prioritized together with ensuring help for those who have developed tinnitus or hearing loss following COVID-19 infection (Beukes, et al., 2020a; Munro, Uus, Almufarrij, Chaudhuri, & Yioe, 2020).

The COVID pandemic has forced healthcare services to investigate new ways of working. These have largely been increasing telehealth practices to limit in person contacts. Such directions are driven by healthcare providers and do not always consider patient preferences. For conditions that are multidimensional and heterogeneous such as tinnitus (Beukes et al. 2020b), patient needs and preferences may differ from those of healthcare providers. The importance of patient preferences in determining treatment choices is increasingly recognized (Mulley et al., 2012). Exploring patient preferences for tinnitus care was investigated in England, by Pryce and colleagues (2018) by interviewing 41 patients who had sought help for their tinnitus. This grounded theory study identified that treatment preferences were for individualized care, tailored information and treatment to assist with psychological adjustments and auditory distraction. The importance of every patient having a unique 'tinnitus profile' and needing individualized treatment was also emphasized by Van de Heyning, Gilles, Rabau, and Van Rompaey (2015). Tinnitus services should be informed around these preferences. These preferences may however have changed due to the COVID-19 pandemic and investigating the support required is thus needed. Preferences may also differ depending on the country or region of the service.

The objective of this study was to gather information from individuals with tinnitus living in Europe to inform stakeholders of the (i) support needed in relation to changes associated with the COVID-19 pandemic, and (ii) suggestions regarding tinnitus care for the future.

Methods

Study Design and Ethical Considerations

To fully explore the support needs for individuals with tinnitus during the pandemic, a cross-sectional mixed-methods study design was applied. This study was part of a larger study exploring tinnitus experiences during the pandemic (see Beukes et al. 2020a). Ethical approval was granted by the Faculty of Science and Engineering Research Ethics Panel at Anglia Ruskin University (Cambridge, UK, reference number FSE/FREP/19/927) for international data collection. To distribute between patients attending the clinic at Antwerp University Hospital ethical approval was also obtained from the Committee for Medical Ethics UZA-UAntwerp (file number 20/20/263). The STROBE reporting guidelines (von Elm, et al., 2007) were used to report the methods and results of the study.

Data Collection

Eligibility to complete the survey was adults aged 18 years or older, reporting the presence of tinnitus, providing informed consent, and living in mainland European countries. Multiple recruitment strategies were used including advertisements in the social media outlets, tinnitus

clinics, and via patient organisations including the Tuut van Tegenwoordig in Belgium, Hoorzaken in The Netherlands and the Hörselskadades Riksförbund in Sweden. The aim was to include both clinical and non-clinical populations from a range of different countries. The survey was available in English, Dutch, Portuguese, German and Swedish. It was not available in other languages such as French or Spanish due to limited resources. The survey was launched on 12 May 2020 and available for around 4 weeks. Online informed consent was required before undertaking the survey and only one submission from each IP address was permitted by the survey software. The survey was distributed online via Qualtrics (Qualtrics, 2005). No randomization of the items was used, and respondents were unable to change their responses once submitted. No identifiable data were collected.

For purposes of this analysis, demographic information such as age, gender, tinnitus duration, use of hearing aids, and help-seeking behaviours were collected. To investigate the support required, two open-ended questions were asked, namely:

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

Data Analysis

Data analysis incorporated a mixed approach, including both quantitative and qualitative analysis. The Statistical Package for Social Sciences (IMB SPSS for Windows V.24.0) was used for statistical analyses (IMP Corp, 2016). Descriptive statistics were used to describe the sample characteristics. Continuous variables were summarized with means and standard deviations and categorical variables were described using frequencies and percentages.

The open-ended questions were analysed using qualitative content analysis described by Graneheim and Lundman (2004). Content analysis enables systematic interpretation of participant statements to identify central aspects (a set of condensed categories) that emerge from careful examination of the raw data using a bottom-up approach. Various steps were involved in the process. Initially, the statements were translated to English by bilingual speakers from the research team, who were also native in Dutch, Portuguese or Swedish. The responses were read repeatedly and coded for ‘meaning units,’ which are statements that relate to the same central category. These meaning units formed the units of analysis for coding. The next process was identifying categories that were repeatedly mentioned. The responses that related to the same category were grouped together. Repeated patterns were further grouped until clear condensed categories and subcategories were identified. Codes were then gradually merged into broader categories and subcategories by grouping thematically similar codes together. Categories were then condensed by combining categories with similarities, ensuring that the categories were mutually exclusive until around 8-12 categories were identified. Category labels were assigned. After selecting the codes and categories the original responses were checked to ensure they were in line with the assigned categories and to identify if any additional categories emerged. The data set was rechecked for consistency. The data coding was performed independently by two researchers. The coding was compared and in case of inconsistencies these were discussed.

Results

Characteristics of the Individuals with Tinnitus

There were 710 eligible respondents who completed the survey from mainland Europe. The majority of the respondents were from the Netherlands (46%; n = 326), Belgium (26%; n = 187) and Sweden (n = 14%; 101). Other countries represented included Austria, France, Greece, Germany, France, Turkey, Switzerland, Italy, Spain, Portugal, and Norway. The mean tinnitus duration was 10 (SD: 11) years, with a range of 0.3 to 60 years. The average age was 51 (SD: 15) years with an age range of 18-100 years. There were more females (n = 419; 59%) than males (n = 284; 40%) and 7 (1%) were gender diverse and/or preferred not to state their gender. A majority of the respondents (62%; n = 441) indicated that they were concerned that they would be unable to obtain support for their tinnitus-related concerns when needed during the pandemic. Of these, 398 (56%) provided free text response to open-ended questions.

Support Required to Manage Tinnitus and Hearing-Related Difficulties

Content analysis of responses to the support question identified four main categories, namely (1) tinnitus-specific support, (2) hearing support, (3) social support and (4) pandemic-related support as shown in Figure 1 and outlined in Table 1. Some respondents (n=54; 14%) said they were unsure what support they needed, some stating that this was due to not knowing if anything can help explained by “Nothing has helped in the past” (Spain, Male, 83 years).

(Insert Table 1 and Figure 1 here)

Tinnitus-Specific Support

Tinnitus-specific needs included continued active care and reassurance. Respondents explained how the pandemic resulted in increased stress, low mood, uncertainties, all causing their tinnitus to be more prominent. They explained that they needed continued care. They had a need for contact with professionals and wished they could have a chat with professionals. Requests were made for both remote care and for physical appointments. Some advice had been sought during the pandemic, mostly through internet searches (14%; n = 96), being in contact with their regular clinic (6%; n = 46) and contacting tinnitus associations (6%; n = 40).

Hearing-Related Support

There were 317 respondents (46%) reporting a hearing loss in addition to tinnitus and a further 144 respondents (20%) struggling to understand in background noise. Hearing devices were used by 29% (n = 209), with the majority of these devices being hearing aids worn in both ears (54%; n = 168/310). Respondents found that the pandemic highlighted communication difficulties and this frustration had a negative impact on their tinnitus. They had a need for communication help due to the problems encountered using face masks and social distancing restrictions. These difficulties were amplified during clinical appointments and a need for written information to supplement what was said was mentioned. Overall, 60 respondents (8%) indicated that they were concerned that they were unable to get support for their hearing or hearing aids during the pandemic. They explained a need for hearing aids to ease communication burdens. There were also respondents who needed hearing aids but could not afford these and desired financial support or free hearing care.

Social Support

Respondents explained that they felt lonely, were struggling with tinnitus and had a need to talk to someone about these experiences. Suggestions included a helpline and peer-support groups. The majority (81%; n = 577) explained that they were not part of a tinnitus support group prior to the pandemic. Some of the respondents (18%; n = 131) used online support

and tinnitus discussion forms. The majority mentioned having good support from their friends and family (69%; n= 495); however, 14% (n= 98) indicated their family was not supportive, and 17% (n=120) lived alone. During the pandemic, most respondents reported that this support was unchanged (83%, 532/637), with 12% (n=74/637) reporting more support and 5% (n = 31/637) reporting less support. The open text responses indicated a need for more understanding communities around them. They felt the impact tinnitus has was not understood and awareness should be raised in the media, in workplaces and to friends and family.

Pandemic-Related Support

Personal and financial support was desired due to the impact of the pandemic. Furthermore, support for the solitude, help with the resulting sleep difficulties and anxiety was requested. Also, mentioned were ideas about ways to cope and stay positive. Respondents indicated that the most frequently used resources that were drawn on to cope during the pandemic were contacting friends and family, relaxing and spending time in nature and outdoors, as seen in Figure 2.

(Insert figure 2 here)

Respondents indicated a need for help regarding other health and mental health problems during the pandemic. Depression was reported by 29% (n = 208), anxiety by 23% (n = 162) and other psychiatric disorders by 7% (n = 52) with some respondents reporting both anxiety and depression and/or psychiatric disorders. Although some were receiving help for mental health problems in the form of medication (38%; n = 130), professional support (31%; n = 105) or online interventions (6%; n = 22), as many as 25% (n= 87/344) indicated that they had no support. Also, additional health problems were reported by 52% (n = 372) with the most frequent problems including back or neck pain (13%; n = 111/844), hypertension (12%; n = 98/844) and chronic allergies (9%; 75/844). Overall, there were 19% (n =138) who indicated that they were concerned that they could not get help for other health-related issues. They expressed a desire for more accessible information regarding what help was available and how to get access to it.

Suggestions for Developing Future Tinnitus Services

Content analysis of responses to the advice/suggestion question identified five main categories, namely: (1) need for understanding professional support and multidisciplinary experts, (2) a greater range of therapies and resources, (3) access to more information regarding tinnitus, (4) prioritizing tinnitus research, and (5) more support for hearing protection and hearing loss prevention, are shown in Table 2 and outlined in Figure 3.

(Insert Table 2 and Figure 3 here)

Need for Understanding and Multidisciplinary Experts

Respondents voiced that they needed professionals who were more understanding and knowledgeable. There were accounts of respondents being dismissed and left for deal with the effects of tinnitus alone. They had a desire for a greater range of professionals to support them. Some realized that there was a relationship between their tinnitus and other difficulties and felt access to a multidisciplinary team with ENTs, psychologists, dentists, physiotherapists and audiologists would be helpful.

Need for Greater Range of Therapies

Furthermore, respondents explained that they desired a greater range of therapies such as mindfulness and cognitive behavioural Therapy. They indicated a need to be treated holistically due to the impact of tinnitus on many other areas of their life. Many also expressed desire towards remote resources such as smartphone applications to be available in their first language and not only in English.

Access to More Information

Respondents expressed a clear need for more information regarding tinnitus. Many had specific questions regarding correlations between tinnitus and COVID-19 or the impact of lifestyle on tinnitus. They wanted access to information provided by experts in the form of videos or webinars to keep them updated on treatments and research findings.

Prioritizing Research

Many respondents wished desire towards finding a cure for tinnitus, although a lower number of respondents highlighted the need for effective treatment strategies.

Protecting Hearing

Respondents expressed a need for further preventative measures regarding how to prevent hearing loss and how to protect hearing loss. They indicated that education regarding protecting hearing should start when children are in school.

Discussion

The objective of this study was to find out what support persons with tinnitus desire during the COVID-19 pandemic as well as suggestions for future tinnitus care services. The recommendations made were based on individuals with tinnitus in Western Europe, mostly from The Netherlands, Belgium, and Sweden. This study has provided the opportunity for those with tinnitus to voice their needs, as guideline development does not always consult patient groups and the public (Fuller et al., 2017).

Support Required for Individuals with Tinnitus

Findings indicated four main support categories, namely *tinnitus-specific support*, *hearing support*, *social support* and *pandemic-related support*. The majority of the respondents (62%) indicated concern that they were unable to obtain the support they required for their tinnitus-related difficulties during the pandemic. This included speaking to a professional about changes in their tinnitus, reassurance, concerns about the virus and help for the resulting anxiety, insomnia and emotional difficulties. The COVID-19 pandemic undoubtedly caused significant disruption to usual healthcare services. Viable ways of continuing care, despite the variability of the pandemic situation, should be sought to ensure those who need help can access such help (Rosenbaum, 2020). Due to differing needs, a range of support options should be considered to adapt service provision. These include remote help such as phone and video calls and also in-person appointments depending on the type of problem and the individual's personal situation. In-person appointments have been complicated by the need to ensure additional measures are in place to ensure safe working practices. These include use of personal protective equipment, less people attending appointments and therefore less crowded waiting areas. The drive for remote healthcare has thus been prioritized, which has advantages for some regarding convenience and access of service provision. For some, remote healthcare is not accessible due to technological or communication barriers. Different

levels of service should be considered to accommodate those only needing reassurance in a different way to those who's tinnitus has been severely exacerbated.

Hearing loss is a risk factor for developing tinnitus, and that was reflected on 46% of the participants who reported a hearing loss and 20% hearing difficulties in noise. More support for these hearing related concerns were desired. This included consistent hearing aid care and repair services as well as the ability to do remote fittings. The insurance and public health provision in each country is very variable and numerous respondents expressed a need for amplification but did not have the means to pay for hearing aids. Addressing hearing loss is an important aspect of tinnitus management (Beukes et al. 2020b). As research shows an association between untreated hearing loss and cognitive decline (Loughrey, Kelly, Kelley, Brennan and Lawlor, 2018), ways of providing accessible and affordable hearing care should be prioritized by healthcare services (Sinha et al., 2020). Communication difficulties were expressed due to the social distancing restrictions and use of masks. More needs to be done to assist the hearing impaired such as use of communication application by health professionals, wider use of promoting good communication tactics and manufacturing and use of communication friendly clear masks (Grote & Izagaren, 2020). Exploring the use of technology to aid communication should be advocated, such as the use of transcription and amplification smartphone applications, particularly in healthcare settings. A need for ways of following meetings conducted remotely was furthermore expressed, particularly by those with a hearing loss in employment. Due to the shift to extensive use of video conferencing, this is an urgent need to aid those struggling and using remote means for work, school and other training courses. This includes educating people to switch on video functions to make lip-reading more accessible, using sign-language interpreters where needed and outlining the content of the course or meeting through notes prior to the meeting taking place. Individual difficulties should be accommodated by consulting with individuals to search for possible solutions.

Many respondents mentioned that drawing on support networks from friends and family helped them cope with the uncertainties and increased stress during the pandemic. There were some participants reporting that the people they lived with did not understand them and some who lived alone. Participants also expressed feeling alone and a need to speak to others about their experiences related to the impact on their tinnitus. A need for this social support in the form of online communities, helplines and social support networks was expressed. Respondents also reported that despite the high prevalence of tinnitus, the general population and employees did not recognize the impact tinnitus has on individuals and how stressful situations such as the pandemic could further amplify such experiences. Raising the profile of tinnitus should be a priority of all tinnitus associations and stakeholders. A study looking at media representation of tinnitus in newspapers and the media in the U.S. identified greater coverage of these such as diagnosis and cause, symptoms, social support, research and development, challenges, symptoms and coping (Manchaiah, Ratinaud, & Andersson, 2018). Efforts are needed to both examine and improve access to tinnitus and hearing-related health information in European languages, especially via the electronic media (e.g., social media) from which many users are likely to gather hearing health information (Manchaiah et al., 2020a).

Tinnitus support groups are often a valuable resource to those with tinnitus as they provide social connectedness and shared social identification (Pryce, Moutela, Bunker, & Shaw, 2019). Considering this, it was interesting that the majority of respondents (82%) reported not attending a support group prior to the pandemic and very few attended an online tinnitus

support group during the pandemic. Many respondents did not appear to be aware of the existence of support groups and reported missing being part of a support group. The need for peer-support and more information about tinnitus was a prominent request during analysis of the responses, regarding what further support is desired. More should be done to actively promote such support groups by both professionals and tinnitus support associations. Cultivating online groups should be prioritized. This could also improve support for those in geographical areas where in-person support groups were not available prior to the pandemic. These groups could also share information regarding current tinnitus research and management strategies, which were other areas of needed support that were identified.

The pandemic led to various personal and financial needs which resulted in increased anxieties and levels of stress. These impacted aspects such as sleep, and respondents expressed a need for help to cope and stay positive during the pandemic. Resources that have been found helpful by some such as making time to relax, exercise and spend time outdoors should be encouraged. COVID-19 information should focus on coping advice together with advice on avoiding contracting the virus. Respondents with additional health and mental health related concerns indicated a need for continued healthcare despite the pandemic. Implementation of telehealth may increase for times when face-to-face healthcare is not possible (Hollander & Carr, 2020; Zhou, Snoswell, Harding, Bambling et al., 2020).

Suggestions for Future Tinnitus Services

The pandemic has forced tinnitus support and clinical services to redesign their service provision to adapt to the changes imposed due to the safety restrictions. Incorporating advice from those with tinnitus during these considerations will ensure the suitability of such service provision. When planning tinnitus support and management services, it is important to allow for input from those actually experiencing tinnitus (Pryce et al. 2018) to increase the suitability of such services.

From this study five directions for future tinnitus care were provided, namely a need for understanding, access to multidisciplinary experts, a greater range of therapies and resources, access to more information, prioritizing research and protecting hearing. Similar findings have been reported when identifying patient preferences in tinnitus treatments in the UK population for individualized care, tailored information and treatment to assist with psychological adjustment and auditory distraction (Pryce et al., 2018). A clear need for understanding and knowledgeable professionals were voiced as some respondents felt unheard and unsupported. They also identified a need to see more experts and a greater range of therapies as they mentioned additional concerns that they associated with tinnitus such as neck or jaw problems. A multidisciplinary approach to managing tinnitus has been shown to be helpful such as including physiotherapy to help provide neck exercises when required (Michiels et al., 2016).

There was also a clear need for psychological input to help with comorbid anxiety and depression. Psychological-based tinnitus therapies such as mindfulness and cognitive behavioural therapy that incorporate relaxation and mindfulness have often been shown to reduce tinnitus distress (Beukes et al., 2018a,b; McKenna, Marks, Hallsworth, & Schaette, 2017). The restrictions of meeting in person due to the pandemic have strengthened the urgent need for further development of tele-audiology and this should be prioritized to ensure continued support is available (Beukes et al., 2019; Manchaiah & Beukes, 2020; Manchaiah et al., 2020b; Swanepoel & Hall, 2020). A need for remote resources such as smartphone applications to be in European languages was also expressed. The advantage of remote

interventions such as internet-based interventions, is the ability to translate them into different languages as has been done for some languages (Andersson et al., 2002; Beukes et al. 2020c; Jasper et al. 2014).

Access to reliable sources of tinnitus information by experts was highlighted by respondents. Finding reliable information on the internet can be difficult (Manchaiah et al., 2018, 2020a). They were particularly interested in current information such as the association between tinnitus and COVID-19 and current research themes. Tinnitus stakeholders should unite efforts to make this information available in a united way and increase the availability of expert videos and webinars. A final suggestion was increasing tinnitus research capacity and funding with a focus on effective treatments and finding a cure for tinnitus.

Clinical Implications

The wider impact of the COVID-19 pandemic has been far reaching on those with tinnitus (Beukes et al., 2020a). The pandemic also provides the opportunity to re-evaluate current healthcare provision and how to strengthen it. This provision has not been readily accessible during the pandemic and a clear need for continued care for tinnitus-related concerns was expressed. Stakeholders should be aware of this additional need and finding ways of providing additional assistance. In addition, ways to address other support needs such as for increased hearing-related difficulties amplified by face masks, video conferencing and social distancing restrictions are required. Clinical and support services should investigate ways of enabling positive social support, peer support and understanding communities, families and friends to further support those with tinnitus. To reduce the financial and emotional burdens of the pandemic, ways of helping with practical aspects and stress reduction should be actively pursued.

Limitations and Future Directions

There are certain limitations in the interpretation of the present study that should be considered. Although this study attempted to capture a wide range of responses from those living in mainland Europe, the respondents were mainly from the Netherlands, Belgium and Sweden. This was partly related to the survey not being available in other languages such as French and Spanish. Future studies should aim to be more inclusive. The results may thus not be fully generalizable to other populations. The data was collected from high-income countries and the suggestions may not be extrapolated to other eastern European countries or low-income countries. In many countries where basic healthcare is limited, the support needs are likely to be very different. Support for these individuals will thus be very different from the support identified from the populations from this study. Furthermore, recruitment was mostly via social media and the respondents may not represent a clinical population of those with tinnitus. Due to the heterogeneous nature of tinnitus and the heterogeneous population, these results will not be generalizable to all populations. This exploratory study has, however, highlighted many themes that need further research. It must also be considered for interpretation purposes that responses may have been influenced by the current pandemic, and the advice regarding future directions may be very different if collected prior to the pandemic. One aspect that was not investigated was preference for outcomes for tinnitus management in Europe. Preferences expressed by those based in England were to remove the tinnitus perception and improve ways of coping and managing tinnitus (Pryce et al. 2018) which can guide research developments. Moreover, there is a need for European clinical guidelines, as clinical practices in tinnitus healthcare vary largely across countries (Cima et al., 2020).

In conclusion, there is a clear need for effective treatments. Individual and group-based guided at present, few such interventions exist. The pandemic may have a positive impact if the outcome is greater coordination and cooperation among professionals in providing tailored, individualised, accessible and evidence-based care for those with tinnitus.

Authorship

This study was conceptualized by EB and designed by EB & VM. Data collection was by EB, VM, GA, VK, LJ, and ML. Data analysis was by EB and LB and interpretation and drafting the article was done by EB. All authors critically revised the article and approved the version to be published.

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Conflict of Interest

The authors have no conflicts of interest to declare

References

- Andersson, G., Strömberg, T., Ström, T., & Lyttkens, L. (2002). Randomised controlled trial of Internet-based cognitive behavior therapy for distress associated with tinnitus. *Psychosomatic Medicine*, 64, 810–816.
- Anzivino, R., Sciancalepore, P., Petrone, P., D'ella, A., & Quaranta, N. (2020). Anzivino, Roberta, et al. "Tinnitus revival during COVID-19 lockdown: how to deal with it? *European Archives of Oto-Rhino-Laryngology*, 1-2.
- Beukes, E. W., Baguley, D. M., Allen, P. M., Manchaiah, V., & Andersson, G. (2018a). Audiologist-guided Internet-based cognitive behavior therapy for adults with tinnitus in the United Kingdom: A randomized controlled trial. *Ear and Hearing*, 39(3), 423-433.
- Beukes, E. W., Andersson, G., Allen, P. M., Manchaiah, V., & Baguley, D. M. (2018b). Effectiveness of guided internet-based cognitive behavioral therapy vs face-to-face clinical care for treatment of tinnitus: a randomized clinical trial. *JAMA Otolaryngology–Head & Neck Surgery*, 144(12), 1126-1133.
- Beukes, E. W., Manchaiah, V., Allen, P. M., Baguley, D. M., & Andersson, G. (2019). Internet-based interventions for adults with hearing loss, tinnitus, and vestibular disorders: A systematic review and meta-analysis. *Trends in Hearing*, 23, 2331216519851749.
- Beukes, E.W., Baguley, D.M., Jacquemin, L. Lourenco, M.P.C.G., Allen, P.A.,

Onozuka, J., Stockdale, D., Kaldo, V., Andersson, G., Manchaiah, V. (2020a) Changes in Tinnitus Experiences during the COVID-19 Pandemic. *Frontiers in Public Health*, 2020; 8 Doi: 10.3389/fpubh.2020.592878.

Beukes, E.W., Manchaiah, V. Andersson, G., Kaldo, V., Baguley, Allen, P.A., D.M., Jacquemin, L. Lourenco, M.P.C.G., Stockdale, D., Onozuka, J. & Maidment, D. (2020b). Are tinnitus subgroups based on hearing-related difficulties. Submitted.

Beukes, E. W., Fagelson, M., Aronson, E. P., Munoz, M. F., Andersson, G., & Manchaiah, V. (2020c). Readability following cultural and linguistic adaptations of an Internet-based Intervention for Tinnitus for use in the United States. *American Journal of Audiology*, 1-13.

Bhatt, J., Harrison, W., Lin, M., & Bhattacharyya, M. (2016). Prevalence, Severity, Exposures, and Treatment Patterns of Tinnitus in the United States. *JAMA Otolaryngol Head Neck Surgery*, 142(10), 959-965.

Biswas R., Hall D.A. (2020) Epidemiology of Tinnitus. In: . Current Topics in Behavioral Neurosciences. Springer, Berlin, Heidelberg. https://doi.org/10.1007/7854_2020_154

Cima, R. F. F., Kikidis, D., Mazurek, B., Haider, H., Cederroth, C. R., Norena, A., . . . Hoare, D. J. (2020). Tinnitus healthcare: a survey revealing extensive variation in opinion and practices across Europe. *10(1)*, e029346. doi:10.1136/bmjopen-2019-029346 %J BMJ Open

El-Shunnar, S. K., Hoare, D. J., Smith, S., Gander, P. E., Kang, S., Fackrell, K., & Hall, D. A. (2011). Primary care for tinnitus: practice and opinion among GPs in England. *Journal of Evaluation in Clinical Practice*, 17(4), 684–692. <https://doi.org/10.1111/j.1365-2753.2011.01696.x>

Fludra, M., Kobosko, J., Gos, E., Karendys-Łuszcz, K., & Skarżyński, H. (2020). Role of personal resources from the perspective of experiencing tinnitus annoyance in adults. *European Archives of Oto-Rhino-Laryngology* (2020) 277:1617–1623. doi.org/10.1007/s00405-020-05843-w.

Fuller, T. E., Haider, H. F., Kikidis, D., Lapira, A., Mazurek, B., Norena, A., . . . Cima, R. F. F. (2017). Different Teams, Same Conclusions? A Systematic Review of Existing Clinical Guidelines for the Assessment and Treatment of Tinnitus in Adults. 8(206). doi:10.3389/fpsyg.2017.00206.

Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24:105-112.

Grote, H., Izagaren, F. (2020). Covid-19: The communication needs of D/deaf healthcare workers and patients are being forgotten. [online] Available at: <https://blogs.bmj.com/bmj/2020/05/07/push-universal-mask-wearing-communication-needs-deaf-forgotten/> [Accessed 22 October 2020].

Hall, D.A., Fackrell, K., Li, A.B. *et al.* A narrative synthesis of research evidence for tinnitus-related complaints as reported by patients and their significant others. *Health Qual Life Outcomes* 16, 61 (2018). <https://doi.org/10.1186/s12955-018-0888-9>

Hollander, J. E., & Carr, B. G. (2020). Virtually perfect? Telemedicine for COVID-19. *New England Journal of Medicine*, 382(18), 1679-1681. doi: 10.1056/NEJMp2003539

IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.

Jasper, K., Weise, C., Conrad, I., Andersson, G., Hiller, W., & Kleinstäuber, M. (2014). Internet-based guided self-help versus group cognitive behavioral therapy for chronic tinnitus: a randomized controlled trial. *Psychotherapy and psychosomatics*, 83(4), 234-246.

Liebensteiner, M. C., I. Khosravi, M. T. Hirschmann, P. R. Heuberger, and The Board of the AGA-Society. "Massive cutback in orthopaedic healthcare services due to the COVID-19 pandemic." *Knee Surgery, Sports Traumatology, Arthroscopy* (2020): 1.

Loughrey, D. G., Kelly, M. E., Kelley, G. A., Brennan, S., & Lawlor, B. A. (2018). Association of age-related hearing loss with cognitive function, cognitive impairment, and dementia: a systematic review and meta-analysis. *JAMA otolaryngology–head & neck surgery*, 144(2), 115-126. doi:10.1001/jamaoto.2017.2513

Manchaiah, V. & Beukes, E.W. (2020). How to develop and deliver an audiological Internet-based intervention. *The Hearing Journal*, April 23, 2020. <https://journals.lww.com/thehearingjournal/blog/onlinefirst/pages/post.aspx?PostID=61>

Manchaiah, V., Ratinaud, P., & Andersson, G. (2018). Representation of tinnitus in the US newspaper media and in Facebook pages: Cross-sectional analysis of secondary data. *Interactive Journal of Medical Research*, 7(1), e9.

Manchaiah, V., Bellon-Harn, M. L., Kelly-Campbell, R. J., Beukes, E. W., Bailey, A., & Pyykkö, I. (2020a). Media use by older adults with hearing loss: An exploratory survey. *American Journal of Audiology*, 29(2), 218–225. https://doi.org/10.1044/2020_AJA-19-00039

Manchaiah, V., Valescu, G., Varadaraj, S., Aronson, E.P., Fagelson, M.A., Munoz, M.F., Andersson, G. & Beukes, E.W. (2020b). Features, functionality, and acceptability of Internet-based cognitive behavioral therapy for tinnitus in the United States. *American Journal of Audiology*, 29(3), 476-490. https://doi.org/10.1044/2020_AJA-20-00002

McKenna, L., Marks, E. M., Hallsworth, C. A., & Schaeffer, R. (2017). Mindfulness-based cognitive therapy as a treatment for chronic tinnitus: a randomized controlled trial. *Psychotherapy and Psychosomatics*, 86(6), 351-361.

Mazurek, B., Haupt, H., Olze, H., & Szczepek, A. (2012). Stress and tinnitus—from bedside to bench and back. *Frontiers in Systems Neuroscience*, 11(6), 47.

McCormack, A., Edmondson-Jones, M., Somerset, S., & Hall, D. (2016). A systematic review of the reporting of tinnitus prevalence and severity. *Hearing Research*, 337, 70–79. <https://doi.org/10.1016/j.heares.2016.05.009>

Michiels, S., Naessens, S., Van de Heyning, P., Braem, M., Visscher, C. M., Gilles, A., & De Hertogh, W. (2016). The Effect of Physical Therapy Treatment in Patients with Subjective Tinnitus: A Systematic Review. *Frontiers in neuroscience, 10*, 545.
<https://doi.org/10.3389/fnins.2016.00545>

Mulley, A., C. Trimble, and G. Elwyn. 2012. Patient preferences matter. The King's Fund.

Munro, K., Uus, K., Almufarrij, I., Chaudhuri, N., & Yioe, V. (2020). Persistent self-reported changes in hearing and tinnitus in post-hospitalisation COVID-19 cases. *International Journal of Audiology*. doi:<https://doi.org/10.1080/14992027.2020.1798519>

Muzurek, B., Boecking, B., & Brueggemann, P. (2019). Association Between Stress and Tinnitus—New Aspects. *Otology & Neurotology, 40*(4), e467-e473.

Newman, C. W., Sandridge, S. A., & Bolek, L. (2008). Development and psychometric adequacy of the screening version of the tinnitus handicap inventory. *Otology & Neurotology, 29*(3), 276-281.

Newman, D., Noh, Y., Talley, E., Karimi, S., & Baldwin, T. (2010). Evaluating topic models for digital libraries. Paper presented at the proceedings of the 10th annual joint conference on digital libraries, Gold Coast.

Nunez-Mir, G. C., Iannone, B. V., Pijanowski, B. C., Kong, N., & Fei, S. (2016). Automated content analysis: Addressing the big literature challenge in ecology and evolution. *Methods in Ecology and Evolution, 7*(11), 1262–1272.

Pryce, H., Hall, A., Shaw, R., Culhane, B. A., Swift, S., Straus, J., & Claesen, B. (2018). Patient preferences in tinnitus outcomes and treatments: a qualitative study. *International Journal of Audiology, 57*(10), 784-790. doi: 10.1080/14992027.2018.1484184

Pryce, H., Moutela, T., Bunker, C., & Shaw, R. (2019). Tinnitus groups: A model of social support and social connectedness from peer interaction. *British Journal of Health Psychology, 24*(4), 913-930. doi: 10.1111/bjhp.12386

Qualtrics (2005). Provo, Utah, US. Available at <https://www.qualtrics.com>

Rosenbaum, L. (2020). The untold toll—the pandemic’s effects on patients without Covid-19. *The New England Journal of Medicine. 382*:2368-2371. doi: 10.1056/NEJMms2009984.

Salako, O., Okunade, K., Allsop, M., Habeebu, M., Toyee, M., Oluyede, G., ... & Salako, B. (2020). Upheaval in cancer care during the COVID-19 outbreak. *ecancermedicalscience, 14*.

Salazar, J., Meisel, K., Smith, E., Quiggle, A., McCoy, D., & Amans, M. (2019). Depression in Patients with Tinnitus: A Systematic Review. *Otolaryngology–Head and Neck Surgery, 16*(1), 28-35.

Saunders, G. H., & Roughley, A. (2020). Audiology in the time of COVID-19: practices and opinions of audiologists in the UK. *International Journal of Audiology*, doi:10.1080/14992027.2020.1814432.

Schlee, W., Hølleland, S.; Bulla, J.; Simoes, J.; Neff, P.; Schoisswohl, S.; Woelflick, S.; Schecklmann, M.; Schiller, A.; Staudinger, S.; Probst, T.; Langguth, B. The Effect of Environmental Stressors on Tinnitus: A Prospective Longitudinal Study on the Impact of the COVID-19 Pandemic. *J. Clin. Med.* 2020, 9, 2756.

Shargorodsky, J., Curhan, G., & Farwell, W. (2010). Prevalence and characteristics of tinnitus among US adults. *The American Journal of Medicine*, 711-718.

Sinha, S., Irani, U.D., Manchaiah, V. & Bhamla, M.S. (2020). Addressing age-related hearing loss through engineering accessible and affordable hearing technology. *PLoS ONE*, 15(9), e0238922. <https://doi.org/10.1371/journal.pone.0238922>

Smith, A. E., & Humphreys, M. S. (2006). Evaluation of unsupervised semantic mapping of natural language with Leximancer concept mapping. *Behavior Research Methods*, 38(2), 262–279.

Swanepoel, D, & Hall, J.W. (2020). Making Audiology Work During COVID-19 and Beyond. *The Hearing Journal*, June 2020, 73(6), 20-24.[doi:10.1097/01.HJ.0000669852.90548.75](https://doi.org/10.1097/01.HJ.0000669852.90548.75).

Trevis, K., McLachlan, N., & Wlison, S. (2018). A systematic review and meta-analysis of psychological functioning in chronic tinnitus. *Clinical Psychology Review*, 60, 62-86.

Van de Heyning, P., Gilles, A., Rabau, S., & Van Rompaey, V. (2015). Subjective tinnitus assessment and treatment in clinical practice: the necessity of personalized medicine. *Curr Opin Otolaryngol Head Neck Surg*, 23(5), 369-375. [doi:10.1097/moo.0000000000000183](https://doi.org/10.1097/moo.0000000000000183).

Vindegaard, N., & Benros, M. (2020). COVID-19 pandemic and mental health consequences: Systematic review of the current evidence. *Brain, Behavior, and Immunity*, <https://doi.org/10.1016/j.bbi.2020.05.048>.

von Elm, E., Altman, D., Egger, M., Pocock, S., Gotsche, P., & Vandembroucke, J. (2007). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. *Lancet*, 370(9596), 1453-1457. [doi:10.1016/S0140-6736\(07\)61602-X](https://doi.org/10.1016/S0140-6736(07)61602-X).

World Health Organization. (2020). *Coronavirus disease 2019 (COVID-19): situation report*. Geneva, Switzerland: WHO. Retrieved from <https://www.worldometers.info/coronavirus/>

Yao, H., Chen, J.-H., & Xu, Y.-F. (2020). Patients with mental health disorders in the COVID-19 epidemic. *Lancet Psychiatry*, 7(4), e21.

Zhou, X., Snoswell, C. L., Harding, L. E., Bambling, M., Edirippulige, S., Bai, X., & Smith, A. C. (2020). The role of telehealth in reducing the mental health burden from COVID-19. *Telemedicine and e-Health*, 26(4), 377-379. [doi: 10.1089/tmj.2020.0068](https://doi.org/10.1089/tmj.2020.0068)

Figure and Table Legends

Table 1: Support needed for managing tinnitus

Category	Subcategory	Number of responses	Examples
Tinnitus support	Active care	44	<p>Possibility of physical contact with hearing specialists instead of by telephone. In my case, by telephone is almost impossible (The Netherlands, Female, 50 years).</p> <p>Finding an audiologist that I can have on a permanent basis. Continuity in the health care chain (Sweden, Female, 65 years).</p>
	Reassurance	25	<p>More support during increased stress due to the pandemic. Don't say it's just anxiety or their imagination. Try to reassure them that the virus will pass and that there's many things they can do to prevent themselves from getting it (Germany, Female, 26 years).</p> <p>Even though I know I'm not crazy, sometimes I need reassurance. As it's really-really bad, at the moment I feel very vulnerable. (France, Female, 60 years).</p>
Hearing support	Communication help	15	<p>Communication problems because of the mandatory distance and face masks during medical appointments (Belgium, Female, 40 years)</p> <p>Help for young and employed hearing impaired persons for Zoom meetings to have these transcribed and interpreted in sign language. (Sweden, Female, 31 years)</p>
	Hearing devices	31	<p>Hearing aid help during pandemic. (Belgium, Male, 73 years)</p> <p>Financial support for hearing aids. (The Netherlands, Female, 62 years).</p>
Social support	Peer-Support	34	<p>More support groups/therapy groups. Support from others in similar situation important, good to share experiences. (Sweden, Female, 57 years)</p> <p>A helpline to help the thought of not being alone. (Sweden, Female, 45 years)</p>

	Understanding communities	17	<p>More discussion of tinnitus on media. (France, Male, 71 years)</p> <p>Raising awareness to colleagues and employers and awareness of the mental health implications. (France, Female, 56 years)</p>
Pandemic support	Ways of coping	68	<p>Care for well-being, posture and stimulating good social relationships, reducing stress and prolonged period of solitude (being alone). (Portugal, Male, 57 years)</p> <p>I believe that it is anxiety for the Corona situation. Everything is so uncertain and insecure, that makes tinnitus and anxiety increase. Perhaps more focus on psychological wellbeing would be good. Even if one, like me, gives the appearance of being strong and stable. (Sweden, Female, 68 years)</p>
	Healthcare	20	<p>Information on where/when and with what one can get help, and when it's open. (Sweden, Female, 39 years)</p> <p>Other health problems (having cancer) have affected my tinnitus. (The Netherlands, Female, 52 years)</p>

Table 2. Suggestions for developing tinnitus care

	Sub-category	Number of responses	Examples
Experts	Understanding professionals	37	<p>I feel sometimes I'm just being dismissed by my hearing doctor because nothing one can do. I feel they don't understand. Try to be more understanding. (France, Female, 64 years)</p> <p>I have experienced that there are quite some ear specialists that do not take tinnitus seriously. Empathetic ability needs to increase on the whole. (Sweden, Male, 72 years).</p>
	Multidisciplinary specialists	24	Talking to a psychologist due to the mental health implication. (The Netherlands, Female, 57 years)

			<p>Listen to the patient. I am totally convinced that my tinnitus has something to do with my jaws. I believe it would be more efficient to be allowed to go to an orthodontist. (Belgium, Male, 55 years)</p>
Therapies	Greater range of therapies	30	<p>More capacity for treatments like Internet CBT (cognitive behavioural therapy). (The Netherlands, Female, 46 years)</p> <p>More counselling/therapy and group meetings, even relaxation clinics like massages. (Sweden, Female, 50 years)</p>
	Remote resources	24	<p>Online training to help manage tinnitus with relaxation techniques and art assignments. (The Netherlands, Female, 52 years)</p> <p>Mindfulness apps in Dutch. (The Netherlands, Female, 63 years)</p>
Information	Increase knowledge	47	<p>Information about the correlation regarding tinnitus and COVID-19. (The Netherlands, Male, 51 years)</p> <p>Information on the impact of healthy living, relaxation, diet and exercise on tinnitus. (Belgium, Female, 52 years)</p>
	Management options	21	<p>What works best- everything I tried was unhelpful. (Norway, Male, 26 years)</p> <p>The material on tinnitus should include a chapter on handling tinnitus at life's emergency moments how I enhance all my routines to match the extra stress it could be other things-a death in the family, a layoff. (Sweden, Female, 59 years)</p>
Research	Cure	51	<p>Focus on finding a cure. (The Netherlands, Male, 24 years)</p> <p>Organize a global challenge with an unbelievable money prize like a billion or something to the one/those who solve or create a medicine. It has been done before with other problems. (Sweden, Male, 56 years)</p>

	Treatments	27	<p>Research into effective treatments (Belgium, Female, 24 years)</p> <p>Research into neck problems and tinnitus by chiropractors. (Sweden, Female, 56 years)</p>
Prevention	Education	17	<p>I think the best thing is preventive measures for the individual, at school and at work regarding hearing loss/ tinnitus. Interventions for children, youth and adults. Correct and qualified occupational guidance. (Sweden, Female, 48 years)</p> <p>Raise awareness under young people. (Belgium, Male, 25 years)</p>
	Protection	9	<p>I would like there to be more investment in preventive measures. Workplace-proper ear protection. Listening to music headphones and earphones. Very noisy environments. (Sweden, Female, 50 years)</p> <p>Hearing protection is needed for those with tinnitus. (The Netherlands, Female, 46 years)</p>

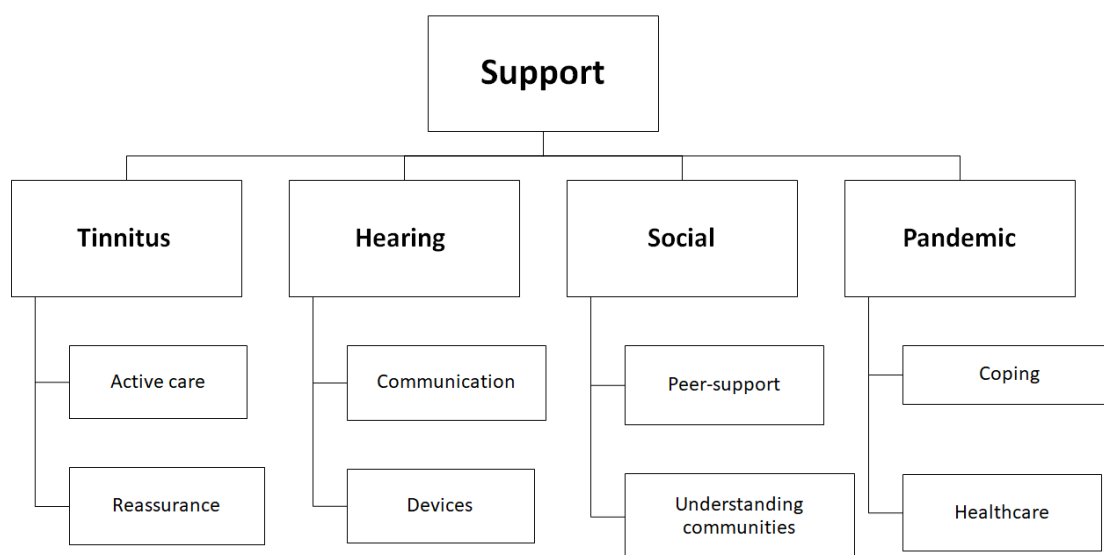


Figure 1: Outline of the support desired by individuals with tinnitus. See Table 1 for explanation of these categories

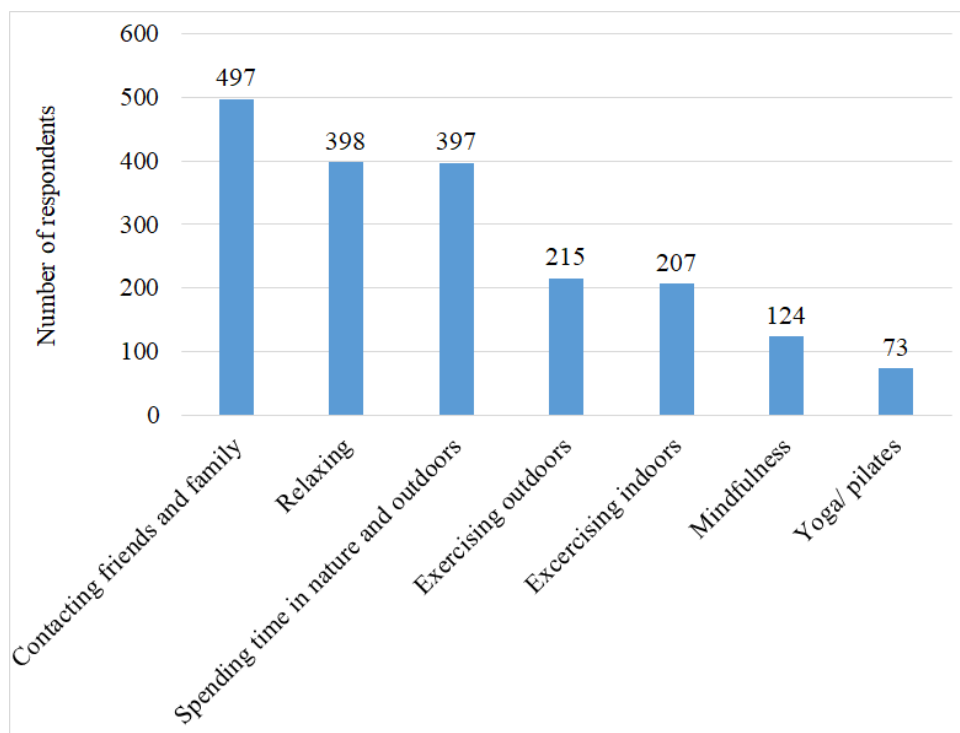


Figure 2. Resources drawn on to cope during the pandemic.

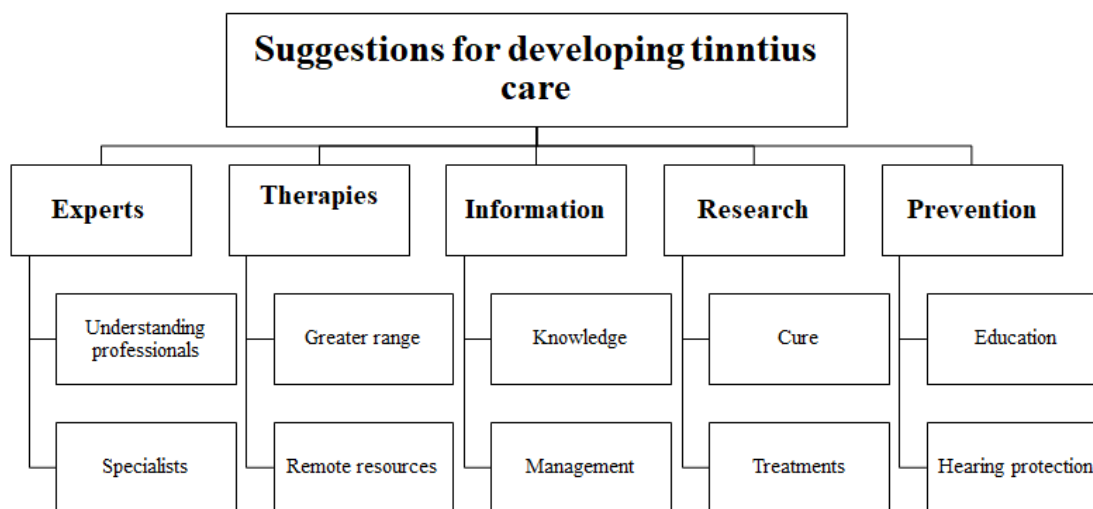


Figure 3. Overview of the suggestions for developing tinnitus care. See Table 2 for an explanation of these categories.