

**Using Participatory Action Research to Redirect Chronic Bothersome Tinnitus
Research and Treatment - an Interview Study**

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Abstract

Chronic bothersome tinnitus is a significantly impairing condition. Despite its high prevalence, current research and treatment practices remain mostly ineffective. The complexity of such professional issues is high, whereby connected stakeholder perspectives vary. Currently, there is only limitedly available research assessing, comparing, and stipulating different stakeholder priorities to redirect professional practices. This qualitative interview study used the first stage of the participatory action research approach to discover and define different stakeholder perspectives on ways of redirecting chronic bothersome tinnitus research and treatment to improve patients' conditions while respecting realistic limitations. Semi-structured online interviews including five participants (two patients, two researchers and medical specialists, one general practitioner) were conducted. Deductive grounded theory and the constant comparative method were used for data analysis. Four categories for research adaptations ((I) patient involvement; (II) more cure less coping research; (III) funding; (IV) publication), and six categories for treatment adaptations ((I) professional support; (II) patient involvement; (III) interdisciplinarity; (IV) professional tinnitus education; (V) clinical treatment guidelines; (VI) psychological treatment) were identified. Participants were found to hold partly similar priorities such as increasing pathophysiological and cure research. Differing ideas or dilemmas between patient and professional needs, and their limitations were addressed too. For instance, patients aimed for increasing their involvement in professional practices, whereby professionals argued that the excessive focus on patients' conditions could reduce their chances of habituation. Particularly facilitating communication between and within stakeholder groups by increasing patient involvement, interdisciplinarity in practices, and reducing barriers to receiving psychological treatment were seen as essential factors for improving tinnitus practices.

Keywords: chronic bothersome tinnitus, stakeholder involvement, participatory action research, treatment adaptations, research adaptations, qualitative, interview, grounded theory, constant comparative method

Introduction

Chronic bothersome tinnitus is a highly burdensome condition, mentally and physically severely affecting individuals over time (Simões et al., 2021). Generally, tinnitus is understood as an individual's auditory perception of sounds like ringing or clicking despite their lacking presence in the external environment (Kreuzer et al., 2013). Experiencing tinnitus for more than six months indicates a chronic condition, whereas bothersome tinnitus patients suffer from a higher severity of symptoms (Tunkel et al., 2014).

Literature estimates of tinnitus' worldwide prevalence range between 5% and 15%. Approximately 1% of the general population reports having bothersome and more severe symptoms (Kreuzer et al., 2013). Tinnitus is considered a very complex, heterogeneous condition encompassing a great variety of risk factors (Appendix A; Baguley et al., 2013). Such risk factors may include external influences like exposure to loud or high noises but also underlying conditions such as traumatic head injuries, tumours, or mental disorders which can contain symptoms like hearing loss or psychological distress (Cima et al., 2019). However, its underlying pathophysiology remains largely unclear (McFerran et al., 2019).

Out of all subtypes (Appendix B), chronic and bothersome tinnitus are considered two of the clinically most relevant and impairing ones (Tunkel et al., 2014). Their combination is particularly straining as it is marked by the experience of prolonged severe mental and physical burden. This often results in high mental distress, more, especially mentally based, comorbidities (Appendix C), and a significantly reduced Quality of Life (QoL) (Cima et al., 2019; Tunkel et al., 2014). Next to patients, healthcare systems which are required to provide additional clinical care, and economies needing to compensate for patients unable to work, are affected as well (Tunkel et al., 2014). All these instances face additional financial burdens due to the condition's complexity, intensity, longevity, and interconnectedness with other clinically relevant conditions (Trochidis et al., 2021). Therefore, well-established research and support systems are needed to help reduce strains on patients themselves but also society as a whole (Tunkel et al., 2014). Given its high clinical and economic relevance, this study will focus on *chronic bothersome tinnitus* which will from now on be referred to as *tinnitus*.

Despite the need for adequate research and treatment, current tinnitus practices are far from optimal and the condition's management is complex. For instance, current research often overlaps in that the efficacy of existing, mostly self-management strategies, is repeatedly tested, while aspects like pathophysiology, cure possibilities (Simões et al., 2021) but also patient perspectives on relevant research topics (Hall et al., 2013) are only limitedly addressed. Lack of funding and low professional involvement in tinnitus research are additional constraints to

further progress in the field (McFerran et al., 2019). Moreover, due to its high heterogeneity and missing pathophysiological information, no effective symptom-reducing or alleviating tinnitus treatment has been found yet. This significantly limits clinicians' possibilities of offering adequate medical support to patients (McFerran et al., 2019). Consequently, current treatments primarily focus on helping patients emotionally cope with their condition. However, considering tinnitus' highly heterogeneous nature, such options are also only limitedly effective, whereas, for some patients, no option works at all (McFerran et al., 2019). Together with the generally limited availability of medical and psychological professionals, patients are often forced to mainly self-manage their condition which can make them feel marooned and even more overwhelmed (Kreuzer et al., 2013; Pryce et al., 2023). This large spectrum of issues related to the organisation and execution of tinnitus research and treatment highlights the need for tackling those problems to help improve patients' conditions, resultingly also reduce burdens on healthcare, professionals, and economies.

The complexity of problems connected to tinnitus practices makes detecting and prioritising issues that restrain patients from improving the most essential. Including patient perspectives in such research can help at enhancing the relevance (Boote et al., 2002) and effectiveness (Vahdat et al., 2014) of practices, whereas incorporating professionals such as clinicians and researchers adds realistic limitations and professional standpoints toward reaching discussed goals (Kindon, 2007, as cited in Cornish et al., 2023). Comparing these perspectives can increase awareness of current discrepancies between stakeholders' priorities, perceived roles, and perceived limitations while aiming to find ways of stipulating those (Bucknall & Hutchinson, 2020; Jagosh et al., 2012) for the primary aim of improving patients' conditions with the current means available. Such research cannot only inspire comparable theoretically based projects but ultimately aims at triggering the findings' practical implementation in the future.

One approach respecting such multi-perspective research is participatory action research (PAR). PAR is an action-oriented approach which aims to constantly involve affected stakeholders in the process of tackling current public health issues (Cornish et al., 2023). Its main stages consist of establishing a collective definition of the issue at hand, determining and executing action redirections to solve the previously defined issue, and reflecting on the processes' success in hindsight (Figure 1A; Baum et al., 2006; Cornish et al., 2023). In this paper, action redirections are defined as the establishment of new or alteration of existing actions within current tinnitus practices. With PAR being an iterative approach, the previously

described steps are constantly repeated to establish a holistic, sustainable change (Baum et al., 2006; Cornish et al., 2023).

PAR has already been increasingly implemented in projects aiming at improving mental health services for patients. Such projects already highlighted PAR as being a significant aid in improving professional practices, increasing patients' wellbeing, and enhancing the research's quality (Ochocka et al., 2002; Schneider, 2012). Despite this evidenced effectiveness, PAR's application to contexts such as tinnitus is still missing. This would, however, offer a deeper, more holistic, action-, and stakeholder-oriented impression of current needs and limitations to execute proposed action redirections in different affected areas. Hence, the issue at stake could be collectively solved. Respecting the current professional struggles connected to tinnitus, such an approach is highly needed which is why it was used for this study.

The main aim of this study was to theoretically detect, compare, and stipulate stakeholder priorities and to establish action proposals on how to redirect current tinnitus research and treatments. This aimed at getting a better understanding of the most important issues connected to current tinnitus practices while inspiring future practically oriented projects to implement the identified action redirections. With this, relevant stakeholders (e.g., patients, clinicians) could desirably be unburdened. A qualitative approach in the form of semi-structured interviews was used for this study's data collection as it helped to gather rich, deep, and exploratory insights into individual perspectives. Due to the issue's discussed complexity and the lacking existing research, this study solely focused on PAR's first stage, the problem definition (Figure 1A). This stage entails the establishment of research relationships between stakeholders and researchers, the development of a common understanding of the issue at hand, the gathering of stakeholder experiences with the discussed problem, a collaborative data analysis, as well as the planning of action redirections to solve the identified issues. Additionally, a constant exchange and reflection of participants and researchers on the study's progress and possible improvements are encouraged (Figure 1B; Cornish et al., 2023). Based on this information, the following main research question was addressed within this paper:

- According to stakeholders personally or professionally dealing with tinnitus, where could tinnitus research and treatment be adapted to help improve patients' conditions?

Moreover, two sub-questions were discussed:

- What are the differences and similarities between the stakeholders' perceived issues, priorities, and suggested adaptations for redirecting tinnitus research and treatment?

- How could the stakeholders' suggested adaptations be stipulated into action redirections to help improve patients' conditions?

Methods

Design Approach

The execution and documentation of this study took place between February and July 2023. The study was based on a constructivist point of view, meaning that multiple individual perspectives and realities were explored and tried to be combined to establish commonly accepted solutions for the issue at hand (Amineh & Asl, 2015). For this, semi-structured one-on-one interviews were conducted by a third-year Bachelor's Psychology student at the University of Twente (UT) in the Netherlands. With this, better explorations, comparisons, and combinations of the different in-depth individual perspectives connected to the research questions were enabled. Overall, one researcher (JK) was involved in the study's organisation, execution, analysis, and documentation. One professional tinnitus researcher held a primary- (JPS) and one professional health psychology researcher held a secondary (GS) advisory role, meaning that both gave feedback at different times and frequencies throughout the study. The primary advisor also helped with recruiting participants.

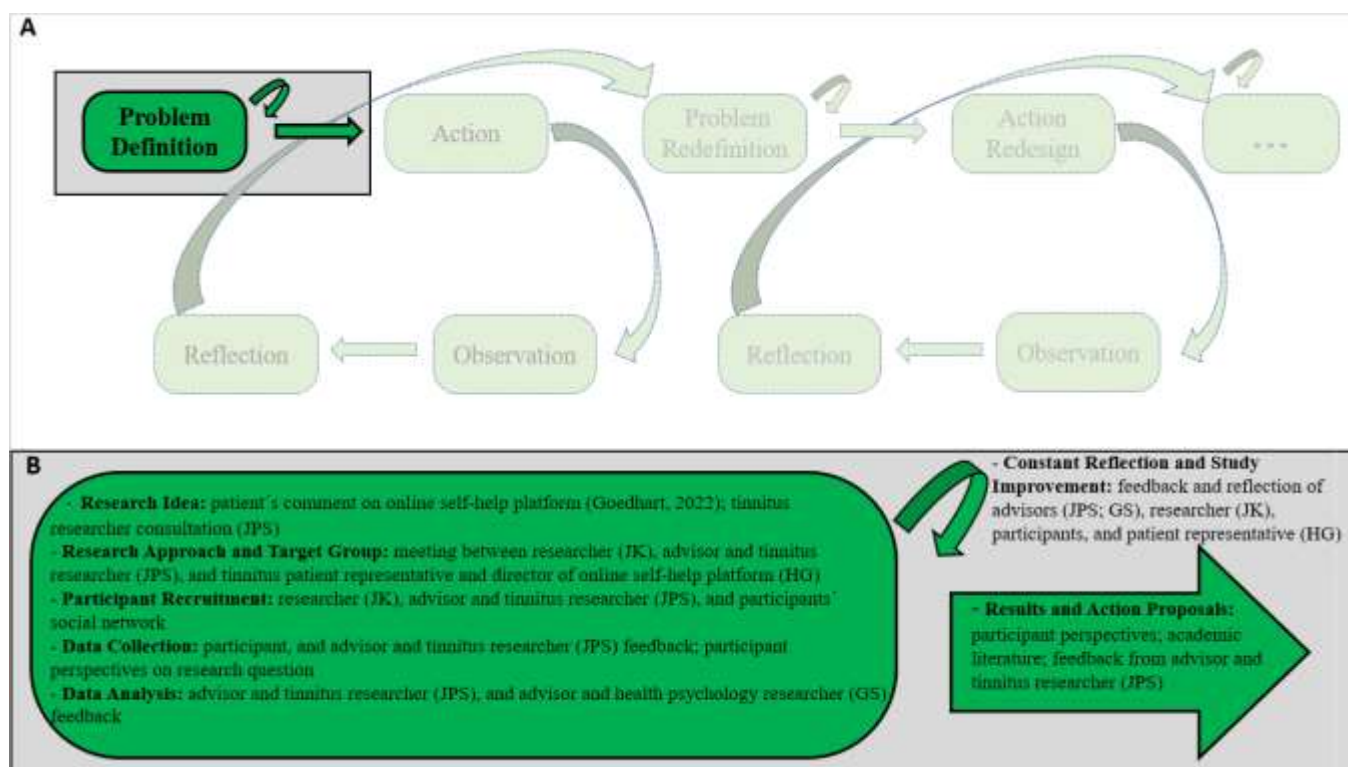
This study was approved by the Ethics Committee of the Faculty of Behavioural, Management and Social Sciences (BMS) of the UT in the Netherlands (230236) before its execution. The Standards for Reporting Qualitative Research (SRQR) was used as a guideline for writing this report to enhance its quality and transparency (O'Brien et al. 2014).

Stakeholder Involvement

Based on the PAR approach, tinnitus stakeholders and participants of this study were involved at different stages throughout the research's progress (Figure 1B).

Figure 1

Iterative Participatory Action Research Process and its Implementation Throughout This Study



Note. Panel A: This figure represents the iterative and separate stages addressed in the participatory action research (PAR) approach. The highlight of the problem definition box shows that this was the focus of this research. Adapted from “Participatory Action Research,” by F. Cornish et al., 2023, *Nat Rev Methods Primers*, 3 (34), Figure 1, p.4. (<https://doi.org/10.1038/s43586-023-00214-1>). Copyright 2023 by Springer Nature Limited. Panel B: This figure illustrates how the first stage of the PAR model was implemented in this study and how tinnitus stakeholders and participants were incorporated throughout the study’s progress. The main steps within the problem definition stage are bold. JK = abbreviation of the researcher; JPS = abbreviation of the primary advisor and professional tinnitus researcher; GS = abbreviation of the secondary advisor; HG = abbreviation of the patient representative and director of an online self-help platform.

Participant Recruitment

Participants were recruited between March and May 2023. Snowball sampling was used as the sampling method. For this, the researcher, the primary advisor, and the participants themselves contacted individuals out of their social networks who fulfilled the below-discussed inclusion criteria. Individuals who agreed to participate were referred to the researcher and an online meeting for the interview was scheduled. Due to the constrained recruitment and data

collection timeframe, the large target group, stakeholders' motivation to participate, and their familiarity with the topic, this method was evaluated as the most fitting. Recruitment stopped after the predetermined timeframe ended.

To be eligible for the study, individuals needed to (a) deal with tinnitus in their personal or professional lives (e.g., patients, patient representatives, clinicians, researchers), (b) be at least 18 years old, and (c) be proficient in English or German. A final sample size of eight participants was aimed for as this seemed feasible within the predetermined recruitment and data collection timeframe. It was argued that this sample size would allow for both, establishing in-depth conversations while also exploring a variety of stakeholder perspectives. Next to this, incorporating two participants per tinnitus background (e.g., patient, researcher, clinician) was desired. This intended at gathering input from a heterogeneous sample, thus, facilitating the comparison between and within different stakeholder group's views.

Materials

Informed Consent and Demographics Form

A document containing questions to gain participants' informed consent (e.g., agreement and awareness of data storage, anonymity, participants' rights) and demographic data (e.g., age, gender, tinnitus background) was created (Appendix D). The form was available in English and German versions.

Interview Question and Probes Slides

To establish a structured but flowing conversation within the interviews, presentation slides were designed. Each slide included one of the in total six main questions (Appendix E) and its exemplary probes (Appendix F). Depending on participants' tinnitus backgrounds, questions were either focused on their personal or professional tinnitus experiences while it was still ensured that the same overarching issue (e.g., tinnitus management, wishes for future tinnitus practices) was addressed. This desirably facilitated both, the comparability of data between different participants, as well as the gathering of unique and individual information tailored to participants' varying backgrounds. Some questions were open, some closely formulated. Particularly patients might be comparatively inexperienced and more insecure when participating in research projects. The combination of both question types was therefore established to not overwhelm participants with too many answer options while still encouraging them to share their own experiences as much as possible. Visually displaying probes and questions also aimed at giving participants the freedom on deciding whether to answer a question based on their first associations or, especially when being unsure about which topics to address, look at the inspirations provided. All slides were available in English and German.

Based on researcher and participant feedback following each interview, the slides were open to constant improvement.

Procedure

Pilot Interview Study

To ensure that technical devices worked and that aspects such as structure, questions, and slides were benefiting the interview process, a pilot recorded online interview with a person not involved in the study was conducted. The Microsoft Teams application was used for this purpose. This way, the feedback could be implemented before the first interview.

Interview Study

All interviews were conducted between April and May 2023. Each interview was held between the researcher and one participant. In some cases, participants and researcher were already familiar with each other beforehand. One day before each interview, the participants were digitally sent the informed consent and demographics form and a link to a Microsoft Teams meeting. They were also informed that in case of feeling uncomfortable responding to some demographic questions, they were free to refrain from answering those.

In each meeting, participants were offered to turn their cameras on or off based on personal preferences. This ensured that they felt comfortable exposing more personal insights on the posed questions. The researcher's camera was always turned on. With this, establishing an interpersonal connection via minimal encouragement such as nodding or smiling was aimed to be established. Throughout the meeting, the researcher shared her screen with the predesigned question-and-probe slides. To avoid possible misunderstandings, the participant was verbally reassured to ask questions whenever some would arise. Participants were explained the project at the start of each interview and the researcher briefly introduced herself. Their consent for participation and data usage was requested at each interview's start and end. At the end of an interview, participants were asked if they would like to receive their interview transcript, video, or the paper once finalised.

The main interview started with the researcher asking the six main interview questions and the probes fitting the interview. If professionals were also suffering from tinnitus or patients were professionals too, the main questions for professionals were used, whereby probes about their personal circumstances were asked. With this, both their perspectives could be respected. The researcher emphasised throughout the procedure that the probes were solely example ideas and that the participant was free to choose other topics they wanted to talk about. This desirably stimulated a wider variety of aspects to be discussed. The researcher asked follow-up questions to gain more in-depth and reflective insights from the participants on topics evaluated as

relevant. The researcher summarised her understanding of the participant's main statements when considered necessary to ensure a correct understanding and/or encourage more elaboration on a topic. After all questions had been discussed, the participant was asked for additional remarks or questions regarding study- or interview-related issues. Ultimately, feedback on the interview was requested.

Data Analysis

Pilot and Interview Study Feedback

After each interview, the participant's and researcher's feedback was reviewed and implemented if considered helpful. This means that possible changes regarding, for instance, improving its procedure or the questions' fluency, relevance, or clarity were considered while ensuring that the research questions were still addressed satisfactorily. After the first interview, a meeting between the researcher and the primary advisor was held. Within this meeting, the researcher's first impressions and possible ideas for adapting the interview were discussed. This ensured gaining a more objective perspective on the possibility of implementing proposed changes.

Input from Six Main Questions

Transcripts. Interview transcription and storage were handled by the researcher. Based on the UT guidelines (University of Twente, 2023), each interview's recordings and final transcripts were stored on the researcher's secured Google-workspace and shared with the advisors. The files are to be deleted in August 2023 after this study's completion. Afterwards, the data will be archived on the UT's secured Areda application for ten years (University of Twente, 2023).

To establish the final transcripts, the researcher read through the automatically generated Microsoft Teams transcripts while simultaneously listening to each interview's audio recording. Parts that did not correctly reflect what was said were adapted. Aspects such as coughs and high amounts of stutters that did not contribute to gathering the meaning of statements were either completely deleted or kept in small amounts when they were considered to reflect, for instance, the participant's uneasiness or uncertainty about what to say. Factors such as used irony and laughs which were solely perceivable in context with the audio and background of the interview were added in brackets to ensure a correct understanding. Personally identifiable information such as names and dates was exchanged with an X to ensure participants' anonymity. After having finished each interview's transcription, the documents were checked again for accuracy and anonymity.

Establishing Codes. Data analysis and the establishment of codes were handled by the researcher and reviewed by the primary advisor to deal with intersubjectivity. To deal with data saturation the researcher reviewed the determined categories, themes, and codes after each coding cycle and adapted them if considered necessary.

To simplify the data management and comparisons across transcripts, the software ATLAS.ti version 9 was used. Using the deductive grounded theory approach (Glaser & Strauss, 1967), codes, themes, and categories were newly established based on the unique information each transcript provided. For each transcript, relevant excerpts fitting the research questions were openly coded (Corbin & Strauss, 2008). This implies that, based on their semantic and contextual meaning, code names were established for each excerpt. With the following axial coding (Corbin & Strauss, 2008), codes entailing the same overarching topic were combined under one theme name. The same coding cycle was repeated for all transcripts separately. This independent coding of each transcript aimed at reducing the researcher's bias towards evaluating information's usefulness based on their reference in previous transcripts. The constant comparative method (Glaser & Strauss, 1967) was then used to combine all transcripts' relevant information. Hereby, the separately established codes and themes were investigated concerning their similarities and differences. Themes across transcripts were then merged or adapted to establish theme names relevant to all transcripts. Finally, the themes were selectively coded (Corbin & Strauss, 2008). This implies that themes addressing a similar issue were merged into one category. Selective coding ended when all categories addressed different thematic aspects of answering the research questions.

Researcher Characteristics and Reflexivity

The researcher has never executed tinnitus research prior to this study and has limited experience with qualitative research. This implies that the study might have been approached differently by more experienced researchers. To deal with this, the researcher was in constant contact with the primary advisor who also is a professional tinnitus researcher. Regular meetings were arranged to reflect upon possible questions and ways of dealing with addressed issues. Additional expertise from more experienced qualitative researchers was sought if problems or uncertainties arose.

The researcher's psychological background might have also influenced this study's execution and outcomes. One result of this might have been the researcher having put a higher focus on discussing ways of enhancing patients' wellbeing and facilitating tinnitus management throughout the interviews. This might have directed participants into revealing more information about these topics and stands in contrast with more medically oriented researchers

whose focus might have been more on reducing the acoustic perceptions and bodily factors associated with tinnitus. Having included participants and advisors with different backgrounds and occupational specifications aimed at establishing a multidisciplinary view and diverse feedback throughout the study. This enabled the researcher to compare perspectives and reflect on the possibility of holding a psychologically centered standpoint. Gaining such insights within the progress of this research enabled the researcher to establish a rhythm of consciously reflecting before, during, and after interviews on how a more objective exploration of participants' priorities could be encouraged. The constant contact with the primary advisor also encouraged the researcher to become more aware of her subjective standpoints and how to purposely use or not use them in the organisation, execution, and documentation of research studies.

Results

Demographical Data

Five individuals agreed on participating and their data to be used for this research (Table 1). Ages ranged between 37 and 68 years ($M = 49.60$, $SD = 13.61$). Two participants identified themselves as female and three as male. Two participants were tinnitus representatives suffering from tinnitus, one worked as a general practitioner (GP), and two were tinnitus researchers and medical specialists with one each practicing as an audiologist and as a neurologist. Both patients have been suffering from tinnitus for five years. Professionals have been confronted with tinnitus between ten and 32 years ($M = 19.00$, $SD = 11.53$). The participants' reference numbers were used in the results section to refer to them anonymously. *PA* referred to *patients*, *PR* to *professionals*, *F* to participants who identified themselves as *female*, and *M* to participants who identified themselves as *male*.

Table 1*Sample Characteristics*

	All (N=5)	Patients (N=2)	Professionals (N=3)
Age, <i>M (SD)</i> years	49.60 (13.61)	55.50 (17.68)	45.70 (12.50)
Gender, <i>n</i>			
Female	2	2	0
Male	3	0	3
Country of Residence, <i>n</i>			
Germany	2	0	2
Finland	1	1	0
United Kingdom	1	0	1
United States	1	1	0
Nationality, <i>n</i>			
German	1	0	1
Dutch	1	1	0
British	1	0	1
American	2	1	1
Highest Academic Degree, <i>n</i>			
Bachelor or Master	1	1	0
Doctoral	4	1	3
Profession, <i>n</i>			
Company Director	1	1	0
Researcher ^a	1	1	0
General Practitioner	1	0	1
Neurologist ^b	1	0	1
Audiologist ^b	1	0	1
Time Dealing with Tinnitus ^c ; <i>M (SD)</i> years	13.40 (11.19)	5.00 (0)	19.00 (11.53)

Note. This table shows the different demographical characteristics of the final sample included in this study. *M* = mean; *SD* = standard deviation.

^a Not connected to tinnitus research. ^b Tinnitus researcher and medical specialist. ^c In professional and/ or personal lives; time since onset of their tinnitus symptoms and/ or professional activities dealing with tinnitus.

Pilot and Interview Study Feedback

The pilot and interview study went satisfactorily and both, participants and researcher, were satisfied with the interview structure, the provided slides, and the questions and probes asked (Appendix G). Resulting from this positive feedback, no changes in structure, slides, or questions were suggested or implemented throughout all interviews.

Interview Study

Interview lengths ranged between 60 and 100 (*Mdn* = 75) minutes. Among the participants, differences and similarities regarding their perspectives towards improving tinnitus research and treatment were identified. In total four categories for the research adaptation area, namely (I) patient involvement (PI), (II) more cure less coping research, (III) funding, and (IV) publication were identified. For the treatment adaptation area, six categories were established: (I) professional support (PS), (II) patient involvement (PI), (III) interdisciplinarity, (IV) professional tinnitus education (PTE), (V) clinical treatment guidelines (CTG), and (VI) psychological treatment (PT). If professionals' opinions differed, they were differentiated based on their occupation (GP vs. researcher/ medical specialist (audiologist vs. neurologist)). If opinions were similar, they were collectively referred to as *professionals*. Due to patients' similar tinnitus backgrounds, they were continuously collectively referred to as *patients*.

Research Adaptations

Patient Involvement (PI). This category discusses participants' opinions and suggestions on involving patients in tinnitus research. Identified themes are *importance of PI*, *ways of implementing PI*, and *limitations of PI*.

Patient Perspective. Both patients reported that PI in tinnitus research was crucial to establish actual improvements in scientific practices and patients' conditions. Hence, without PI, they feared that research would target irrelevant topics that were not related to achieving a cure and not helping them at enhancing their condition. Despite the importance of PI and their high motivation to participate, both patients perceived current tinnitus research to be too focused on professional perspectives. To facilitate PI, they suggested that researchers could contact tinnitus self-help platforms to request feedback on their study ideas. However, patients

also experienced that successful PI was often complicated since some professionals had difficulties dealing with their criticism:

“I think the hard part is dealing [with feedback]. It means you also have to open yourself up to criticism and I think a lot of researchers say that they are open to that but when it actually happens, they're very, very upset.” (PA1, F)

Such difficulties were perceived as impeding the establishment of relevant tinnitus research which increased patients' dissatisfaction with the current situation.

Professional Perspective. Professionals also perceived the tinnitus community as very willing and motivated to participate in research. They also indicated PI as being crucial in detecting patients' research priorities, achieving actual improvements in their conditions, and ensuring the research's relevance. On the other hand, limitations and challenges of PI were mentioned: Due to their high willingness and desperation to reduce their suffering, patients might be exploited by some researchers. For instance, researchers might test various kinds of treatments on patients which would not improve their condition but instead made them feel more hopeless and increased their struggles to move on with their life outside of their condition:

“I think that fundamentally the tinnitus patients are looking for a solution and they are very famous for being willing to go through almost any therapy you can think up even on the verge of quackery. If you can instil in them some kind of hope that it might help, they're really suffering and they will do anything to improve their tinnitus which also makes them more vulnerable to people wanting to take advantage of them for taking this medication, this laser therapy, or these magic magnetic waves. Lots of people will take advantage of them or lots of them would be willing to be taken advantage of if there's a small sliver of hope that they could be helped.” (PR5, M)

Moreover, even though researchers certainly needed PI to discover patients' viewpoints and experiences on certain topics, actual PI would sometimes be complicated since certain research guidelines might not be fulfillable.

More Cure less Coping Research. This category discusses participants' opinions towards the topics future tinnitus research should increasingly focus on to help improve patients' conditions. Themes are *importance of cure research*, *ways of facilitating cure research*, and *limitations of cure research*.

Patient Perspective. Patients stated that the main focus of research should be on finding a cure or at least treatments reducing tinnitus symptoms. However, they felt like current

research would constantly focus on finding ways of better coping with tinnitus which was not in their interest:

“Achieving a cure should be the ultimate aim of research. I say ‘should be’ because there's a lot of research that's actually not aimed at a cure, but it's aimed at yet another coping or management strategy where I feel like ‘We already have this’.” (PA1, F)

To find a cure, patients argued that research should be focused more on discovering tinnitus' pathophysiology and underlying mechanisms influencing the condition.

Professional Perspective. The professionals agreed that finding a cure would be the ultimate aim of research since then, all other treatments would not be needed anymore and burdens on patients and professionals would be reduced. However, other topics such as enhancing current management strategies should not be fully neglected either as they could help patients to better deal with their tinnitus while waiting for the cure. The professionals further agreed with patients that, to achieve successful cures and symptom-reducing treatments, more research should be done on tinnitus' pathophysiology and its underlying mechanisms. Cure research should be enhanced by increasing motivation and interest in researchers from different disciplines and giving them the freedom to explore the direction they wanted. One problem with this complex, often longitudinal research process was that researchers still wanted and needed to publish work. Therefore, based on their pressure to regularly publish, many researchers would currently test tinnitus treatments solely based on a guess that they might be effective and without supporting evidence behind. This often lead to insignificant and rather unhelpful results for which the time could have been invested in building a solid background knowledge on tinnitus:

“We need more foundational understanding of what tinnitus is and what tinnitus does. Only when you understand what's broken can you come up with theories of what you could do to affect these broken things in a more positive direction. [...] until we don't know what exactly breaks, you can't develop a test for applying treatments. But that's what we do in research, because otherwise, I couldn't publish. So what do you do? You guess. [...] And then you see not really effective tinnitus treatments.” (PR5, M)

Funding. This category discusses participants' perspectives on the role of funding in tinnitus research and its redirection. Identified themes are *importance of increasing funding*, *ways of increasing funding*, and *obstacles to increasing funding*.

Patient Perspective. Increasing the financial support for tinnitus research was seen as very important by patients to improve tinnitus research and include more patient perspectives in novel projects. This could be achieved by establishing objective measures for tinnitus as this made condition and treatment improvements more measurable, desirably attracting more pharmaceutical companies to financially support the research.

Professional Perspective. Professionals also perceived the lacking funding as critical for establishing important tinnitus research projects. This lacking financial support was also the reason why only a little number of researchers investigated tinnitus and why advancements in research were partly lacking:

“[...] you can't expect just based on the area of work that you're going to get a sufficient amount of funding to do the complex tasks that you have in front of you. And so the quality of much tinnitus research is very, very low because if you didn't produce a lot, and if you didn't produce positive, significant results, you're going to lose your funding. And so what do you do? You either say, well, I'm getting out of the tinnitus business because I can make more progress somewhere else or you're risking doing things that actually aren't good for making progress in the area of tinnitus.” (PR5, M)

A problematic factor when trying to increase funding was that, to increase the chances of funding, researchers needed to make large claims that were often not scientifically proven. These studies often had negative results which, if published, would most likely make researchers lose their funding. Hence, the kinds and amounts of research done were influenced by the amount of funding, whereas the amount of funding was again influenced by the significance of research results which put researchers in a vicious cycle:

“What you risk is that if you want money in tinnitus, you're going to be inclined to make claims that are maybe bigger than the evidence basis that you have and if you don't have positive results to not present those negative results as loudly as you probably should because then you risk that you're gonna reduce your future funding. So, if we're completely honest with the way we do research, then we're shooting ourselves in the foot” (PR5, M)

Publication. This category focuses on how the number and the content of published tinnitus research could influence patients' condition and wellbeing. Defined themes are *importance of publication* and *obstacles of publication*.

Patient Perspective. Patients reported that, despite their acceptance of self-managing their tinnitus due to currently lacking successful treatments, they wanted to see that research and actions were nevertheless taking place:

“We want to be self-empowered [...] but we also want to see actions from others” (PA2, F)

Professional Perspective. Professionals also expected that, for patients, just knowing that research was taking place made them more hopeful about their condition. However, one participant also reported struggling between showing that research was done and publicising only when findings would gradually improve patients’ lives to not trigger false hopes:

“I personally don't publicize my own results a lot because my viewpoint is I want to publicise them when we've found something that needs to get out there because it's really going to change things [...] So what my approach is usually to sort of quietly get on with the research and then share it widely when it reaches a point where it needs to be.” (PR3, M)

Moreover, the dilemma between working on longer, more complex projects without being able to inspect other important topics for a longer time versus regularly publishing work which was only very limitedly advancing the field was addressed.

Treatment Adaptations

Professional Support (PS). This category focuses on participants’ perspectives on patients receiving professional support to improve their tinnitus condition. Themes are *importance of PS, current experiences with PS, ways of increasing PS, limitations of PS, and ways of dealing with PS limitations.*

Patient Perspective. Patients wanted to be more informed about the possible development of their tinnitus and receive more professional support in dealing with their condition. Especially in the beginning, they regarded this as very important since no one seemed to introduce them to how their wellbeing and symptoms would most likely develop based on professionals’ experiences and expertise or what they could do to deal with their condition. Both patients felt like they did not receive this kind of support at the start of their tinnitus. They argued that having some kind of “ally” would have helped them feel less distressed in the beginning:

“I was just kind of trying to work this through myself. So again if that could have been avoided, boy, that would have been a big help [...] [Somebody who] lead[s] you through the maze of getting to the point where you're habituated and keeps encouraging you that it's going to happen. That's where I think the need is right now.” (PA2, F)

Moreover, patients would like to be able to attend more organised informational sessions or workshops about the progress and current knowledge on research and treatment options. This could help them at discussing, exploring and understanding their condition and possible treatment approaches. However, they also knew that such informational sessions have already been organised before but since research has not been evolving much, they have been cancelled after some time.

Professional Perspective. Professionals also experienced that sometimes just informing patients about their condition's background and possible progress could make a huge difference in patients' tinnitus-related distress and QoL. One important factor they saw was expressing their experiences about how conditions usually improved. Nevertheless, one still needed to stay realistic:

“I think an overly positive view can be almost as harmful as an overly negative view. [...] at least for the majority of people with tinnitus, an optimistic view or a fairly optimistic view can help. It's not misleading to say most people's tinnitus symptoms do improve but it takes a long time for them to improve. It's not quick even where it does happen it can take many, many months or even years.” (PR3, M)

They further advocated for distinguishing between milder and more severe cases, as, for the former, giving basic information about tinnitus at the beginning was usually sufficient, whereas, for the latter, possibilities were more limited and additional, especially psychological, treatment options should be regarded. Moreover, professionals should educate patients on the danger of seeking too many possible treatments and focusing too extensively on the physical and psychological burden connected to their condition as this avoided the brain from getting used to the symptoms and becoming habituated:

“The act of seeking treatments for the tinnitus sound itself gives a very strong signal to the brain to keep monitoring the tinnitus and to keep treating it as important and as a threat. I worry that the act of seeking treatment damages and hinders habituation, which we know does work for most people. So, I think a lot of my advice to people is, yes, the research is happening but please let it happen, and don't go seeking out the very latest

treatments in every applicable option, because I think all it's going to do is harm.” (PR3, M)

Patient Involvement (PI). This category discusses participants’ opinions towards actively involving patients and their needs in their professional tinnitus treatment. The identified themes are *importance of PI in treatment* and *limitations of PI in treatment*.

Patient Perspective. According to patients, every treatment should be patient-centered. However, especially when visiting their GP, they wished their condition to be addressed more, even if only shortly, to feel more understood and validated in their feelings. From their current experience, this was often lacking:

“[...] these old fossil type of doctors who believe that they know what's best for you and they're going to tell you what to do kind of thing [...] when I go to my primary care physician now, it's about getting labs done and getting tests and things. Tinnitus has never been brought up. It's never discussed. So it's kind of ignored.” (PA2, F)

Professional Perspective. Professionals confirmed knowing that patients wanted to be asked about their needs in treatment. However, due to their currently limited possibilities, one clinician addressed that as a medical professional, focusing too much on satisfying patients’ needs took away the possibility for patients with other illnesses to receive actual effective and symptom-reducing treatments. Therefore, he aimed at sending such patients rather to psychologists or psychiatrists to help them cope with tinnitus:

“Given that you can't cure the problem with medicine, then the goal would be to get them to the psychologists and psychiatrists who can try to cure them, maybe with medication more commonly through therapy. So I don't know what I would want my ENT to do. They're wasting their time. They're not talking to other patients whom they can maybe heal compared to if they're talking to the tinnitus patient, whom they can't heal.” (PR5, M)

Moreover, professionals reported that current clinical practices had difficulties deciding between standardising treatments, hence, facilitating better research on their effectiveness, and increasing patient-centered treatment while neglecting possible research evolvments to be made.

Interdisciplinarity. This category discusses participants' opinions towards interdisciplinary tinnitus treatment. The themes are *importance of interdisciplinarity, ways of increasing interdisciplinarity, and obstacles of interdisciplinarity.*

Patient Perspective. As general criticism on the current tinnitus treatment, a patient mentioned that the current placement of tinnitus in the ENT area should be loosened so that more cooperation between the different departments happened. This would help at respecting tinnitus' complex and heterogeneous nature.

Professional Perspective. The professionals also encouraged this view. It was emphasised that more clinics or interdisciplinary treatment options should be established in which the patient would be treated more holistically:

“Obviously, a single approach with a focus on one aspect of tinnitus is not very promising, which can be seen in the fact that individual treatments only have a low chance of success. [...] it certainly makes sense to have interdisciplinary therapy approaches and people from different specialist groups that try to work together and [...] have more specialist outpatient clinics in which different doctors are who work in different specialist areas, including neurologists, psychologists [...] in which we see the patient in his entirety and try to achieve an improvement.” (PR4, M)

One professional also addressed the option of having a fixed day on which patients could visit an interdisciplinary clinical setting and be checked by all medical and psychological areas. With this, less waiting time would be achieved and findings could be directly combined and discussed across disciplines. Yet, with the limited capacity of such clinics, only the severe cases would be addressed which generally had a lower chance of achieving a substantial reduction in their suffering. Moreover, these interdisciplinary clinics needed to limit patients' visits. Otherwise, they would consult them over and over again in the hope of finally detecting an effective treatment for themselves:

“You can't treat it [tinnitus] with a high degree of success and they will overrun our clinic if you let them because they're suffering so much” (PR5, M)

Professional Tinnitus Education (PTE). This category discusses participants' perspectives on the current tinnitus education of professionals. The identified themes are *importance of PTE and perspectives on increasing PTE.*

Patient Perspective. Patients generally saw the need for professionals to be better informed about tinnitus because, from their experience, little was known by the ones they consulted:

“Again, going back to my experience and I've heard this from so many people that your GP and ENT doctor and audiologists know almost nothing about tinnitus. [...] at least improving that a little bit would already help” (PA1, F)

Professional Perspective. Professionals expressed that during their medical studies, tinnitus was a very little discussed topic. The GP agreed with the patients and expressed that he would like the focus on tinnitus to be increased. On the contrary, a medical specialist perceived increasing tinnitus awareness in medical studies as not profitable since there currently were no huge insights that could be given due to the lacking research done. Hence, first research and more useful results needed to be achieved and then, these could be addressed in the medical studies:

“While informing doctors is always nice, they're informed of a tonne of stuff and at the end, they're going to say ‘Well, what do I do differently? Because of what you told me, I will be kind, will give them my attention and send them to psychiatry.’ OK, but you don't need to make that a push in medical education.” (PR5, M)

Clinical Treatment Guidelines (CTG). The following category addresses participants' perceptions of current guidelines for clinical tinnitus treatments. Themes discussed are *importance of CTGs, experiences with CTGs, and ways of improving CTGs.*

Patient Perspective. Patients criticised that many of the professionals they consulted were not aware of the current CTGs. To increase the research input, one patient further suggested that the clinical guidelines should be changed towards including registries where clinical tests and assessments made could be directed, to have more data to assess:

“[...] if there were some way of rewriting those clinical guidelines to include that and there are registries where that imaging study could go and be evaluated with cause everything's about big data now too. So if you have thousands of these things to look at, you know, maybe some pattern would emerge.” (PA2, F)

Professional Experience. Underling patients' perspectives, the GP argued to not know of current tinnitus treatment guidelines. A medical specialist also mentioned that it was common that standardised, mostly old and partly irrelevant guidelines were used for assessments:

“There are certain things in certain guidelines that don't make any sense and everybody knows it, but they're in the guideline. Maybe it's an old guideline or maybe it's just been passed down throughout the years and it's just stayed in there because some powerful person believes in it. No one else does. That's the foundation and then you adapt based on your own clinical experience as well as your capabilities” (PR5, M)

Psychological Treatment (PT). This category discusses participants' currently perceived perspectives on offering psychological treatment to tinnitus patients. Themes are *importance of PT, ways of increasing PT, and obstacles of PT.*

Patient Perspective. Patients reported that they perceived PT as being particularly important for newly developed tinnitus cases to help individuals cope with their condition. However, for patients like themselves who became habituated, psychological treatment was said to be rather unhelpful, unless proven to be significantly more effective than other treatment approaches:

“I would have to be really, really convinced that this had something to offer to make me interested in it. However, I think the opportunity is for people who have newly developed it. I think there's a great need there to provide them with that kind of hope, like we were talking about before. You know, if there are therapies and psychology that would integrate that kind of stuff into it or lead you through the maze of getting to the point where you're habituated and keep encouraging you that it's going to happen. Then, I think that's where the need is right now.” (PA1, F)

Patients criticised that their experiences with psychological treatments were marked by long responding times, directive instead of patient-centered approaches, and rather outdated practices:

“It's [psychological treatment] also very much like top-down. It's not patient-centered, but it's just telling the patient what they should be doing and how you should be thinking about your tinnitus instead of, you know, really working with the patient. So I don't think that's a good model for counselling. I think it should always be patient-centered. So yeah, it wasn't actually super helpful.” (PA1, F)

Professional Perspective. Especially since researchers were still getting to know tinnitus better and searching for a cure, professionals deemed it important to improve psychological care for patients even though this only helped with coping and not reducing the

symptoms. However, the professionals perceived many patients as holding prejudices towards psychological treatment and not wanting to go to a “head doctor”. One professional also indicated that, even though some patients expected him to, medical professionals were not there to provide the emotional support that psychologists offered. Therefore, he would strongly recommend that patients sought support from psychological professionals. A way of circumventing direct psychological treatment would be the increased focus on providing care via online applications. This could serve the same function as psychological treatment but, for patients unwilling to go to in-person therapy, still offered an option of seeking such support in another way. Despite the proposal of circumventing psychological care, it was also stated that the first priority should still be to reduce the present stigma on psychological treatment. If that would not be possible, increasing the physical and timely proximity in which patients received psychological treatment after having finished their medical assessments should be the main focus:

“And so if I can't reduce the stigma, then I need to reduce the amount of friction required to get you into that person's office, because then if I can reduce friction, then despite the stigma I can get you in that door next door based with most any stigma you want to come up with cause I'm walking you to the door. I'm introducing you and I'm sitting you down, so I don't really care what the stigma is.” (PR5, M)

Discussion

Using the PAR approach, this study identified stakeholders’ priorities for improving tinnitus research and treatment. The common primary aim was to find a cure to reduce patient suffering. Other priorities included increasing the funding and publication of studies and establishing more interdisciplinary research to better explore cure possibilities. Especially at the beginning of patients’ conditions, treatments should focus more on supporting and informing patients about tinnitus. Moreover, more interdisciplinary treatment approaches which also included the psychological department should be facilitated. Lastly, patients should be more involved in the establishment and execution of tinnitus research and treatments to increase the practices’ relevance and resultingly help in improving their conditions.

Next to these general priorities, dilemmas between stakeholder perspectives were identified. These mostly included that some patients’ needs could not be met since professionals were limited in their possibilities of satisfying them (Appendix H, Appendix I). For instance, patients’ priorities were highly centred around increasing patient-oriented practices and establishing more cure- instead of additional management research. However, professionals

addressed that such complex and longitudinal cure-oriented studies were often not financially funded, leaving little possibility to investigate these topics. Additionally, high patient involvement might avoid patients' habituation to their tinnitus which made professionals more hesitant with including patients in such practices. Another priority for patients was to receive more professional support from clinicians throughout the progress of their condition. The clinicians, on the other hand, indicated that their time constraints and missing options to successfully reduce patients' symptoms made them focus more on patients whose conditions they could actually improve. Moreover, they rather perceived that these needs for emotional support should be approached by psychologists instead of medical professionals.

Based on these dilemmas, stipulations between patients' needs and professionals' limitations were made (Appendix H; Appendix I). As the first stipulated action redirection, establishing better communication among tinnitus stakeholders was defined. This also includes a reflective increase in patient involvement in tinnitus practices. This means that possible issues (e.g., avoiding habituation) should be communicated to patients while then letting them decide the extent to which they seek treatment or engage in research. Openly communicating needs and limitations further aims at letting stakeholders better understand each other's actions while collaboratively finding ways of satisfying both parties with the decisions made. A study by Pryce et al. (2018) already investigated ways in which shared decision-making and better communication within tinnitus treatment could be reached. They opted for establishing basic therapeutic skills not only for psychologists but particularly for medical professionals to facilitate more patient-centered treatments. Such skills enhanced treatments' effectiveness and increased patients' satisfaction (Pryce et al., 2018). Examples of implementing such interactions between stakeholders in research are this study, as well as the Core Outcome Measures in Tinnitus (COMiT-ID) initiative in which researchers collaborated with tinnitus patients and clinicians to map their priorities for treatment outcomes (Hall et al., 2018).

Connected to enhancing communication among stakeholders, increasing interdisciplinarity within tinnitus practices is desired. This can facilitate gaining a more holistic view of tinnitus and supports the collaborative exploration of, for instance, pathophysiological factors. Such interdisciplinary pathophysiological research has already been initiated (Knight, 2009), however, it still needs to be more widely implemented in the tinnitus context. Other ways of increasing interdisciplinarity are organising interdisciplinary assemblies like the Tinnitus Research Initiative meeting (Langguth et al., 2007), or supporting interdisciplinary research projects such as the European School for Interdisciplinary Tinnitus Research (ESIT) (Shekhawat et al., 2022). Moreover, the establishment of interdisciplinary clinics like the

Multidisciplinary Tinnitus Clinic at the University of Regensburg (Vielsmeier et al., n.d.) should be encouraged. This can facilitate a more holistic assessment and treatment of tinnitus. Interdisciplinary collaborations can also facilitate the treatment of possible comorbidities. Especially while no cure is available, this can be a major aid in reducing patients' suffering and tinnitus severity (Kreuzer et al., 2013). Moreover, including disciplines such as psychology in these clinics can also help at reducing physical barriers to seeking treatment (Reardon et al., 2016).

Lastly, while searching for a cure, patients should be increasingly offered the option of seeking psychological support. With the current stigmas on such treatments, again, communications between patients and professionals need to be established in which possible reasons and ways of addressing those are explored. Clinicians should still be aimed at providing a general understanding and emotional support for patients but it should be openly communicated that further management support can be found in self-help groups or psychological treatments. To reduce the barrier to seeking psychological support, Mehdi et al. (2020) investigated and listed recommended smartphone applications that were specifically directed at helping tinnitus patients manage or, to a limited extent, treat their condition. With the more flexible use of such applications, they detected patients to be less in need to seek in-person psychological or medical treatment, hence, unburdening healthcare providers while enhancing their condition (Mehdi et al., 2020). As found by Rüsç et al. (2005), two possibilities for reducing the current stigma towards psychological treatment were to support contact between patients and care providers and to explore and educate patients about the background of such stigmatisations.

Strengths and Limitations

Due to the timely restricted research, the sample for this study was smaller than aimed for which is why data saturation could not be firmly established. Stakeholders such as ENTs, psychiatrists, and psychologists were not represented within this sample. Participants had strikingly high education levels with the lowest possessing a Bachelor/ Master University degree and the highest being a professor. Moreover, all participants dealt with tinnitus for at least five years, the highest being 32 years. Resultingly, the interests of newly established, not habituated, highly suffering, and less highly educated patients are not represented within this sample. Moreover, the experiences of newly established professionals who might have received different tinnitus education in their studies were not respected.

Despite its limitations, this study set an essential first step towards increasing insights on tinnitus stakeholder experiences and priorities to improve tinnitus research and treatment.

From the researcher's current knowledge, this is the first study detecting, comparing, and stipulating researcher, clinician, and patient perspectives on this issue while using PAR to incorporate stakeholders throughout the study's processes. This study established a guideline based on which patients' conditions can be enhanced and, resultingly, stakeholders such as professionals, healthcare systems, and economies can be unburdened in the future. With the heterogeneity to the extent possible between and within stakeholder groups, a more holistic overview of issues connected to tinnitus practices could be established. Awareness of tinnitus was increased by letting professionals reflect on their contributions towards improving practices and unburdening patients.

Recommendations for Future Research

Future research should establish more longitudinal studies which include a larger and more heterogeneous sample (e.g., regarding professions, length of dealing with tinnitus, level of education, severity of suffering). Moreover, the next PAR steps following the problem definition should be acted upon (Figure 1A). This means the addressed action redirections should be implemented in the tinnitus research and treatment context and should be iteratively improved based on constant interactions and reflections between stakeholders. Until now, there are no studies which executed these recommendations. However, Koch et al. (2002) iteratively implemented the PAR approach in a five-year-study which aimed at improving nursing clinicians' wellbeing at their workplace. As they found, participants reported significantly enhanced individual and community wellbeing at the end of the study (Koch et al., 2002) which illustrates the importance of implementing the next PAR steps into tinnitus practices over time too.

Conclusion

This study found that stakeholders had partly similar, partly different expectations, needs, and perceived limitations on how to redirect tinnitus research and treatments. The common main goal was to achieve a pathophysiological understanding of tinnitus to develop a cure so that no treatment for patients would be needed anymore. Generally, it was found that priorities and limitations of tinnitus research and treatment are often not communicated between patients and professionals which restrain many patients from improving their condition while being dissatisfied with the professional support offered. Moreover, professionals are facing issues that might not be solvable within solely one discipline, but which instead need a multidisciplinary approach (e.g., pathophysiological research). Based on these issues, the main priorities for redirecting tinnitus research and treatment are summarised as:

- 1) Enhancing communication within and between stakeholders personally and professionally affected by tinnitus (e.g., by establishing meetings/ workshops; in professional treatments)

Acting towards this priority can aid in reaching the other main priorities:

- 2) increasing reflective use of patient involvement within professional practices (e.g., increasing professionals' transparency about the risks associated with patient involvement such as reduced habituation; based on the provided information, letting patients decide whether to participate or not)
- 3) increasing interdisciplinarity in tinnitus research and treatment (e.g., interdisciplinary clinics or research projects to holistically establish pathophysiology and cure; treatment of comorbidities)
- 4) reducing barriers to receiving psychological treatment while still no cure is available (e.g., online applications, communications about stigma)

These main action redirections can be seen as evidence for the importance of multi-perspective communication, therefore, also as evidence for the importance of the research done within this study. They can also be seen as a target and guideline for future projects which practically implement these proposals. Future research should focus on iteratively implementing the PAR approach within the context of redirecting and improving tinnitus research and treatment. For this, a longer timeframe of conducting the study with larger and more heterogeneous samples is advised to establish a prolonged and sustainable change.

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Appendix A
Common Tinnitus Risk Factors and Their Affected Areas

Affected Area	Possible Conditions
<i>Outer Ear</i>	Wax blockage of outer ear channel Otitis of outer ear channel Obliterative exostoses
<i>Middle Ear</i>	Otitis media with effusion Otosclerosis
<i>Inner Ear</i>	Presbycusis Noise-induced hearing loss Ménière's disease Sudden hearing loss Acoustic neuromas
<i>Muscular</i>	Palatal myoclonus Tensor tympani myoclonus Patency of eustachian tube
<i>Cardiovascular</i>	Glomus jugular or glomus tympanicum Mitral or aortic stenosis
<i>Pharmacological</i>	Benzodiazepines withdrawal Induction from ototoxic drugs
<i>Metabolic</i>	Hyperthyroidism Diabetes Hypertension
<i>Haematologic</i>	Anaemia
<i>Arthrogenous</i>	Dysfunction of temporomandibular joint

Affected Area	Possible Conditions
<i>Impairment of cognitive-emotional reaction system</i>	Concentration disturbance <ul style="list-style-type: none"> - Attentional problems - Memory deficit - Executive function deficit -Loss of control/ helplessness/ resignation -Dysfunctional thoughts - Fear reactions - Safety behaviours/ avoidance
<i>Psychological/ psychiatric</i>	<ul style="list-style-type: none"> - Psychological trauma - Distress - Major affective event - Depression - Anxiety/ panic disorder
<i>Trauma</i>	<ul style="list-style-type: none"> - Traumatic brain injury - Neurosurgical

Note. This table shows commonly associated risk factors of tinnitus and the areas in which they usually develop. Adapted from “A multidisciplinary European guideline for tinnitus: diagnostics, assessment, and treatment”, by R. F. F. Cima et al., 2019, *HNO*, 67 (Suppl 1), Table 7, p.20. (<https://doi-org.ezproxy2.utwente.nl/10.1007/s00106-019-0633-7>). Copyright 2019 by Springer Nature.

Appendix B
Common Tinnitus Subtypes and Their Definitions

Type of Tinnitus	Definition
<i>Subjective</i>	Only the affected individual can hear the sound
<i>Objective</i>	The sound can also be heard by an external person (e.g., general practitioner using a stethoscope)
<i>Temporary</i>	Apparent for < 6 months
<i>Chronic</i>	Apparent for > 6 months
<i>Primary</i>	No identifiable cause; possibly associated with sensorineural hearing loss (SNHL)
<i>Secondary</i>	Specific underlying cause other than SNHL
<i>Bothersome</i>	Distressed patient; negatively affected Quality of Life (QoL); patient is actively seeking therapy and management strategies to deal with tinnitus
<i>Non-bothersome</i>	No significant effect on patient's QoL; usually only triggering curiosity/ concern about how it evolved and how the condition may develop

Note. This table includes the most commonly identified tinnitus subtypes and their brief definitions. SNHL = sensorineural hearing loss; QoL = Quality of Life. Adapted from “A review of tinnitus,” by A. Esmaili & J. Renton, 2018, *Australian journal of general practice*, 47 (4), Table 1, p.206. (<https://search.informit.org/doi/abs/10.3316/INFORMIT.486760499184679>). Copyright 2018 by Royal Australian College of General Practitioners. Adapted from “Clinical Practice Guideline: Tinnitus,” by D. E. Tunkel et al., 2014, *Otolaryngology–Head and Neck Surgery*, 151 (2_suppl), Table 1, p.3 (<https://journals-sagepub-com.ezproxy2.utwente.nl/doi/epub/10.1177/0194599814545325>). Copyright 2014 by American Academy of Otolaryngology—Head and Neck Surgery Foundation.

Appendix C

Common Tinnitus Comorbidities and Their Affected Areas

Affected Area	Possible Comorbidities
<i>Hearing and vestibular disorders</i>	Hearing loss Disturbance of auditory perception Hyperacusis Vestibular disorders
<i>Mood disorders</i>	Adjustment disorder Dysthymia Depressive episode Recurrent depressive episodes
<i>Anxiety disorder</i>	Phobic disorders Anxiety disorder Generalised anxiety disorder Anxiety and depressive disorder, mixed
<i>Reaction to severe stress and adjustment disorders</i>	Acute reaction to burdening Posttraumatic stress disorder Somatoform disorder Somatisation disorder Hypochondriasis Psychological and behavioural factors in another classified disease Insomnia

Note. This table illustrates comorbidities commonly associated with chronic bothersome tinnitus and the overarching area affected by them. Adapted from “A multidisciplinary European guideline for tinnitus: diagnostics, assessment, and treatment”, by R. F. F. Cima et al., 2019, *HNO*, 67 (Suppl 1), Table 1, p.12. (<https://doi-org.ezproxy2.utwente.nl/10.1007/s00106-019-0633-7>). Copyright 2019 by Springer Nature.

Appendix D

English Version of Informed Consent and Demographics Form

Informed Consent Information

Dear participant,

thank you for agreeing to participate in this interview study which is part of my Psychology Bachelor's thesis written in collaboration with the University of Twente in the Netherlands.

This study particularly addresses individuals personally or professionally dealing with chronic bothersome tinnitus and aims at discovering their different experiences with tinnitus research and treatment condition. Moreover, it will be investigated how current tinnitus research and treatments can be redirected and adapted to help patients improve their conditions.

The research will be conducted via a recorded online interview which will take approximately one hour. You are kindly asked to answer all questions honestly and indicate if questions are unclear as this is of significant importance for getting valuable information and coming to suitable conclusions regarding the research question.

The data of your interview will be stored securely and confidentially, and all personal information such as names and dates will be anonymised to ensure that data cannot be traced back to you as a person. When agreeing to participate in this study, you accept that the anonymised responses in this interview will be used for the researcher's Bachelor's thesis and might be used for later scientific work on this research issue.

It is not expected that there are any risks associated with your participation in this research project, but you have the right to withdraw from the research at any time without any need to justify your decision. Moreover, the study was approved by the BMS Ethics Committee.

If you have any questions after participating, please feel free to contact the researcher (j.kajuter@student.utwente.nl) or the supervisor (j.pianosimoes@student.utwente.nl) of this project.

If you want to send a filed complaint, please contact the BMS Ethics Committee (ethicscommittee-bms@utwente.nl).

Informed Consent

Please Tick the Appropriate Boxes

Yes **No**

Taking Part in the Study

I have read and understood the study information, or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.

I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.

Use of the Information in the Study

I understand that the information I provide will be used for the Bachelor's Thesis of Julia Kajüter, studying at the University of Twente in the Netherlands and that it might be used for upcoming scientific articles in the future.

I understand that personal information collected about me that can identify me, such as my name or where I live, will not be shared beyond the study team and that this information will directly be anonymised when transcribing the interview.

I agree that my information can be quoted anonymously in research outputs, meaning that I cannot be identified as the person that has given the quoted statements.

I agree to be audio/video recorded and I understand that the recordings will be stored securely and confidentially and will be deleted after one year.

Future Use and Reuse of the Information by Others

I give permission for the information that I provide in the online interview to be archived
 as anonymised transcripts (names, dates, and any other personal information provided
 will be exchanged with an X) so it can be used for future research about similar topics.

Signatures

Name of participant [printed]

Signature

Date

I have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands what they are freely consenting.

Researcher name [printed]

Signature

Date

Demographics***Please Fill in the Appropriate Information***

What gender do you identify with?

Female Male non-binary Other: _____

What is your age in years? _____

What is your nationality? _____

What is your highest level of education? _____

What is your current occupation? _____

(If you are currently not employed: What was your last occupation?
_____)

Appendix E

English Version of Six Main Interview Questions

Questions for Patients/ Patient Representatives:

1. Could you give me some information about yourself and your tinnitus background?
2. What are your personal experiences with managing tinnitus?
3. Would you say that you mainly self-manage your tinnitus condition or do you receive (e.g., psychological or medical) help to better deal with it?
4. Do you generally feel confident about self-managing your condition?
5. What role does tinnitus research play for you and your way of managing your tinnitus condition?
6. What are your personal hopes and suggestions for future tinnitus research and your wishes for yourself to improve your condition?

Questions for Professionals (Clinicians and Researchers):

1. Could you give me some information about yourself and your professional background?
2. What are your personal and professional experiences with tinnitus?
3. According to you, which role does self-management play for tinnitus patients and their ways of dealing with tinnitus?
4. Do you feel confident about dealing with patients who are (expected to) suffer from tinnitus?
5. What role does tinnitus research play for you and your profession?
6. What are your personal hopes and suggestions for future tinnitus research, clinical management, and patients suffering from tinnitus?

Appendix F

English Version of Probes as Shown on Presentation Slides

Probes for Patients/ Patient Representatives:

Question 1:

- **What** are the **symptoms** of your tinnitus?
- **When** did the symptoms **start**?
- Are the symptoms **consistent** or **irregular**?
- Have you ever received **professional treatment** for your tinnitus? (f.ex. by consulting an **ENT** doctor, **medical/ psychological** care,..)
- **How burdened** do you feel by your condition?/ How much does it **impact** your **daily life**?
- Next to your tinnitus, are there **other physical** or **psychological illnesses** that you suffer from?

Question 2:

- Easy/ Difficult (Why? (e.g., (No) **support** systems, previous **experiences** with self-management in other conditions, part of **self-help groups**/ receiving **professional treatment** that helps, good **knowledge** of clinicians/ oneself on how to deal with it))

Question 3:

- If **Yes: Which** help do/ did you get?
- **Why** do you (not) get additional help?
- Is there any **help** you would consider important for dealing with tinnitus that you **did not get yet? Which? Why** didn't you get it yet? (f.ex. too expensive, too long waiting lists, too far away, fear that professionals will not take your condition seriously/ have too little expertise to help you,...)
- Do you believe that (not) getting help **influenced** the extent to which you feel **confident** in **managing** your tinnitus condition? **Why? If Yes: How?**

Question 4:

- **Why** do you (not) feel confident about self-managing tinnitus?
- **What** would **help** you to feel (even) **more confident** about managing it? (f.ex. other support groups/ more exchanging experiences with other affected individuals, more tailored tinnitus research/ more updates on research, practical workshops, professional psychological treatment,...)

Question 5:

- Large/ small/...; **Why?**

- Are there **topics** in tinnitus **research** that, according to you, are still **too largely ignored** even if they would **help** you to **better deal** with your condition? (f.ex. tinnitus management, cures, treatment options, reasons for tinnitus emergence,..); **Why** are they important to you/ **How** would research in this area **help you** with dealing with tinnitus?
- Would you **inform** yourself about the **progress** of research projects if you knew that they **addressed personally relevant** topics? If **Yes**: **Which** topics would that be?
- Do you generally feel like tinnitus **research** could make you feel **more confident** in **managing** tinnitus? **Why**? **How**? **Which topics** would need to be addressed to make you feel more confident in self-managing tinnitus?

Question 6:

- finding a **cure**
- finding **better ways** of **supporting self-management** of tinnitus
- **more patient involvement** in research and treatment development
- increasing **professional support** and **expertise** to seek professional help with one's tinnitus condition if needed

Probes for Professionals (Clinicians and Researchers):

Question 1:

- What is your **profession**?
- **Since when** are you working in this field?
- Which **professional education** did you follow to be able to work in your occupation?
- Which **specialisations** or special **interests** do you have in your profession?
- In which fields related to your occupation do you already have **work experience**?

Question 2:

- How **often** are you **confronted** with tinnitus in your professional life?
- To what extent has tinnitus been **addressed** in your **professional education**?
- Are you **satisfied** with your **knowledge** of tinnitus or would you like to know more about it? If **Yes**: What/ in **which areas** would you like to know more? **Why** do you **not know enough** about these areas yet (e.g., no advanced training on this issue, no research on it yet, lacking time to inform yourself)? What needs to **change** so that you **feel satisfied** with your knowledge of tinnitus?
- According to you, does tinnitus get the **attention** it **deserves/ needs**?
- Based on your experience, **how** do tinnitus patients **experience** their condition? How **burdened** are they? What are their **biggest issues**?

Question 3:

- **Why?**
- **What** do you **do** when patients who (are expected to) suffer from tinnitus visit you? Is there a **guideline** you follow? Where does the **focus** of your **treatment** lie (e.g. offering professional help, psychological support, empowering patients to self-manage their condition)
- What do you think your **patients need from you** as a professional? Do you think you can **fulfil these needs**? **How** could you **satisfy** their needs even **more**? Do you think **patients** are **satisfied** with your way of treating tinnitus/ Do you think your treatment is **sufficient** for helping them deal with it?
- According to you, what is **currently missing** in professional **tinnitus treatment** so that patients are/ feel more supported when suffering from tinnitus?

Question 4:

- Large, small,... **Why?**
- **How** can, according to you, tinnitus **self-management** can be more **supported** (e.g., by you as a professional, psychological support, research, self-help groups,..)? How can **you help** patients at **becoming more confident** in self-managing their condition? How do you **already help patients** with **self-managing** tinnitus when they visit you?
- Do you think it is **more important** to **support** the **professional** treatment of tinnitus (e.g. medical or psychological treatment) or the **self-management** of affected individuals? **Why?**

Question 5:

- Large/ small/...; **Why?**
- Do you think research can help you at **improving** your **treatment** of tinnitus patients? How? Research in which **area**? Which role does **patient and provider-oriented** research play in this respect?
- Do you think research can **help** patients **better deal** with/ **self-managing** their condition? How? Which **topics** should be more addressed to reach this? **Why?** How could these topics be **approached** in **future research**?
- From your experience, to what **extent** do **professionals** dealing with tinnitus patients consider tinnitus **research** for their occupation? What could be **changed** in research or professional aspects so that **professionals** would take research **more into account** when treating tinnitus patients?

Question 6:

- finding a **cure/ successful treatment**
- finding **better ways of supporting self-management** of tinnitus
- **more patient and provider involvement** in research and treatment development
- more **advanced training** on tinnitus topics
- **better preparation** in **studies** for professions dealing with tinnitus
- **changes** in professional tinnitus **treatment** (e.g., adapting diagnostic plans/ guidelines and increasing their availability) and/ or tinnitus **research** focuses

Appendix G

Pilot and Interview Study Feedback Elaboration

All participants reported their satisfaction with the interviews. For instance, one participant's feedback was:

“It [interview] was a pleasant experience. The questions are not about nuclear science or anything like that. It's very relatable. [...] I think you're really well organised. It's not 30 questions but you have just the right amount of questions and having those bullet points to prompt I think is really helpful because trying to recall things is sometimes just not that easy.” (PA2, F)

Hence, the structure provided by the slides made participants feel comfortable and certain of what to expect while not fearing to forget about asked questions or lose track of thought. The researcher and participants did not perceive the slides as hindering or distracting but they were rather seen as a useful “backup” which encouraged a more comfortable atmosphere. The questions were also seen as fitting and understandable.

Appendix H

Commonly Perceived Issues of Tinnitus Research, Dilemmas, Suggested Redirection Actions, and Literature and Participant Evidence

Categories ^a	Identified Priorities and Resulting Dilemmas ^b	Underpinning Evidence for Priorities and Dilemmas ^c	Stipulated Main Priorities ^d	Suggested Action Redirections to Meet Main Priorities ^e	Underpinning Evidence for Suggested Action Redirections ^c
Patient Involvement (PI); Funding	<p>Increasing PI: avoiding habituation due to excessive focus on condition (-)</p> <p><i>and</i></p> <p>taking advantage of patients' desperation and motivation to participate, worsening their condition (-)</p> <p><i>and</i></p> <p>some PI projects not fitting academic standards and not financially supported (-)</p> <p><i>and</i></p> <p>some researchers not dealing well with criticism (-)</p> <p><i>but</i></p> <p>more relevance and effectiveness in research (+)</p>	<p>Jastreboff & Jastreboff, 2000 ; PR3, M</p> <p>PR3, M ; PR5, M</p> <p>PR5, M</p> <p>PA2, F ; PA1, F</p> <p>Boote et al., 2002 ; Vahdat et al., 2014 ; PA1, F ; PA2, F ; PR3, M ; PR4, M</p>	<p>Increase PI only to a certain extent to still facilitate habituation.</p> <p>Increase researchers' openness towards involving stakeholders, particularly patients.</p>	<p>- workshops for patients and professionals in which they can exchange their perspectives and ideas on research</p> <p>- offer patients to participate in research but communicate/open up about the impact it might have on their condition</p>	<p>PA2, F</p> <p>Stouffer et al., 1991</p>

Categories ^a	Identified Priorities and Resulting Dilemmas ^b	Underpinning Evidence for Priorities and Dilemmas ^c	Stipulated Main Priorities ^d	Suggested Action Redirections to Meet Main Priorities ^e	Underpinning Evidence for Suggested Action Redirections ^e
More Cure Less Coping Research; Funding	<p>Increasing Cure Research: lacking financial and professional support for such complex and longitudinal projects (-)</p> <p><i>and</i></p> <p>ignoring development of more easily establishable coping strategies (-)</p> <p><i>but</i></p> <p>unburdening patients, professionals, and society when finding a cure (+)</p>	<p>Cederroth et al., 2013 ; PR5, M</p> <p>PR5, M</p> <p>McFerran et al., 2019 ; PA1, F ; PA2, F ; PR3, M ; PR4, M ; PR5, M</p>	<p>Increase research on tinnitus cures and pathophysiology, yet keep a small amount of other (e.g., self-management/ psychological) treatment research to support patients while a cure is searched for.</p>	<p>- establishing objective measurements of tinnitus to attract research funding</p> <p>- registering clinical trials and connected materials in databases to facilitate research with more data</p>	<p>McFerran et al., 2019 ; PA2, F</p> <p>Tunkel et al., 2014 ; PA2, F</p>

Categories ^a	Identified Priorities and Resulting Dilemmas ^b	Underpinning Evidence for Priorities and Dilemmas ^c	Stipulated Main Priorities ^d	Suggested Action Redirections to Meet Main Priorities ^e	Underpinning Evidence for Suggested Action Redirections ^c
Publication; Funding	<p>Increasing Number of Publications: fewer possibilities to investigate more important complex topics (e.g., cures) due to risk of losing funding (-)</p> <p><i>and</i></p> <p>increased hopelessness among patients if no significant results achieved (-)</p> <p><i>and</i></p> <p>restricting habituation due to high focus on patients' conditions (-)</p> <p><i>but</i></p> <p>increased public awareness, triggering more funding in research if significant results (+)</p> <p><i>and</i></p> <p>show that efforts are being made, keeping patients' hope (+)</p>	<p>PR3, M ; PR5, M</p> <p>PR3, M</p> <p>Jastreboff & Jastreboff, 2000; PR3, M</p> <p>PR3, M</p> <p>PA2, F ; PR3, M</p>	<p>Publish studies if they were done but stay realistic about what they mean for the tinnitus community.</p> <p>If possible, focus on reducing the number of studies (therefore also number of publications) to focus on more complex issues (e.g., cure research).</p>	<p>- Disclosing and communicating risks of staying too involved in research activities to patients</p> <p>- establishing objective measurements to increase funding, then focus on more complex issues (e.g., pathophysiologies, cure)</p>	<p>Stouffer et al., 1991 ; PR3, M</p> <p>Jackson et al., 2019 ; McFerran et al., 2019 ; PAR2, F ; PR4, M</p>

Categories ^a	Identified Priorities and Resulting Dilemmas ^b	Underpinning Evidence for Priorities and Dilemmas ^c	Stipulated Main Priorities ^d	Suggested Action Redirections to Meet Main Priorities ^e	Underpinning Evidence for Suggested Action Redirections ^e
Funding	<p>Increasing Funding: lacking freedom to explore tinnitus in directions relevant to tinnitus stakeholders (e.g., patients, clinicians) (-) <i>and</i> pressure to only focus on topics that will most certainly produce positive results, hence, more complex research (e.g., for cures) is more restricted (-) <i>but</i> increased amount of tinnitus research possible, therefore, more likely to gain more insights into tinnitus compared to less funded research (+)</p>	<p>PR5, M</p> <p>PR5, M</p> <p>PR5, M</p>	<p>Finding ways of increasing funding for more exploratory tinnitus research. Establishing possibilities to explore tinnitus from different disciplines.</p>	<p>- establishing objective measurements of tinnitus to attract funding - more interdisciplinary collaborations between researchers - organising more assemblies in which interdisciplinary exchange and discussions towards tinnitus are encouraged</p>	<p>Jackson et al., 2019 ; McFerran et al., 2019 ; PAR2, F ; PR4, M</p> <p>Hall et al., 2015</p> <p>Langguth et al., 2007</p>

Note. This table includes a summary of participants' commonly perceived issues related to tinnitus research, identified dilemmas between participant options, stipulations of these dilemmas, concluded suggested action redirections, and supporting evidence based on scientific literature and participant statements. PA = patient; PR = professional; M = male; F = female; PI = patient involvement; minus sign (-) = counter-argument

against reaching this priority; plus sign (+) = pro-argument in favour of reaching this priority; *and* = addition to previous (counter-) argument; *but* = introduction of first pro-argument.

^a As identified and defined in this paper's results section. ^b Most relevant priorities as mentioned by participants and described in this paper's results section; dilemmas as identified by contrasting participants' needs and perceived limitations for reaching certain main priorities; main priorities in this column are in bold. ^c Based on published literature and participants' statements. ^d Based on assessment on how to combine patients' needs and professionals' limitations. ^e Action redirections = the establishment of new or alteration of existing actions within current tinnitus practices; examples based on published literature and participants' statements.

Appendix I

Commonly Perceived Issues of Tinnitus Treatment, Dilemmas, Suggested Redirection Actions, and Literature and Participant Evidence

Categories ^a	Identified Priorities and Resulting Dilemmas ^b	Underpinning Evidence for Priorities and Dilemmas ^c	Stipulated Main Priorities ^d	Suggested Action Redirections to Meet Main Priorities ^e	Underpinning Evidence for Suggested Action Redirections ^e
Professional Support (PS)	<p>Increasing PS: limited capacities for other patients for whom effective treatments are available (-)</p> <p><i>and</i></p> <p>less empowerment by self-managing tinnitus; dependency (-)</p> <p><i>and</i></p> <p>losing money and time on unevidenced and unsuccessful treatments (-)</p> <p><i>and</i></p> <p>possibility of patients focusing too much on PS while reducing chances of habituation (-)</p> <p><i>but</i></p> <p>can support tinnitus management and help patients better deal with their condition (+)</p>	<p>PR5, M</p> <p>PR5, M</p> <p>PA1, F</p> <p>Jastreboff & Jastreboff, 2000 ; PR3, M</p> <p>PA1, F ; PA2, F ; PR3, M ; PR4, M ; PR5, M</p>	<p>Increasing professional support and communication about patients' needs at the beginning of their condition.</p> <p>Reducing PS over time.</p> <p>Referring patients to publicly available support systems (e.g., self-help groups) and psychological support systems.</p>	<p>- Communicating clinicians' limited possibilities</p> <p>- increasing availability and awareness of (online) self-help groups and psychological treatment</p> <p>- Giving fairly optimistic view that condition will most likely improve over time</p> <p>- facilitating multidisciplinary support</p> <p>- establishing general set of therapeutic skills in medical professionals</p>	<p>Pryce et al., 2018 ; PR3, M ; PR4, M ; PR5, M</p> <p>Mehdi et al., 2020 ; Stouffer et al., 1991 ; PA1, F ; PA2, F ; PR3, M ; PR4, M ; PR5, M</p> <p>Stouffer et al., 1991 ; PR3, M</p> <p>Cima et al., 2019 ; PR4, M ; PR5, M</p> <p>Pryce et al., 2018 ; PA1, F ; PA2, F ; PR3, M ; PR4, M ; PR5, M</p>

Categories ^a	Identified Priorities and Resulting Dilemmas ^b	Underpinning Evidence for Priorities and Dilemmas ^c	Stipulated Main Priorities ^d	Suggested Action Redirections to Meet Main Priorities ^e	Underpinning Evidence for Suggested Action Redirections ^e
Professional Support (PS)	<p>Increasing PS for Severe Cases:</p> <p>Reducing chances of helping less severe cases more easily with less effort (-)</p> <p><i>but</i></p> <p>helping patients who need help the most and are the most affected by their condition (+)</p>	<p>PR5, M</p> <p>PR5, M</p>	<p>Establishing basic tinnitus assessments and treatments for less severe cases while referring to systems facilitating self-management (e.g., self-help groups).</p> <p>Establishing more professional and individual support for more severe cases.</p>	<p>- communicating currently limited availabilities and possibilities of professional support to patients</p> <p>- informing patients about the likely improvement of their condition over time</p> <p>- guiding patients through their condition while also empowering them to explore self-management strategies themselves</p> <p>- establishing more (online) self-help and (standardised) psychological treatment options</p>	<p>Pryce et al., 2018 ; PR3, M; PR5, M</p> <p>Stouffer et al., 1991 ; PA1, F ; PA2, F ; PR3, M ; PR4, M ; PR5, M PA2, F</p> <p>Andersson, 2022 ; Mehdi et al., 2020 ; PA1, F ; PA2, F ; PR3, M ; PR4, M ; PR5, M</p>

Categories ^a	Identified Priorities and Resulting Dilemmas ^b	Underpinning Evidence for Priorities and Dilemmas ^c	Stipulated Main Priorities ^d	Suggested Action Redirections to Meet Main Priorities ^e	Underpinning Evidence for Suggested Action Redirections ^e
Patient Involvement (PI); Professional Support (PS); Clinical Treatment Guidelines (CTG)	<p>Increasing PI:</p> <p>Fewer possibilities of researching the effectiveness of currently applied treatments due to their lacking standardisation (-)</p> <p><i>and</i></p> <p>less likely to habituate (-)</p> <p><i>and</i></p> <p>restricted use of CTGs which were often requested by patients (-)</p> <p><i>but</i></p> <p>achieving more patient satisfaction and effectiveness of treatments, possibly enhancing patients' conditions (+)</p> <p><i>and</i></p> <p>exploring novel ways of tinnitus management and treatment together with patients, hence, gaining more insights into individual needs (+)</p>	<p>PR5, M</p> <p>PR3, M</p> <p>PA1, F ; PA2, F ; PR5, M</p> <p>PA1, F; PA2, F</p> <p>PA2, F</p>	<p>Establishing standardised treatment procedures that entail more patient-oriented communication and the option of including patients within the establishment of a fitting treatment.</p>	<p>- developing treatment guidelines that professionals are informed about (e.g., during advanced training; including more reflected and communicated patient involvement that addresses patients needs but also professionals' limitations)</p>	<p>Tunkel et al., 2014 ; PA1, F ; PA2, F ; PR4, M</p>

Categories ^a	Identified Priorities and Resulting Dilemmas ^b	Underpinning Evidence for Priorities and Dilemmas ^c	Stipulated Main Priorities ^d	Suggested Action Redirections to Meet Main Priorities ^e	Underpinning Evidence for Suggested Action Redirections ^e
Psychological Treatment (PT); Patient Involvement (PI); Professional Support (PS)	<p>Increasing PT: High stigma (-)</p> <p><i>and</i></p> <p>patients' physical proximity and timely barriers (-)</p> <p><i>and</i></p> <p>patients' expectations to receive adequate emotional support from clinicians (-)</p> <p><i>and</i></p> <p>old and too standardised psychological treatments that are not working for everyone (-)</p> <p><i>but</i></p> <p>reducing strains on clinicians and patients since PT currently best option to reduce patient suffering (+)</p>	<p>Britt et al., 2008 ; PR3, M ; PR4, M ; PR5, M</p> <p>Britt et al., 2008 ; Mohr et al., 2010 ; PR5, M</p> <p>PA2, F ; PR5, M</p> <p>PA1, F ; PA2, F</p> <p>PA1, F ; PA2, F ; PR3, M ; PR4, M ; PR5, M</p>	<p>Trying to increase number of patients that seek or try PT for tinnitus.</p> <p>Establishing better communication between professionals and patients to exchange different perceptions, expectations, and limitations of what medical/ psychological tinnitus treatments can provide.</p>	<p>- facilitating communication between professionals and patients, their needs and how these can be satisfied best</p> <p>- Increasing physical proximity between medical and psychological professionals' locations (e.g., placed in the same clinic)</p> <p>- increasing online psychological treatment/ support for tinnitus patients</p> <p>- establish treatment guidelines for tinnitus treatment that can be referred to by patients and professionals</p>	<p>Pryce et al., 2018</p> <p>PR5, M</p> <p>Andersson, 2022 ; Mehdi et al., 2020 ; PR3, M ; PR5, M</p> <p>Tunkel et al., 2014 ; PA1, F ; PA2, F ; PR4, M</p>

Note. This table includes a summary of participants' commonly perceived issues related to tinnitus treatment, identified dilemmas between participant options, stipulations of these dilemmas, concluded suggested action redirections, and supporting evidence based on scientific literature and participant statements. PA = patient; PR = professional; M = male; F = female; PT = psychological treatment; PI = patient involvement; PS = professional support; CTG = clinical treatment guidelines; minus sign (-) = counter-argument against reaching this priority; plus sign (+) = pro-argument in favour of reaching this priority; *and* = addition to previous (counter-) argument; *but* = introduction of first pro-argument.

^a As identified and defined in this paper's results section. ^b Most relevant priorities as mentioned by participants and described in this paper's results section; dilemmas as identified by contrasting participants' needs and perceived limitations for reaching certain main priorities; main priorities in this column are in bold. ^c Based on published literature and participants' statements. ^d Based on assessment on how to combine patients' needs and professionals' limitations. ^e Action redirections = the establishment of new or alteration of existing actions within current tinnitus practices; examples based on published literature and participants' statements.

