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Hallucinations in Hearing Impairment: How Informed Are Clinicians?

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Background and Hypothesis: Patients with hearing impairment (HI) may experience hearing sounds without external sources, ranging from random meaningless noises (tinnitus) to music and other auditory hallucinations (AHs) with meaningful qualities. To ensure appropriate assessment and management, clinicians need to be aware of these phenomena. However, sensory impairment studies have shown that such clinical awareness is low.

Study Design: An online survey was conducted investigating awareness of AHs among clinicians and their opinions about these hallucinations.

Study Results: In total, 125 clinicians (68.8% audiologists; 18.4% Ear-Nose-Throat [ENT] specialists) across 10 countries participated in the survey. The majority (96.8%) was at least slightly aware of AHs in HI. About 69.6% of participants reported encountering patients with AHs less than once every 6 months in their clinic. Awareness was significantly associated with clinicians' belief that patients feel anxious about their hallucinations ($\beta = .018$, $t(118) = 2.47$, $P < .01$), their belief that clinicians should be more aware

of these hallucinations ($\beta = .018$, $t(118) = 2.60$, $P < .01$), and with confidence of clinicians in their skills to assess them ($\beta = .017$, $t(118) = 2.63$, $P < .01$). Clinicians felt underequipped to treat AHs (Median = 31; $U = 1838$; $P_{\text{FDRadj}} < .01$).

Conclusions: Awareness of AHs among the surveyed clinicians was high. Yet, the low frequency of encounters with hallucinating patients and their belief in music as the most commonly perceived sound suggest unreported cases. Clinicians in this study expressed a lack of confidence regarding the assessment and treatment of AHs and welcome more information.

Key words: hearing-impairment/auditory hallucinations/awareness/online survey/deafferentation

Introduction

Beyond the well-known symptom of tinnitus, hearing impairment (HI) is frequently accompanied by the perception of more complex sounds without corresponding external stimuli, ie, auditory hallucinations (AHs). AHs

can be distinguished from tinnitus by their meaningful qualities.^{1,2} While early descriptions of this phenomenon date back more than 100 years,³ a recent large-scale cross-sectional study demonstrated that 16% of individuals with HI have experienced AHs, including hearing voices.⁴ The occurrence increased further to 24% in individuals with severe HI. Currently, approximately, 430 million individuals are assumed to suffer from disabling HI.⁵ This number is expected to almost double by the year 2050.⁵ Given this high worldwide prevalence, one might expect to encounter hearing-impaired patients experiencing hallucination frequently in clinical settings.

Typically, AHs in HI occur in the absence of delusions or thought disorders, and patients maintain good insight into their hallucinations,⁶ which phenomenologically differ from most hallucinations in patients with schizophrenia spectrum disorder. Unlike hallucinations in psychosis, the underlying mechanisms in HI are assumed to be a reaction to the lack of afferent sensory input and described by the deafferentation model.⁷⁻⁹ According to this model, decreased sensory input causes a lower threshold for signal detection in higher-order brain areas and changes in spontaneous activity in the bottom-up stream of auditory perception. Together, these 2 maladaptive compensation mechanisms generate the perception of hallucinations.^{7,10-12} While still under debate, recent findings support this theory.^{13,14}

Given these phenomenological and supposed pathophysiological differences, AHs in HI may require other therapeutic interventions than AHs in psychiatric or neurological disorders regarding their treatment. For instance, in addition to current pharmacological interventions for hallucinations, which are primarily aimed toward the latter populations, AHs in HI benefit from non-pharmacological interventions targeted toward the improvement of hearing.⁸ Contrary to the popular belief that AHs in HI consist of music, voices were most frequently observed in this patient group.⁴ This finding suggests an increased likelihood that deafferentation hallucinations are mistaken for psychotic hallucinations, due to similar phenomenology.

While HI patients who experience AHs show a much lower need for care compared with patients experiencing hallucinations due to other disorders, some reports indicate that AHs in HI are experienced as stressful or bothersome.^{15,16} Indeed, a substantial proportion of HI patients with hallucinations face increases in distress or disfunction and form an important target group for treatment.¹⁷ Although treatment may not be needed in most HI patients with AHs, who present with lower levels of distress or disfunction, clear explanations and prognosis are most welcome to prevent worries and shame surrounding the experience.^{18,19} Clinicians' awareness can greatly contribute to this.

Although little is known about levels of awareness of AHs in HI among clinicians, studies show a lack

of knowledge of the visual variant of these hallucinations (Charles Bonnet syndrome, ie, visual hallucinations due to eye disease) among general practitioners and ophthalmologists.²⁰⁻²² Consequently, patients with Charles Bonnet syndrome might not receive proper information regarding their experiences, which can negatively influence their quality of life.²⁰

To prevent this for HI, it is important to investigate clinicians' awareness about this phenomenon and to assess their level of knowledge about it, as they might encounter patients with these hallucinations. Considering the absence of clear guidelines on the appropriate management, assessment, and the interdisciplinary nature of these hallucinations, we expected to observe similarly low levels of awareness as for Charles Bonnet syndrome.

Method

A survey consisting of 29 questions and statements covering awareness, typical treatment, and opinions about AHs in HI was created for this study (see [supplementary appendix](#)). Answers were either on a 5-point Likert scale or a scale of 1 to 100. The survey was created in the web-based survey tool Qualtrics and made available in English, German, and Dutch. To ensure that all participants had a similar understanding of the term AHs, we provided the following definition in the instruction of the survey: "Hallucinations are sounds a patient hears that have no external source and to which the patient gives a meaning. This can entail very complex sounds like voices, music, animal sounds, but can also be rather simple like the sound of a machine or running water." The link to the survey was distributed among the network of the members of this working group and the mailing lists of the British Society of Audiology (www.thebsa.org.uk), the German Society for Audiology (Deutsche Gesellschaft für Audiologie, www.dga-ev.com), and the circle Clinical Audiology of the Dutch Association for Clinical Physics (Kring Klinische Audiologie, www.nvkf.nl).

All data were inspected for random answers and survey completion before analysis. Ten responses were deleted due to respondents either not reaching the end of the survey or not answering any questions.

Statistical Tests

General findings are reported using descriptive statistics. For numerical (ordinal or continuous) data, means, modes, and SDs were calculated; for categorical data, percentages were used. Correlations between awareness and other variables were calculated using Spearman's correlations. Missing data were excluded from descriptive analyses. An overview of the missing cases is given in the [supplementary appendix](#).

Regarding the statements in the survey, we tested whether the mean response deviated from a score of

$m = 50$ using one sample Mann-Whitney U tests. We considered a significant deviance of this score as the sample either agreeing ($m > 50$) or disagreeing ($m < 50$) with the statement.

An ordinal regression was performed to determine which variables explained awareness of AHs. Model variables were selected using a stepwise approach with both forward and backward selection. For the ordinal regression analysis and correlation analysis, missing data were imputed using mean imputation for numerical data and mode imputation for categorical data. All descriptive and correlation analyses as well as Mann-Whitney U tests were performed in Python 3.8 using the SciPy package²³; the ordinal regression was performed in RStudio using the MASS package.²⁴

The Local Research Ethics Committee from the University Medical Center Groningen exempted this study from full review (METc 2021/422). General Data Protection Regulation (GDPR) guidelines were followed.

Results

A total of 125 survey replies were valid and included in the analysis. The participants had an average age of 44.68 years (SD = 10.68) and consisted of 62 men and 63 women (49.6% male, 50.4% female). Most participants worked in the field of audiology (68.8%), followed by Ear-Nose-Throat (ENT) specialists (18.4%). About 37.6% of the participants were based in Germany ($N = 47$; 24 females, 23 males), 28.8% in the Netherlands ($N = 36$; 11 females, 25 males), and 22.4% in the United Kingdom ($N = 28$; 20 females, 8 males). The remaining 11.2% were grouped together as “other” ($N = 14$; 8 females, 6 males) due to small group sizes (see the [supplementary appendix](#) for the remaining countries). The results demonstrate that the clinicians were aware of AHs in HI, with 29.6% being very much aware, 39.2% being moderately aware, 12% being somewhat aware, 16% being slightly aware, and only 3.2% being not at all aware (figure 1). Most participants learned about hallucinations in HI via their patients, who either have AHs (57.6%) or mentioned it (54.4%), followed by their residential training (42.4%), and by reading scientific articles (32%). Only a minority learned about this phenomenon during their basic medical training (12.8%). Regarding the phenomenology of the hallucinations, most clinicians in our sample (56.5%) believed that music was most commonly perceived by patients (figure 2), whereas less than half considered any of the other types of sounds, such as bells and ringing (18.5%), voices (12.1%), and animal sounds (2.4%).

Statements

Out of the 16 statements presented to participants, 14 were significantly different from $m = 50$, which we interpreted as the group either agreeing or disagreeing with

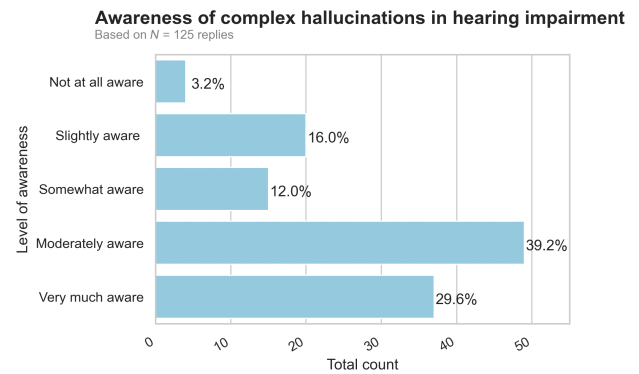


Fig. 1. Distribution of level of awareness of AHs among the sample of clinicians ($N = 125$). Awareness was measured on a 5-point Likert scale. The x-axis shows the total count, and the y-axis shows answer possibilities. Each bar is annotated with the percentage of responses falling into this category. *Note:* AHs, auditory hallucinations.

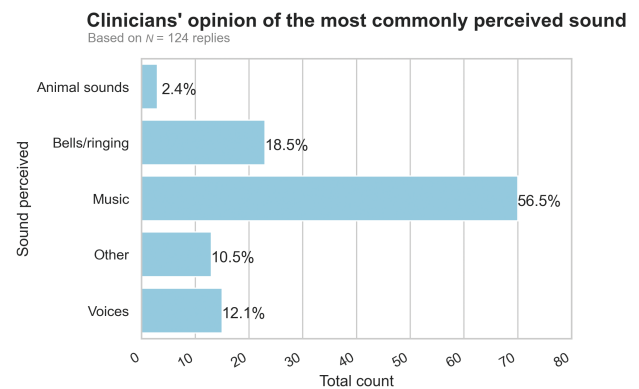


Fig. 2. Distribution of answers to “what is in your opinion the most common sound perceived” given by a total of $N = 124$ participants. The x-axis shows the total count, and the y-axis shows answer possibilities. Each bar is annotated with the percentage of responses falling into this category.

the statement. All P -values were adjusted for false discovery rates (FDR).²⁵ Our sample agreed with the following statements:

- Assessment and treatment of AHs in hearing-impaired patients should be organized through interdisciplinary collaborations (Mdn = 85; $U = 347$; $P_{\text{FDRadj}} < .01$).
- Concerning patients with HI and AHs, I believe that they can benefit from proper psycho-education (Mdn = 80; $U = 353.5$; $P_{\text{FDRadj}} < .01$).
- I believe that clinicians in my field of practice should be more aware of AHs in HI (Mdn = 72; $U = 868$; $P_{\text{FDRadj}} < .01$).
- I consider AHs in hearing impairment a clinically relevant topic in general (Mdn = 71; $U = 1429$; $P_{\text{FDRadj}} < .01$).
- I consider AHs in hearing impairment a clinically relevant topic in my field of practice (Mdn = 70.5; $U = 1247$; $P_{\text{FDRadj}} < .01$).

- Concerning patients with hearing impairment and AHs, I believe that they feel anxious about their hallucinations (Mdn = 70; $U = 801.5$; $P_{FDRadj} < .01$).
- It is necessary to include the assessment of AHs in hearing-impaired individuals in clinical guidelines on hearing impairment (Mdn = 60.5; $U = 1876.5$; $P_{FDRadj} < .01$).
- Concerning patients with hearing impairment and AHs, I believe that they feel embarrassed about their hallucinations (Mdn = 60; $U = 1625.5$; $P_{FDRadj} = .03$).

The sample disagreed with the following statements:

- I consider myself capable to conduct proper treatment of AHs in a hearing-impaired patient (Mdn = 31; $U = 1838$; $P_{FDRadj} < .01$).
- AHs and tinnitus in hearing-impaired patients are 2 presentations of the same phenomenon (Mdn = 32; $U = 1797.5$; $P_{FDRadj} < .01$).
- Concerning patients with hearing impairment and AHs, I believe that they spontaneously report their hallucinations with their treating physician (Mdn = 40; $U = 1535.5$; $P_{FDRadj} < .01$).
- Concerning patients with hearing impairment and AHs, I believe that they feel free to talk about their hallucinations with their treating physician (Mdn = 40; $U = 1738$; $P_{FDRadj} < .01$).
- Concerning patients with hearing impairment and AHs, I believe that they have a mental illness (Mdn = 50; $U = 891$; $P_{FDRadj} < .01$).
- Concerning patients with hearing impairment and AHs, I believe that they should be referred to a psychiatrist (Mdn = 50; $U = 937.5$; $P_{FDRadj} < .01$).

No significant agreement or disagreement was found for the following 2 statements:

- I consider myself capable to conduct proper assessment of AHs in a hearing-impaired patient (Mdn = 50; $U = 1876.5$; $P_{FDRadj} = .76$).
- It is easy to distinguish AHs from tinnitus (Mdn = 45; $U = 2873$; $P_{FDRadj} = .48$).

Clinical Experience

We asked our sample how frequently they encountered HI patients with AHs in their clinic. Most surveyed clinicians (36.8%) reported seeing a patient present with these hallucinations once a year or less, whereas 32.8% saw them once every 6 months, 19.2% saw them once a month, and 11.2% saw them at least once a week (figure 3). Many never (66%) discussed the possibility of patients developing hallucinations and rarely (39%) inquired about the presence of hallucinations.

Clinicians in our sample usually treat patients by providing treatment for their HI (24%), providing psycho-educative information (18.9%), or providing psychological interventions (14.5%; figure 4).

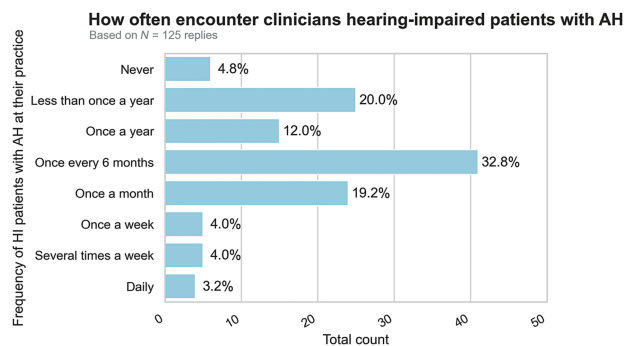


Fig. 3. Answers to “In your practice how often do you encounter patients with AHs” by $N = 125$ participants. The x-axis shows the total count, and the y-axis shows answer possibilities. Each bar is annotated with the percentage of responses falling into this category. *Note:* AHs, auditory hallucinations.

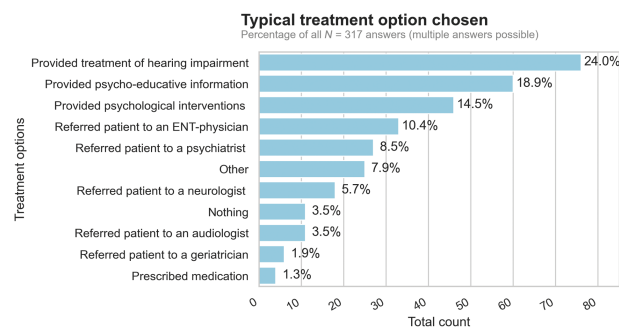


Fig. 4. Answers to “When you encountered a hearing-impaired patient with AHs, what did you do” by $N = 125$ participants. Multiple answers were possible. The x-axis shows the total count, and the y-axis shows answer possibilities. Each bar is annotated with the percentage of responses falling into this category. *Note:* AHs, auditory hallucinations.

The vast majority (93.6%) would like to learn more about hallucinations in HI.

Relationship With Awareness

The level of awareness expressed by clinicians correlated significantly positive with the participants’ belief that clinicians in their own field should be more aware of AHs in HI ($c = .27$, $P_{FDRadj} = .04$). Awareness also correlated positively with whether the participant believed that patients were anxious about their hallucinations ($c = .25$, $P_{FDRadj} = .04$).

The chi-squared analysis revealed that awareness levels differed between countries ($\chi^2 (12, 125) = 26.68$, $P_{FDRadj} = .01$) with a subgroup of German participants having a lower level of awareness (figure 5). Awareness also differed regarding how often clinicians encounter patients experiencing AHs in HI in their clinic ($\chi^2 (28, 125) = 109.06$, $P_{FDRadj} < .01$), with more encounters being associated with higher awareness.

Furthermore, the regression analysis demonstrated that clinicians’ awareness of hallucinations in HI was associated with their agreement on the following statements:

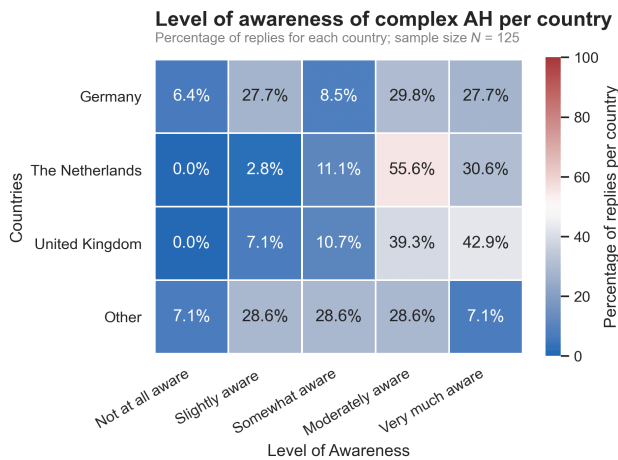


Fig. 5. Awareness of AHs in HI among the sample ($N = 125$), arranged by country. Percentages are given per country. Awareness was measured on a 5-point Likert scale. The x-axis shows answer possibilities, and the y-axis shows the different countries. *Note:* AHs, auditory hallucinations; HI, hearing impairment.

- Concerning patients with HI and AHs, I believe that they feel anxious about their hallucinations ($\beta = .018$, $t(118) = 2.47$, $P < .01$),
- I believe that clinicians in my field of practice should be more aware of AHs in HI ($\beta = .018$, $t(118) = 2.60$, $P < .01$), and
- I consider myself capable to conduct proper assessment of AHs in a hearing-impaired patient ($\beta = .017$, $t(118) = 2.63$, $P < .01$).

We here described the main results of our analysis. For additional information, see the [supplementary appendix](#).

Discussion

In this online study, we investigated clinicians' awareness of the existence of AHs in HI and their opinions regarding hallucinations. Our results show that clinicians are generally aware of AHs occurring in HI. Interestingly, the frequency with which the participants of our survey encountered patients with HI and AHs was relatively low, with almost 70% of all clinicians reporting to see them less than once per half year. Clinicians also believed music to be the most common sound perceived by these patients. Our sample consisted mainly of audiologists and ENT specialists, 2 clinician groups who encounter hearing-impaired patients daily. This suggests AHs being either underreported or mistaken for tinnitus, which may be associated with hallucinations not being an integral part of anamnesis. While clinicians consider AHs and tinnitus to be different phenomena, questions addressing the perception of sound heard inside the head, which are commonly asked during clinical assessment, may not be sensitive enough to distinguish AHs from tinnitus.

Importantly, our sample was not very confident regarding their skills to address or treat hallucinations, and

to a lesser degree to assess them. This was reflected in their desire for more information and need for interdisciplinary treatment approaches. This lack of confidence in their assessment skills, a belief that patients feel anxious about their hallucinations, and the belief that colleagues should be more aware of hallucinations in HI were associated with the awareness level expressed by the clinicians. Additionally, we found that awareness of AHs in HI among clinicians was lower among a small group of specialists from Germany and from a group of other countries.

Nevertheless, the overall high awareness level is reassuring considering earlier reports of a lack of knowledge about Charles Bonnet syndrome.^{20,21} While audiologists and ENT specialists are not primary care providers, most HI patients visit these clinicians for consultation of their HI.²⁶ Given the prevalence level of AHs in HI, namely 16% of all HI people,⁴ it is understandable that clinician groups, who primarily work with HI patients, would encounter patients with hallucinations regularly and, therefore, be aware of this phenomenon. However, in response to the question about how often our participants encountered patients with hallucinations, most clinicians expressed that they encounter them rather infrequently. Almost 70% of our sample indicated they came across patients with AHs less than once every half year, which is particularly low and is unlikely to correspond to the prevalence of 16%.⁴ This discrepancy might be due to AHs being mistaken for tinnitus or patients not disclosing their hallucinations. Indeed, clinicians expressed that they felt like patients neither spontaneously acknowledged their hallucinations nor felt free to discuss them with clinicians in charge. As AHs are currently not always addressed during audiological consultations, this symptom might often go unnoticed or mistaken for tinnitus. By relying on patients to report their hallucinations and not directly inquiring themselves, clinicians might introduce a skewed picture of the actual prevalence of AHs. As patients also undergo negative experiences in the setting of tinnitus care,²⁶ fear of stigma might make patients more reluctant to disclose their hallucinations spontaneously,¹⁸ as AHs are commonly seen as a sign of mental illness and frequently lead to embarrassment and fear in patients experiencing them.^{18,19} Including assessment and psycho-education about AHs into the consultation of HI could contribute to the awareness and de-stigmatization of AHs.

Moreover, our sample believes that hallucinations occurred mainly as music. As mentioned above, this might be related to patients having more reservations to talk about hearing voices than music, as hearing voices is commonly associated with psychiatric illness, thus motivating patients not to disclose their nonmusical AHs. Another explanation might be the overrepresentation of musical hallucinations in HI in the literature, with articles selectively investigating musical hallucinations but

not inquiring after other hallucinations.^{3,6,16,27–29} This may not be representative of AHs in HI, as (1) other disorders can cause musical hallucinations⁸ and (2) hallucinations in HI are not limited to music. Voices have been shown to be perceived as often as or even more frequently than music by hearing-impaired individuals.⁴ Yet, clinicians in our sample do not seem to see this in their clinical settings. As the perception of voices has historically been associated with psychiatric and neurological disorders,^{30–32} differentiating between AHs due to HI and other causes might be harder than initially thought. Comparisons between AHs in neurodegenerative disorders and HI showed no differences regarding their phenomenological features, aside from insight into their nature.³³

AHs in HI were considered a relevant topic, whose treatment requires interdisciplinary collaborations. While interdisciplinary approaches have been suggested to be beneficial in understanding AHs in schizophrenia,^{34,35} the interdisciplinary nature of hallucinations in HI makes it also advantageous to be targeted from different clinical angles. In recent years, our understanding of the epidemiological and phenomenological nature of hallucinations in HI has advanced; yet, insight into underlying mechanisms and the availability of proper psychoeducation is limited. Since clinicians from different specialisms, such as psychiatrists, audiologists, and family physicians, might encounter patients with AHs, no clear guidelines and information might delay appropriate patient care. Even though improvement of hearing abilities with hearing aids or implants is found successful in overcoming AHs in some cases,^{8,12} certain risk factors, such as depressive symptoms and emotional loneliness,¹⁷ can be combatted from a psychological perspective. Additionally, drawing on the advances in the management of hallucinations in a psychiatric setting could be valuable regarding the management of AHs in HI.³⁶ While psychological services are offered within larger audiological settings, this is not the norm.²⁶ Therefore, doubts regarding the assessment and treatment of hallucinations among audiologists are understandable.

Limitations

As the clinicians surveyed for this article are self-selected, meaning they chose to participate in this study, our sample might contain a bias in terms of interest or understanding of AHs in HI. This could have implied higher levels of awareness in our participants compared with clinicians in general. Thus, our sample might not reflect all clinicians encountering hallucinations in HI. Additionally, having a sample consisting mainly of audiologists and ENT specialists might overrepresent their views, especially because many other clinician groups might interact with this patient group regularly. For future studies, it would be essential to include a larger variety of clinicians to provide a thorough picture of the current awareness levels.

Especially, awareness and opinions of primary care providers are essential as they are the first contact and play a fundamental role in the further course of assessment. However, as patients experiencing HI are usually referred to audiologists or ENT specialists, our sample is a useful start in bringing awareness of AHs into the picture.

While most questions in the survey allowed multiple answer possibilities, the question regarding the most commonly perceived sound was forced choice. This potentially lowered the number of replies opting for different answers than music. While this was a deliberate choice from our side to investigate whether there is still a bias toward musical hallucinations, this might have influenced the results.

The use of Likert scales as answer possibilities for several of the questions might have made it difficult for respondents to precisely express their opinions as labeled categories do not necessarily capture fine-tuned differences. However, Likert scales are commonly used for surveys, and all ordinal items were presented in the intended order (lowest to highest) to help the participants understand the relationship between response possibilities.

Participants in this survey worked in a limited number of countries, which can be considered Western societies, with the majority being European. Differences in medical systems, the training of clinicians, and the typical discourse of treatment might have influenced our results and made them less generalizable. Additionally, the appreciation and understanding of AHs have been shown to differ between cultures.^{32,37} Therefore, opinions and knowledge about hallucinations as described by our sample might not reflect other cultures.

Future Directions

The limited information available seems to affect the knowledge and awareness of clinicians regarding hallucinations in HI. It is, therefore, crucial to find ways to provide them with the latest developments in this field. In the short term, this could be done via workshops or direct communication of recent findings; however, in the long-term, changes in clinical guidelines and more emphasis on hallucinations in HI during clinical specialization training might be a better solution.

In terms of future research, it would be useful to extend the current findings by examining awareness in a wider range of clinicians, including experts from other fields and more countries. The current study gave a glimpse into the knowledge of mainly audiologists and ENT specialists within Europe, which is an important first step. Expanding the data into more clinical specialties will allow us to get a clearer picture of the current knowledge among clinicians and identify groups who would benefit from more information and training.

Another focus for further research is the ideal approach toward hallucinations in HI as the lack of clarity

surrounding this topic has hampered the development of clinical guidelines. While some studies investigated treatment options, especially for musical hallucinations,^{8,38,39} a randomized clinical trial comparing different treatment possibilities for AHs in HI is needed. This may include not only known treatments for hallucinations, such as neurostimulation and pharmacological interventions,^{36,40,41} but also approaches used in tinnitus, such as masking and psychotherapy.^{42,43}

While we focused on patients with hallucinations due to HI, most HI patients do not develop hallucinations. It is, therefore, of great importance to detect factors contributing to the experience of hallucinations. Knowing who is at risk for hallucinations will help increase detection rates and the development of effective treatment methods.

Conclusion

Awareness among the 125 surveyed clinicians in this study was positive. Over 95% of the participants were at least somewhat aware of AHs occurring in HI. However, clinicians seem to encounter patient experiencing such hallucinations less frequently than prevalence levels suggest. This points toward the possibility that many patients with these symptoms have been overlooked in clinical settings. Furthermore, clinicians lack confidence regarding the assessment and treatment of these hallucinations and would like to receive more information about them. There is an imperative to meet this need in a variety of ways and settings.

Supplementary Material

Supplementary material is available at *Schizophrenia Bulletin*.

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