

Awareness of hyperacusis management among hearing health care professionals - a nationwide telephonic survey

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Abstract. Hyperacusis has recently attracted professional attention. Previously, this topic was not well researched or documented. In many instances, due to a lack of understanding regarding the diagnosis, the pathophysiology and treatment options, patients' complaints were ignored. Hyperacusis is defined as an abnormally strong reaction to sound occurring within the auditory pathways. In the present study, an attempt has been made to make a telephonic survey regarding awareness of hyperacusis by asking a set of 19 questions from otorhinolaryngologists and audiologists in almost all parts of India. It is found that 56.6% of the participants report that hyperacusis is not diagnosed in their clinics, 73.4 % do not know the etiology, 33.3% manage hyperacusis and tinnitus simultaneously while others are not sure which should be managed. Decreased sound tolerance, including hyperacusis, misophonia, and phonophobia, is a challenging topic to study and treat. The etiology is not clear, neural mechanisms are speculative and treatments are not yet proven. The general recognition of decreased sound tolerance, as a problem requiring attention and proper treatment, should be considered a priority in the community of hearing professionals.

Key words: Hyperacusis, awareness, survey

1. Introduction

Disorders of loudness perception, for long a clinical enigma, can represent a serious challenge to the patient. In these cases, patients do not leave their homes. Their lives, and the lives of their families, are totally controlled by the issue of sound avoidance. It is not necessarily loud sounds, but even quiet sounds, which can cause discomfort. Decreased sound tolerance might reflect a physical discomfort, or can be related to a dislike or a fear of sound (1).

Hyperacusis has been defined as 'unusual tolerance to ordinary environmental sounds' (2)

and, more pejoratively, as 'consistently exaggerated or inappropriate responses to sounds that are neither threatening nor uncomfortably loud to a typical person'. Terms such as "oversensitive hearing," "hyperacusis," "phonophobia," "recruitment," "dysacusis," and "auditory hyperesthesia," were used interchangeably (and incorrectly) to describe decreased sound tolerance, and discomfort or pain in the ears, associated with sound exposure (3).

Misophonia is defined as the dislike of sound, (4). Phonophobia has been defined as the 'fear of sound' and has been used for patients expressing a fear of certain sounds, or all sounds and resulting from abnormal activation of the limbic and autonomic nervous systems. In neurology, phonophobia tends to be used specifically for the loudness intolerance reported by some patients with migraine (5). Common to both hyperacusis and phonophobia is the implication that the experience can be evoked by sounds of low intensity and that sounds in general, rather than

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specific sounds, are problematic. The majority of patients with decreased sound tolerance have misophonia, but only some of them are phonophobic. Phonophobia and misophonia both carry a suggestion that the intolerance may be specific to certain sounds with emotional associations. However, neither hyperacusis, nor misophonia nor phonophobia have any relation to hearing thresholds. Patients with hyperacusis, misophonia or phonophobia may have normal hearing, or they may be hearing impaired. Central and peripheral conditions associated with hyperacusis have been listed in table-1.

Loudness recruitment describes an experience commonly associated with cochlear hearing loss and specifically with dysfunction of the outer hair cells of the organ of Corti: with a rising sound level, the perceived loudness increases faster than normal. This phenomenon may be distinguished from hyperacusis if the individual perceives sound of moderate intensity as uncommonly loud (recruitment) or sound of low intensity as uncomfortably loud (hyperacusis) but the two experiences are not mutually exclusive. Loudness recruitment does not, however, vary with mood (6).

Lack of robust epidemiological data is a major shortcoming of the published work on hyperacusis. A coincidence of tinnitus complaint and of experiences of hyperacusis has been widely noted. Among patients attending tinnitus clinics with a primary complaint of tinnitus the prevalence of hyperacusis is about 40% and in patients with a primary complaint of hyperacusis the prevalence of tinnitus has been reported as 86% (7).

The peripheral conditions identified involve facial nerve dysfunction. Since the facial nerve innervates the stapedial reflex, which is a mechanism for reducing the perceived intensity of impulse sound, these conditions may reduce the efficacy of that reflex and hence increase the perceived intensity of sound. There are some central conditions which can cause hyperacusis. Lyme disease is a systemic infection with the tick-borne spirochaeta *Borrelia burgdorferi* which targets specific body organs including the peripheral and central nervous systems (8). There are, however, reports of hyperacusis in Lyme disease without facial nerve dysfunction (9). Williams syndrome is a disorder characterized by deficits in conceptual reasoning, problem solving, motor control, arithmetic ability and spatial cognition (10) with an incidence of 1 in 20, 000 live births. As many as 90% of individuals with this syndrome report hyperacusis (3) and a proposed mechanism is 5 hydroxytryptamine (5-

HT) dysfunction (11). Other conditions in which hyperacusis has been reported are middle cerebral aneurysm (12) and migrainous cerebral infarction (13).

Acoustic shock disorder (ASD) is an involuntary response to a sound perceived as traumatic (usually a sudden, unexpected loud sound heard near the ear), which causes a specific and consistent pattern of neurophysiological and psychological symptoms. These include aural pain/fullness, tinnitus, hyperacusis, muffled hearing, vertigo and other unusual symptoms such as numbness or burning sensations around the ear. Typically, people describe acoustic shock as feeling like they have been stabbed or electrocuted in the ear. If symptoms persist, a range of emotional reactions including post traumatic stress disorder, anxiety and depression can develop (14).

Table 1. Conditions Associated with hyperacusis

Central	Peripheral
Migraine	Bell's Palsy
Depression	Ramsay-Hunt Syndrome
Post-traumatic stress disorder	Stapedectomy
Head injury	Perilymph fistula
Lyme disease	
William's syndrome	

Andersson, et al. (15) investigated the prevalence of hyperacusis in the adult Swedish population through internet and a postal study. Of 1167 individuals who clicked upon the web banner 595 responded, a response rate of 52%. The point prevalence of hyperacusis in this group was 9%. The postal group comprised 987 individuals of whom 589 responded (response rate 60%) and the point prevalence was 8%. Incidence data for hyperacusis does not seem to have been reported anywhere.

Thus, a telephonic survey was done all over India covering the major parts of Northern Southern, Eastern and Western parts of India to know about the awareness and status of hyperacusis assessment and management protocols among hearing health care professionals in India.

1.1. Need of the study

Until recently it has not been possible to quantify the handicap associated with hyperacusis (16). Only two instruments have been published for this purpose till date. Khalfa et al., (17) describe data from a self-report hyperacusis questionnaire with 14 items. Nelting et al., (18)

questionnaire is at present available only in German and neither has been shown to be sensitive to treatment effects, but such instruments do represent a step forward. Fabijanska et. al., (19) undertook a postal questionnaire of tinnitus in Poland which included an unspecified question on hyperacusis. Regional differences were also reported. A weakness of this report is the lack of specificity. Incidence data for hyperacusis do not seem to have been reported anywhere.

In various clinics in India, patients with hyperacusis are misdiagnosed to have tinnitus and are wrongly intervened with the patient having no benefit from the intervention. Also none of the clinics in India consider the fact that they should also run assessment and management protocols for hyperacusis. Loudness tolerance, recruitment and tinnitus among various health care professionals are not the common consensus in Indian context and thus literature survey revealed none. So there is an immense need of the study to develop awareness among the professionals who are directly and indirectly related to hearing health care.

Aim

To study the status of hyperacusis management issues in various hearing health care setups.

Objective

To develop a questionnaire to study the hyperacusis assessment and management status in various hearing health care setups in India.

1.2. Methodology

Participants

A total of 300 participants consisting of 243 otorhinolaryngologists and 57 Audiologists in India.

Inclusion criteria

Otorhinolaryngologists with a minimum of MS degree in ENT and for Audiologists a minimum of BASLP with RCI registration in India.

ENTs and Audiologists have a minimum of 5 years experience in their respective field.

All the participants have valid contact numbers for further correspondence.

Tool

Questionnaire development

A total of 25 closed set questions (appendix-I) were formulated in English by the authors based on their experience regarding hyperacusis assessment and management and from the review of literature and feedback of the patients about their problems who are many times misdiagnosed and referred from other disciplinary clinics like

clinical psychology, psychiatry, otorhinolaryngology and neurology.

This questionnaire was given to three audiologists, one ENT surgeon and one psychologist for face validity of the questionnaire.

Construct validity was done by using a 5 point rating scale for each question where 5 corresponds to most worthy question and 1 corresponds to least worthy question.

Out of the 25 questions, 19 were falling in the 4 or 5 weightage in the Likert scale and these were taken into consideration. Chronbach alpha was applied to measure the internal consistency and found to be highly correlated. $\alpha=0.81$

Test-retest reliability

The questionnaire was administered on 300 professionals and re-administered on 300 professionals after one month to measure the test-retest reliability and Pearson's correlation was found to be 0.9.

Scoring

Out of the 19 questions, question number 1, 2, 3, 6, 8, 11, 15 and 16 are polar questions where the answer could be given in yes or no only. Question number 4, 5, 7, 9, 10, 12, 13, 14 and 19 are multiple choice questions where four closed set options were allowed and one among the options had to be selected as the answer. Question number 17 and 18 are also polar questions but the answers were to be provided as same or different.

The correct answers were subjected to percentage calculation among 300 participants all over India and tabulated in a spreadsheet.

Statistical analysis

Statistical analysis was done through SPSS software (version 16) and the values were depicted on a bar diagram.

Procedure

From the websites of different institutes and ISHA directory 2011, the contact numbers of concerned Audiologists and ENTs were taken.

Telephonic interview was conducted by using Nokia E63 mobile phone wherein the selected 19 questions were asked to the 300 professionals with their consent. The interview was auto recorded in a 2 GB micro SD card (101804441053) for further analysis.

Questionnaire administration was completed in 10 minutes for each respondent.

The responses were later analyzed and the responses were tracked in a spread sheet in Microsoft excel 2007.

Appendix-I

Serial no.	Questions	Response
1.	Are you aware of the term hyperacusis?	Yes/No
2.	Do you diagnose tinnitus along with hyperacusis in your clinic?	Yes/ No
3.	Do you have separate clinic for tinnitus along with hyperacusis?	Yes/ No
4.	How many hyperacusis cases are enrolled in a year in your clinic?	<50, >50, >100, no cases.
5.	What sort of diagnostic protocol do you use for hyperacusis?	Audiological, Audiological and Psychological, Psychological, Radiological.
6.	Do you think team approach is important for the management of hyperacusis?	Yes/No
7.	Which type of protocol do you prefer for the management of hyperacusis?	Tinnitus masking, Tinnitus Retraining Therapy, Cognitive Behavior Therapy, Medical.
8.	Can you differentiate between tinnitus/ hyperacusis/ phonophobia/ misophonia?	Yes/No
9.	How many hyperacusis cases are discharged from your set up in a year?	<50, >50, >100, no cases.
10.	What do think about the common etiology of hyperacusis?	Anatomical, Psychological, Physiological, Not known.
11.	Do you think that hyperacusis may occur with hearing loss?	Yes/No
12.	Which of the following staff are involved in hyperacusis program in your organization?	Audiologist, ENT, Psychologist, Others.
13.	What is the primary referral for the hyperacusis?	Audiological, Medical, Psychological, Self preference.
14.	How do you maintain a record of hyperacusis management?	Manually, Computerised, Both, Not maintained.
15.	Do you get any funds to support the hyperacusis management program?	Yes/No.
16.	If your cilinic/ hospital does not have a hyperacusis program, are you interested in starting the program?	Yes/No
17.	Are the tests for hyperacusis and recruitment samne or different?	Same/ Different.
18.	Management of tinnitus and hyperacusis is same or different?	Same/ Different.
19.	In a person with both tinnitus and hyperacusis, which one would you manage first?	Tinnitus, Hyperacusis, Both, Not known.

2. Result and Discussion

It is evident from table-2 and figure-1 that only 43.4% of the participants answered yes to question number 2, which means hyperacusis is not diagnosed in most of the setups in India and it is ignored. When asked whether they have a separate clinic for tinnitus along with hyperacusis, only 93.3% of the participants responded 'no'. Only 10% of the participants said that less than 50 cases of hyperacusis are enrolled

in a year in their setups although the prevalence of hyperacusis has been found to be 15.2% by in a postal questionnaire of tinnitus in Poland (19). Only 3.3% of the participants said that an audiological and psychological diagnostic protocol should be administered for hyperacusis and 96.7% of the participants could not say what protocol should be used for hyperacusis diagnosis. The protocol given by Jasterboff and Jastreboff (1) specifies after audiological and medical evaluation, the protocol requires

Table 2. Response obtained from the participants in percentage

Questions	Options	Percentage response
question1	Yes	100%
	No	0%
question 2	Yes	43.40%
	No	56.60%
question3	Yes	6.70%
	No	93.30%
question4	<50	10%
	>50	0%
	>100	0%
	no cases	90%
question 5	Audiological	0%
	Audiological and psychological	3.30%
	Psychological	0%
	Radiological	0%
question6	Yes	10%
	No	90%
question 7	tinnitus masking	
	tinnitus retraining therapy	3.30%
	cognitive behavior therapy	3.30%
	Medical	3.30%
question 8	Yes	10%
	No	90%
question9	<50	6.60%
	>50	0%
	>100	0%
	no cases	93.40%
question 10	Anatomical	0%
	Psychological	10%
	Physiological	16.60%
	not known	73.40%
question 11	Yes	66.60%
	No	33.30%
question 12	Audiologist	13.30%
	ENT	13.30%
	Psychologist	13.30%
	Others	0%
question 13	Audiological	3.30%
	Medical	6.60%
	Psychological	3.30%
	self preference	0%
question 14	Manually	9.90%
	computerised	0%
	Both	0%
	not maintained	91.10%
question 15	Yes	3.30%
	No	96.60%
question 16	Yes	100%
	No	0%
question 17	same	19.60%
	Different	80.40%
question 18	same	19.90%
	Different	80.10%
question 19	Tinnitus	30%
	Hyperacusis	20%
	Both	33.30%
	not known	16.70%

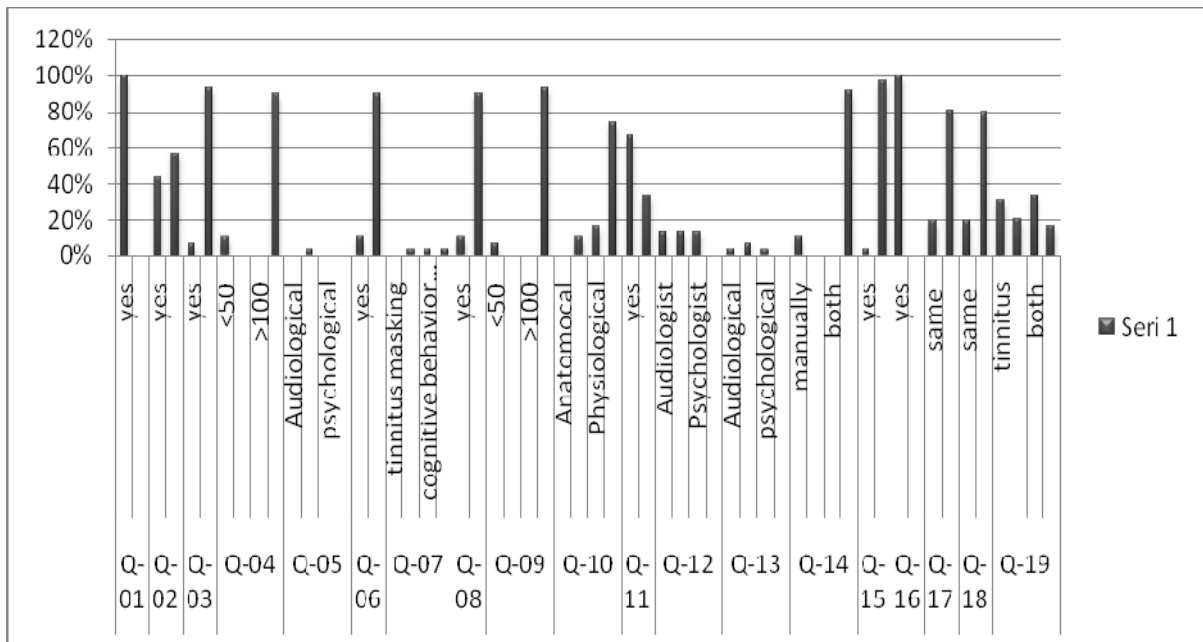


Fig. 1. Graph showing the percentage responses of the participants to the various questions.

classification of the patient according to the tinnitus and hyperacusis state, and then 'directive counseling' about the auditory system, about mechanisms of tinnitus and hyperacusis and about the distress associated with them. Of the total, only 10% of the participants said that a team approach should be administered for hyperacusis. Andersson and Lyttkens (20) specifies that for the psychological distress associated with tinnitus, cognitive behavioural therapy (CBT) has been identified as the treatment of choice, and this seems a reasonable strategy to counter the anxiety and stress associated with hyperacusis, together with information counseling, relaxation therapy and sound therapy. The answer to the management protocol preferred for hyperacusis, only 3.3% of the professionals said tinnitus retraining therapy, cognitive behavior therapy and medical management each and the rest 91.1% could not specify any hyperacusis management protocol. 90% of the participants could not differentiate between the terms tinnitus, hyperacusis, misophonia and phonophobia.

Of the total, 93.4% of the professionals said that no cases of hyperacusis are discharged from their clinics in a year. When interviewed about the etiology of hyperacusis, 73.4% of the participants said that the etiology is not known. In the majority of cases, the etiology of hyperacusis is unknown. The lack of strong epidemiological data and the lack of an animal model for hyperacusis prevent us from proving

the validity of any theory of the potential mechanisms responsible for hyperacusis (1). When asked about the co-occurrence of hyperacusis and tinnitus, 66.6% of the participants agreed to the question tinnitus and hyperacusis can occur simultaneously. 13.3% of the participants said Audiologist, ENT and Psychologist are involved in hyperacusis program in their organization. When asked about the primary referral for the hyperacusis management, 3.3% of the participants said audiological and psychological management each, while 6.6% agreed to medical management and the rest 86.8% of the participants did not know where should be a patient referred for hyperacusis management. 91.1% of the participants said no record is maintained for hyperacusis management. 96.6% of the professionals said that they do not receive any funds for hyperacusis management program. All the participants agreed to start a program for hyperacusis management in their setups if they are provided funds. 80.4% of the participants said that the tests for hyperacusis and recruitment are different. 80.1% of the participants said that the management of tinnitus and hyperacusis is different, while 19.9% of the participants said that the management of tinnitus and hyperacusis is same. 30% of the participants said that management of tinnitus should be done first, 20% said hyperacusis should be managed first, 33.3% said both tinnitus and hyperacusis should be managed simultaneously while 16.7% did not know which one should be managed first.

3. Conclusion

Decreased sound tolerance, including hyperacusis, misophonia, and phonophobia, is a challenging topic to study, and a challenging symptom to treat. Many questions are unanswered; the etiology is not clear, neural mechanisms are speculative and treatments are not yet proven. Above all, the general recognition of decreased sound tolerance, as a problem requiring attention and proper treatment, should be considered a priority in the community for hearing professionals. There is limited data available regarding the prevalence of decreased sound tolerance. However, research indicates that hyperacusis and tinnitus frequently co-exist in the same ear. Approximately 40% of tinnitus patients exhibit some degree of decreased sound tolerance, with 27% requiring specific treatment for hyperacusis. A study of 100 patients with hypersensitivity to sound showed that 86% of them suffered from tinnitus (1). It has been cited that significant hyperacusis probably exists in at least 1 - 1.5% of the general population (1). Epidemiologic studies and prevalence rates about hyperacusis are not well described, mechanisms are speculative and anatomic sites and etiology is, unfortunately, not well documented. Most typically, advice offered to those who insisted upon help was to 'use ear plugs,' or 'learn to live with it' (1).

The hyperacusis has a ranging effect that varies from individual to individual. However, if the Hyperacusis Management Program (Chears London, centre for conducting Hyperacusis Programme, Dr. Josephine Marriage) is carried out on people with hyperacusis, there would be a calming effect on the severity of hyperacusis and sleep disturbance, anxiety, anger, hypertension, unhappiness that is actually caused due to the hyperacusis. The hyperacusis management programs runs in the following steps: 1. Profile of hyperacusis should be taken. 2. Impact of the problem on family members and others. 3. Understanding of condition by all carers leading to consistency in management. 4. Behavioural desensitization 5. Auditory desensitization. 6. Follow-up regime. The program was administered on 10 patients with hyperacusis, with 5 having both tinnitus and hyperacusis, with fruitful results. Thus program helped to improve quality of life of the patients with hyperacusis. The program can be implemented on children as well as adults. It has also been seen that the people who have an early intake on the management program have a faster road to recovery compared to the people who have a later intervention. It has

been proven that early intervention is always better as it helps to rule out many factors that may have a long drawn effect later such as memory, positive thinking.

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