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RESEARCH ARTICLE



## Hyperacusis and social media trends

Aniruddha K. Deshpande<sup>a,b</sup>, Shruti Balvalli Deshpande<sup>b,c</sup> and Colleen A. O'Brien<sup>b,c</sup> 

<sup>a</sup>The Hear-Ring Lab, Department of Speech-Language-Hearing Sciences, Hofstra University, Hempstead, NY, USA; <sup>b</sup>Long Island Doctor of Audiology (AuD) Consortium, NY, USA; <sup>c</sup>Department of Communication Sciences and Disorders, St. John's University, Queens, NY, USA

### ABSTRACT

**Purpose:** In recent years, social media has taken on a new role of helping spread awareness about numerous health conditions, including hyperacusis. Individuals with hyperacusis, which is an atypical response to sound that individuals with normal hearing would find acceptable, are turning to social media platforms to learn about and seek guidance regarding their condition, to communicate with healthcare providers, as well as to find support in other members of the hyperacusis community. The purpose of this study was to investigate trends of social media portrayal of hyperacusis.

**Methods:** This investigation systematically analyzed and quantified information related to hyperacusis on three currently popular social media platforms – Facebook (pages and groups), Twitter and YouTube. Further, we noted participation trends across the platforms. The keyword 'hyperacusis' was searched on each platform, and results were manually scraped by two reviewers based on numbers of 'likes', 'members', 'followers', 'views', 'comments' and other social media metrics.

**Results:** Over half of the recorded online activity was seen on YouTube, followed by Facebook pages. YouTube was dominated by videos of individuals sharing their experiences with hyperacusis, while Facebook pages were a popular platform for service providers like audiologists. Misinformation and other false claims were found across all platforms, but predominantly on Facebook pages and YouTube.

**Conclusions:** This investigation suggests that individuals in the hyperacusis community turn to social media to learn about their condition and share their experiences. Results of this investigation will equip audiologists with information regarding the current portrayal of hyperacusis online and on social media platforms. Audiologists and other hearing health professionals may use these findings to better counsel patients with hyperacusis.

### KEYWORDS

Hyperacusis; social media; internet; Facebook; Twitter; YouTube; misinformation

## Introduction

Hyperacusis is the heightened sensitivity to average environmental sounds that most individuals would find acceptable. This decreased tolerance to external sound often results in atypical responses to these noises, including discomfort, aggravation and distress [1]. This hypersensitivity manifests itself uniquely in different people, and some individuals have varying symptoms depending on the environment and their temperament [2]. A key aspect of hyperacusis is the type and degree of emotional responses that sufferers experience. Some frequently cited symptoms include phonophobia, inattention, irritability, sleep disturbances and social isolation [3]. Further, 50% of individuals with hyperacusis have a comorbid psychiatric disorder, including anxiety or depression [1]. Because many

people with hyperacusis have such extreme reactions to sound, they frequently modify their lifestyles and occupational practices, which can make already stressful situations even more challenging [4].

Until recent decades, hyperacusis did not receive significant research or clinical attention; so overall epidemiological information has been limited [2]. Today, it is estimated that approximately one-tenth of the adult population experiences hyperacusis, with some estimates as high as 15% [1]. The condition is also known to occur in children [5]. Although there is still no universally accepted cause of hyperacusis, many cases are often associated with tinnitus, noise exposure, and cochlear hearing loss [3]. Investigations have estimated that between 40% and 86% of hyperacusis patients experience tinnitus [3], and both conditions have serious and debilitating effects on

emotional stability, mental health, sleep and attention [6]. The reduced tolerance to sound is also associated with other conditions, including migraines, autism, post-traumatic stress disorder, Lyme disease, Bell's palsy and Meniere's disease [1,3]. Although no cure for hyperacusis has been currently identified, counselling, sound therapy, social support and use of hearing protection have shown to help individuals manage their hyperacusis [6].

As the internet and social media have surged in popularity in recent years, societal awareness of hyperacusis has increased, and the behaviours of the hyperacusis community have consequently changed. The internet is used by over three-quarters of adults in the United States, and an estimated 80% of these individuals have searched for health-related information, like hyperacusis, online [7]. Approximately 65% of Americans actively use social media platforms, including Facebook, Twitter and YouTube [8]. Although many presume that social media is used predominantly for informal public interactions, it also has the capacity to connect people worldwide to professional knowledge and related information [9]. Indeed, many individuals discuss, share and find support regarding health conditions using social media networks, which are real-time virtual platforms of information-sharing and content-generation [10].

One area that has been profoundly impacted by the rise of the internet and social media is the healthcare industry, because now people have global access to health information at the highest rates in history, according to the World Health Organization [11]. Online social media platforms provide instant access to medical information, which can help shape and improve patient behaviours [12]. Additionally, social media allows for discussions of health experiences and creation of virtual support groups for various conditions [13]. By contacting and communicating with those with similar experiences, people who live with chronic conditions, like hyperacusis, may feel more emboldened and capable of managing their conditions [2,14].

There are many positive and advantageous effects of the internet and social media, but one of the most significant pitfalls of online platforms is that the provided information is not always accurate or safe. Investigations reveal that about 50% of websites contain questionable information, which is potentially harmful to consumers, especially in regard to healthcare [12]. Our group [13] recently found a similar trend on social media platforms for tinnitus. This phenomenon is commonly known as 'misinformation', which is shared information that is accepted as accurate initially, but later determined to be

imprecise or misleading [15]. Misinformation has the potential to be particularly damaging in situations where false statements regarding health conditions are spread. Internet users with hyperacusis must remain vigilant of potential misinformation. Further, audiologists and hearing health professionals should be aware of online information pertaining to hyperacusis and only share information that is precise and understandable to the public.

The purpose of this investigation was to investigate the presence of hyperacusis-related information on social media platforms. This study comes as the continuation of an investigation by our group analyzing social media utilization by individuals with tinnitus [13]. Because the two conditions frequently co-occur [2], the authors theorized that it would be advantageous to investigate social media trends in both communities. Although social media has been studied in many respects, the online portrayal of hyperacusis remains largely uninvestigated. Findings from the current analysis will be useful not only to the hyperacusis community but also to the healthcare professionals who help manage the condition.

## Methods

We performed a systematic analysis of hyperacusis-related information displayed on social media platforms based on similar investigations of tinnitus [13] and the hearing aid [10] and cochlear implant [16] communities. The authors included three social media platforms in the investigation based on ease of quantifiable data-collection, global popularity and use across age groups [17]. Data was collected from Facebook (pages and groups), Twitter, and YouTube during the period of 16 July 2017 to 9 August 2017.

## Ethical considerations

Institutional Review Board (IRB) approval was sought, despite authors making no interactions with any individual social media user, account or related result. All data were collected from publicly available social media search results.

## Acquisition, classification and quantification of social media results

In terms of acquisition, Facebook pages, Facebook groups, Twitter accounts and YouTube videos were comprehensively examined by searching the term 'hyperacusis'. Inclusion eligibility was assessed via a

two-tier procedure. First, results on each social media platform must have amassed a minimum number of social media metrics – at least 10 ‘likes’ and 5 ‘posts’ for Facebook pages; at least 10 ‘members’ for Facebook groups; at least 10 ‘followers’ and 5 ‘tweets’ for Twitter accounts; and at least 100 ‘views’ for YouTube videos. It should be noted that Facebook groups can be categorized as either public or closed depending on their privacy status, and both types of groups were included in this investigation. A group description and the number of members is available to all users, even for closed groups. Similarly, YouTube offers numerous sorting options and the two-tier procedure was repeated for the first 100 videos for three sorting options (i.e. Relevance, View count and Rating).

For the second-tier inclusion procedure, social media search results were included only if they were relevant to the audiological condition of hyperacusis – all irrelevant pages were eliminated from our analyses. If any result shared inaccurate or questionable information related to hyperacusis, it was included in our investigation but categorized as ‘misinformation’.

This investigation’s exclusion criteria were comprised of the following: (1) Results that were not in English; (2) Results that failed to meet the numerical inclusion criteria described above and (3) Results that were considered irrelevant to the audiological condition of hyperacusis.

In an attempt to minimize targeted results, the investigators logged out of their personal accounts (whenever possible), cleared both browser history and cookies, and searched in Firefox’s (Version 52.2.1) private browsing mode.

In terms of classification, results were analyzed and categorized by two independent reviewers (AKD, COB). All social media results were placed into one of eight categories based on its title, description, and review of its first ten posts, when applicable. Categories were created based on previous investigations of social media utilization in the audiology community [1,10,16]. The eight categories included

effects of hyperacusis), service provider/institution (people/organizations qualified to provide hyperacusis intervention), promotion of a product (endorsing a hyperacusis-related product), fundraising (raising money for research and support), and misinformation (information that is scientifically inaccurate or uninvestigated). It should be noted that investigators categorized social media results as misinformation if they lacked peer-reviewed evidence. Many of these results may seem reliable to the layperson (i.e. discussions of diet changes or acupuncture to eliminate hyperacusis) but did not have scientific basis as of August 2017. If categorization of any social media result was not initially agreed upon, the reviewers conversed until a consensus was reached based on the above definitions.

In terms of quantification, all results were enumerated on the basis of various metrics reflecting social involvement. Specifically, we quantified the total number of ‘likes’ for Facebook pages; the number of ‘members’ for Facebook groups; the numbers of ‘tweets’, ‘followers’, and ‘likes’ (how many other tweets the account has liked) for Twitter accounts; and video upload date, video duration, and numbers of ‘subscribers’ (people who follow a YouTube account), ‘views’, ‘likes’, ‘dislikes’ and ‘comments’ for YouTube videos. See our previous manuscript [13] for additional details regarding the acquisition, classification and quantification of social media results.

### Interaction quotient

Since the level of engagement is not readily apparent on YouTube, we analyzed social media metrics further for each video. To gauge active versus passive levels of involvement, we defined active actions as liking, disliking, or commenting on a video; while viewing (view count) was considered as a passive action. Based on these metrics, we devised an interaction quotient (IntQuo) as follows:

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$$IntQuo = \frac{\text{Number of likes} + \text{Number of dislikes} + \text{Number of comments}}{\text{Number of views}}$$


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information sharing (distributing hyperacusis information), personal story (sharing an individual’s story), support group (sharing advice and encouragement), hyperacusis management (means of minimizing the

A lower value of the interaction quotient indicates less interaction with the video (e.g. a value of zero would mean no active interaction with the video), while a higher value indicates greater active interaction with the video.

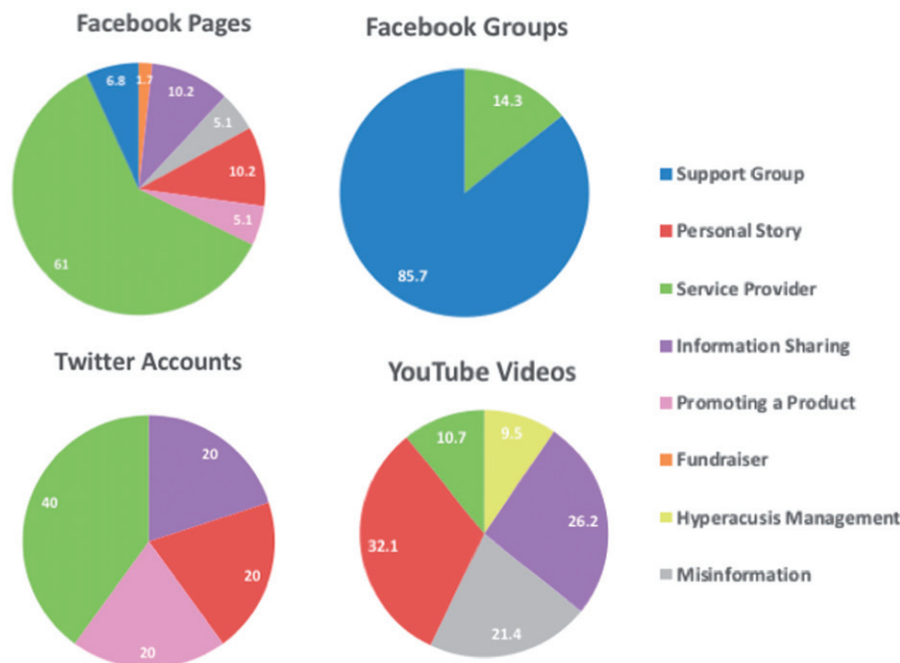


Figure 1. Social media utilization and categorization across platforms.

### Statistical analyses

After all social media results across the three platforms were categorized and quantified, authors completed descriptive statistics on all data. Microsoft Excel (Version 16.15) and IBM SPSS Statistics (Version 23) were used to generate the mean, median, standard deviation, range and interquartile range (IQR) of the data. Since social media results may not be normally distributed [8,18]; we performed non-parametric analyses on our data. Specifically, the Kruskal–Wallis test was used to assess differences between categories for Twitter and YouTube.  $p$  values  $< .05$  were deemed statistically significant.

### Results

Initially, 273 social media search results related to hyperacusis were identified from our searches across the three platforms. Only 155 results ultimately met the inclusion criteria, 54.19% of which were YouTube videos ( $n = 84$ ), 38.06% were Facebook pages ( $n = 59$ ), 4.52% were Facebook groups ( $n = 7$ ) and 3.23% were Twitter accounts ( $n = 5$ ). Figure 1 represents the categorization of social media resources across platforms.

#### Facebook pages

Our investigation initially identified 78 hyperacusis-related Facebook pages; 14 were removed for failing to meet inclusion criteria, and five more pages were

removed for not being relevant to hyperacusis. The remaining 59 pages included in our analysis amassed 48,015 likes (mean = 814; SD = 2953.8), revealing the amount of user-engagement on Facebook pages.

The top three categories seen on Facebook pages, based on the number of pages that appeared in the results, were service provider ( $n = 36$ ; 61%), personal story ( $n = 6$ ; 10.2%), and information sharing ( $n = 6$ ; 10.2%). For each category, we assessed the number of likes. The results are displayed in Table 1, and are as follows: service provider (total likes = 16,791; mean = 466; SD = 657.8; range = 14–2820; IQR = 479); information sharing (total likes = 2166; mean = 361; SD = 695.9; range = 16–1775; IQR = 565.8); personal story (total likes = 1575; mean = 262.5; SD = 140.3; range = 105–509; IQR = 206.8). The remaining 18.6% of Facebook pages originated from four other categories.

#### Facebook groups

Thirty-three Facebook groups related to hyperacusis initially resulted from our searches, and 26 were eliminated for failing to meet our investigation's inclusion criteria. Seven groups remained, consisting of 4252 members (mean = 607.42; SD = 903.98; median = 67; range = 16–2103; IQR = 1705). Six of these groups were categorized as support group ( $n = 6$ , 85.7%), and one group was categorized as service provider ( $n = 1$ , 14.3%). Table 1 displays all results related to Facebook groups.

Two of the seven Facebook groups pertaining to hyperacusis were public, and five were closed. Each of



**Table 1.** Descriptive statistics for Facebook pages and Facebook groups, including the top three categories of each.

Facebook Pages	Number of pages (%)	Total Likes	Mean	Standard Deviation	Median	Range	Interquartile Range
Total	59	48,015	814	2953.8	205	14–22,528	330
Service provider	36 (61.0%)	16,791	466	657.8	212	14–2820	479
Information sharing	6 (10.2%)	2166	361	695.9	65.5	16–1775	565.8
Personal story	6 (10.2%)	1575	262.5	140.3	242	105–509	206.8
Facebook Groups	Number of groups (%)	Total Members	Mean	Standard Deviation	Median	Range	Interquartile Range
Total	7	4252	607.42	903.98	67	16–2103	1705
Public Groups	2 (28.57%)	32	16	0	16	16–16	–
Closed Groups	5 (71.42%)	4220	844	990.4	310	19–2103	1869
Support group	4 (80%)	4153	1038.25	1027.79	1015.5	19–2103	1747.5
Service provider	1 (20%)	67	67	0	67	67–67	–

**Table 2.** Analysis of the top category of Twitter accounts' numbers of followers and tweets.

Twitter Accounts	Number of Accounts (%)	Total	Mean	Standard Deviation	Median	Range	Interquartile Range
Total followers	5	3980	796	464.33	627	500–1616	631.5
Service provider	2 (40%)	1127	563.5	89.8	563.5	500–627	–
Total tweets	5	11,637	2327.4	3416.88	867	199–8390	4429
Service provider	2 (40%)	1623	811.5	866.21	811.5	199–1424	–

the two public groups had 16 members, totaling 32 members (mean = 16; SD = 0). Both were categorized as support group. Because the sample size of public groups was small, detailed analyses according to category were not possible. The five closed groups amassed 4220 members (mean = 844; SD = 990.4; range = 19–2103; IQR = 1869). The two categories of closed groups were support group ( $n=4$ ; 80%; total members = 4153; mean = 1038.25; SD = 1027.79; range = 19–2103; IQR = 1747.5) and service provider ( $n=1$ ; 20%; total members = 67; mean = 67; SD = 0).

The Wilcoxon Test was used to analyze and compare the public and closed Facebook groups. This nonparametric testing revealed no significant difference ( $p=.180$ ) between public and closed Facebook groups in terms of number of members.

### Twitter accounts

Initially, 17 Twitter accounts were identified under the 'People' tab in our searches. Eight did not meet the inclusion criteria and four were removed for being irrelevant to hyperacusis. The remaining five accounts included in our investigation amassed a total of 3,980 followers (mean = 796; SD = 464.33; range = 500–1,616; IQR = 631.5) and produced a total of 11,637 tweets (mean = 2327.4; SD = 3416.88; range = 199–8390; IQR = 4429).

Because there was a relatively small number of Twitter accounts included in our investigation, detailed analyses of the category breakdowns were not possible. However, the most common category was service provider ( $n=2$ , 40%), and we analyzed this category in terms of the number of followers and tweets. This

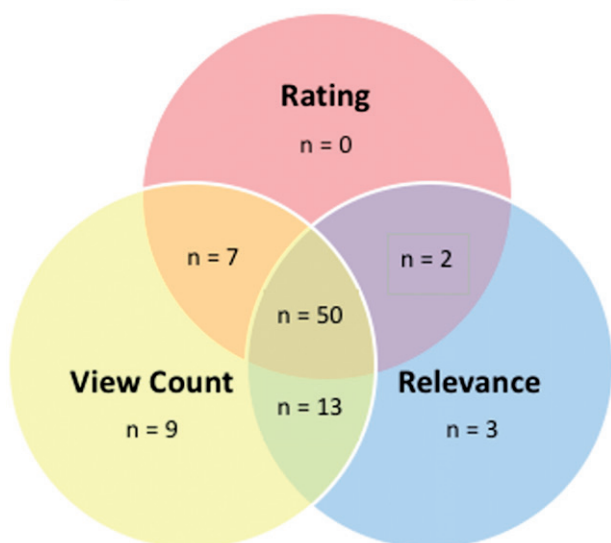
information, which is displayed in Table 2, is as follows: a total of 1127 followers for accounts categorized as service provider (mean = 563.5; SD = 89.8; range = 500–627), and a total of 1623 tweets produced by service provider accounts (mean = 811.5; SD = 866.21; range = 199–1424).

### YouTube videos

YouTube offers multiple sorting options for viewing videos, including Relevance, View count and Rating. We searched the term 'hyperacusis' and analyzed the results for three of these options, examining only the first 100 videos (5 pages of results) for each, which yielded 300 videos. After eliminating videos that resulted from more than one sorting option, 145 individual videos remained. Forty-two videos were subsequently removed for not meeting the inclusion criteria and 19 more were removed for being irrelevant to the audiological condition of hyperacusis. The remaining 84 videos were included in our investigation. The breakdown and overlap of resulting videos for each YouTube sorting option are displayed in Figure 2.

Table 3 depicts all descriptive statistics for the total, mean, and median number of views for each YouTube sorting option. The 84 YouTube videos amassed a total of 1,073,884 views (mean = 12,784; SD = 58,484.59), 23,624 likes (mean 281.24; SD = 2,180.98), 418 dislikes (mean = 4.98; SD = 19.3), 5557 comments (mean = 5; SD = 464), and had a total duration of 25:28:02 (hh:mm:ss) (mean = 00:18:11; SD = 00:01:31). All descriptive statistics pertaining to YouTube videos can be found in Table 4. Additionally, although the number of YouTube subscribers was not a particularly

### Analysis of YouTube Sorting Options



**Figure 2.** Breakdown of three YouTube sorting options (Relevance, View Count, Rating) and resulting overlap.

**Table 3.** Analysis of YouTube's three sorting options. Note that only the first 100 videos were assessed for each sorting option.

YouTube Videos	Total Number of Videos	Mean Number of Views	Median Number of Views
YouTube Videos	84	12,784	281.24
Relevance	68	14,867	1411
View count	79	8376	1265
Rating	59	9635	1726

valuable statistic because it reflects subscription to the video's creator, and not the video itself, the number of subscribers to accounts creating hyperacusis-related YouTube videos ranged from 0 to 1.3 million (mean = 20,044.75, SD = 142,719.59).

YouTube videos included in our investigation were posted over the period of 20 April 2008 to 21 July 2017 and ranged in duration from 00:00:15 to 09:00:25. Three-quarters of the videos were shorter than 10 minutes. A breakdown of video duration is depicted in Figure 3.

Personal story ( $n = 27$ , 32.1%), information sharing ( $n = 22$ , 26.2%), and misinformation ( $n = 18$ , 21.4%) were the three most common categories of YouTube videos. They were further analyzed in terms of number of views, likes, dislikes, comments and total duration, and descriptive statistics are shown in Table 4.

When analyzing differences between categories among the top three categories, the Kruskal–Wallis test found no significant differences in the number of views ( $H(2) = 1.822$ ,  $p = .402$ ), likes ( $H(2) = 2.680$ ,  $p = .262$ ), dislikes ( $H(2) = 4.425$ ,  $p = .109$ ), or comments ( $H(2) = 3.148$ ,  $p = .207$ ). Significant differences

were found in duration ( $H(2) = 6.822$ ,  $p = .033$ ) across categories. Post hoc testing (Bonferroni correction) indicated personal story videos were significantly longer than both information sharing and misinformation videos.

It should be noted that of the three social media platforms included in our investigation, YouTube videos yielded the highest amount of misinformation across all three sorting options; view count yielding the most misinformation (19%), followed by Relevance (17.6%) and Rating (13.6%).

### Interaction quotient

In the present investigation of hyperacusis videos on YouTube, the IntQuo ranged from a low value of 0 to a high of 0.089. All IntQuo values are detailed for the top three YouTube categories in Table 5. Per cent interaction is also calculated for ease of viewing.

The Kruskal–Wallis test found a significant difference in IntQuo between the top three video categories on YouTube ( $H(2) = 6.277$ ,  $p = .043$ ). Bonferroni correction indicated that personal story videos had a significantly higher IntQuo than information sharing.

### Discussion

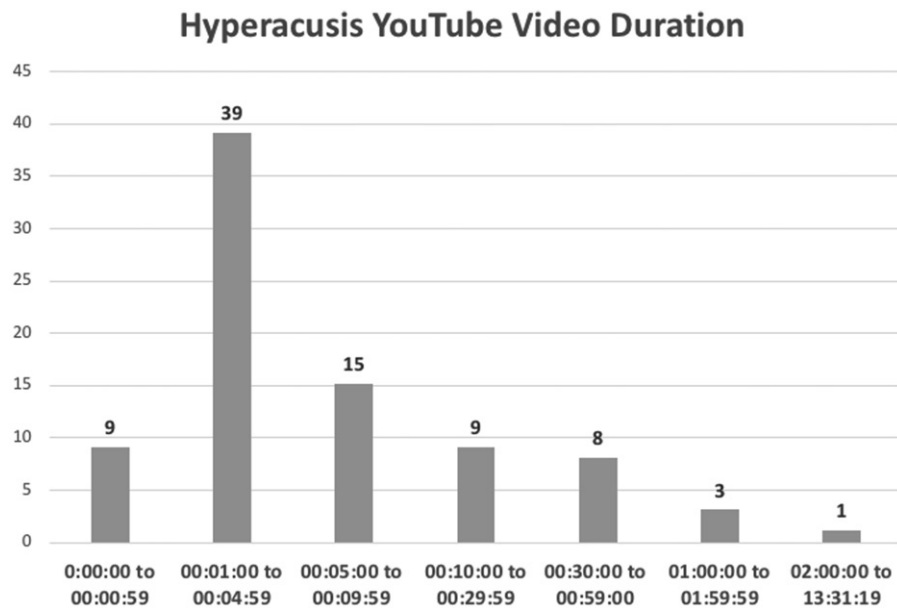
The present investigation revealed that a diverse array of hyperacusis-related information can be found on various social media platforms. Our results indicate that individuals interested in hyperacusis use Facebook pages, Facebook groups, Twitter and YouTube to obtain information about the condition, share their own experiences, advocate for increased awareness of the condition, seek support from individuals who understand their condition and to connect with medical professionals capable of managing the effects of hyperacusis. The highest amount of hyperacusis-related activity and information was seen on YouTube, which is currently the second-most utilized internet website globally [19]. Of the three investigated social media platforms, YouTube yielded the greatest number of results to the keyword 'hyperacusis', followed by Facebook pages, Facebook groups and Twitter.

### Facebook pages

Of the three investigated social media platforms, Facebook pages yielded the most diverse results, consisting of seven of the eight categories. Facebook pages were dominated by service providers (61%), consisting largely of private practice audiologists,

**Table 4.** Descriptive statistics pertaining to overall, personal story, information sharing, and misinformation YouTube videos.

YOUTUBE Videos	Total	Mean	Standard Deviation	Median	Range	Interquartile Range
<b>Overall</b>						
Views	1,073,884	12,784	58,484.59	1179	103–411,613	4082
Likes	23,624	281.24	2180.98	9	0–19,989	25.5
Dislikes	418	4.98	19.3	1	0–127	2
Comments	5557	5	464	3	0–4256	13.5
Duration	25:28:02	00:18:11	00:01:31	00:04:37	00:00:15–09:00:25	00:08:32
<b>Personal story</b>						
Views	419,737	15,545.8	66,336.6	1697	125–346,979	3867
Likes	20,654	764.96	3842.18	16	0–19,989	24
Dislikes	139	5.15	22.6	0	0–118	1
Comments	4581	169.67	816.85	7	0–4256	11
Duration	03:32:14	00:07:51	00:22:29	00:03:40	00:00:24–01:33:21	00:03:56
<b>Information sharing</b>						
Views	114,860	5,220.9	14,710	1224	265–70,071	2105.3
Likes	349	15,864	18.99	10	0–76	21.5
Dislikes	60	3.73	7.77	1	0–37	2
Comments	207	9.41	21.86	2	0–101	9
Duration	04:00:04	00:10:54	00:18:15	00:02:30	00:00:15–01:06:21	00:07:20
<b>Misinformation</b>						
Views	88,673	4926.28	9223.55	459.5	103–37,053	8358.3
Likes	1541	85.6	243.14	1.5	0–1023	59.5
Dislikes	81	4.5	7.89	1	0–32	6.3
Comments	465	25.83	58.32	1.5	0–241	30.3
Duration	03:19:43	00:11:05	00:22:29	00:03:40	00:00:24–01:33:45	00:03:56

**Figure 3.** Breakdown of YouTube video durations.**Table 5.** Descriptive statistics for YouTube interaction quotient (IntQuo) for the top three YouTube categories.

INTERACTION QUOTIENT (IntQuo)	Mean IntQuo	Mean Percent Interaction	Standard Deviation	Median	Range	Interquartile Range
Information Sharing	0.00994	0.994%	0.00784	0.00874	0–0.02553	0.01089
Misinformation	0.01268	1.268%	0.01217	0.00771	0–0.04502	0.01610
Personal Story	0.02815	2.815%	0.02686	0.01709	0–0.08962	0.03901

medical doctors and research institutions offering their services to the hyperacusis community. The most liked Facebook page, with over 22,000 likes, was a support group for individuals dealing with the effects of hyperacusis.

### Facebook groups

Our analysis included seven Facebook groups, two of which were public and five were closed. It should be noted that the contents of the closed groups could



not be verified since the authors did not ask permission to join the groups. Therefore, only the group's description was used to categorize each group, and accuracy of information shared within the private groups could not be verified. Six of the seven groups were categorized as support group (85.7%). Most of the groups were targeted toward both the hyperacusis and tinnitus populations, and fostered a space for communication, encouragement, advice, commentary, camaraderie and advocacy for the hyperacusis community. We wanted to investigate whether the privacy of a closed group resulted in more people enrolling in those groups. We found that there was no significant difference in the number of members in the two types of groups. In other words, the privacy setting of Facebook groups may be secondary to the process of information-gathering and experience-sharing for people with hyperacusis. Additionally, over half of the groups in our investigation had fewer than 100 members, indicating that these online groups are not considerably popular relative to the larger Facebook community.

### **Twitter accounts**

Twitter was determined to be the least popular platform in our investigation, with only five accounts under the 'People' tab resulting to the keyword 'hyperacusis'. Service provider was the most common category (40%), but the most-followed Twitter account, with 1616 followers, belonged to an author of a book about hyperacusis, and thus was categorized as promoting a product (20%). The most active Twitter account, with 8390 tweets, was run by a psychologist sharing his experiences with hyperacusis, categorized as personal story (20%). The authors speculate that Twitter is not currently the ideal platform for the hyperacusis community to discuss the condition because the complex nature and consequences of hyperacusis cannot be easily compressed into 280 characters, which is the current limit for Tweets.

### **YouTube videos**

Our investigation found that YouTube contained the greatest amount of activity of the three social media platforms searched. The majority of the videos were categorized as personal story (32.1%), generally depicting individuals with hyperacusis sharing their experiences with the condition, including feelings of frustration, anxiety, depression and isolation. Authors speculate that YouTube was the most popular social media platform in this investigation because

hyperacusis sufferers seek an opportunity to verbalize their frequently misunderstood experiences. It should be noted that half of these personal story videos had fewer than 1000 views, and therefore are not reaching an abundance of internet users.

Our analyses revealed that there was a significant difference in duration between hyperacusis management and all other categories. The one hyperacusis management video included in our investigation was a nine-hour video of pink noise, so it is not surprising that this video was significantly longer than videos from all other categories, the majority of which were under five minutes long.

Lastly, YouTube yielded the highest amount of misinformation (21.4%) of the social media platforms investigated. Of the three YouTube sorting options, the lowest percentage of misinformation was found when sorting by Rating (13.6%), followed by Relevance (17.6%) and View Count (19%). Videos in this category generally discussed scientifically unfounded causes for the condition and 'cures' for hyperacusis that are currently uninvestigated. Misinformation related to hyperacusis is discussed in greater depth later.

### **Interaction quotient**

Our investigation of IntQuo for YouTube assessed active versus passive involvement with videos. We found that personal story videos had a significantly higher interaction quotient than information sharing, indicating that users were more likely to 'like', 'dislike', or 'comment' on videos categorized as personal story. The authors speculate that due to the private and intimate nature of many of the personal story videos, in which people share their experiences and struggles with hyperacusis, social media users may feel more inclined to interact with these videos. Information sharing videos, on the other hand, generally disseminated hyperacusis-related information in a passive nature, likely not encouraging further participation from the viewer.

It should be noted that the authors believe there needs to be more transparency on social media platforms regarding activity metrics. For instance, on Facebook Pages, the only social media metric available is the number of 'likes' (and the related metric of 'followers'). Because of the limited information available, creating an interaction quotient for all three platforms was not possible in this investigation. This information would be useful for researchers and social media users who want to compare activity across other social media platforms besides YouTube.

### ***Comparison of the portrayal of tinnitus and hyperacusis on social media***

The present investigation comes as the continuation of a series of studies systematically investigating social media utilization by individuals with tinnitus [13]. Though common trends were noted in the online portrayal of tinnitus and hyperacusis, significant differences were also observed. First, our investigation of tinnitus yielded considerably more results than our investigation of hyperacusis. Our searches for tinnitus generated 1459 results before exclusion, while our searches of hyperacusis generated only 273 results. Further, results of our tinnitus investigation generally showed much higher rates of social media involvement than found in the present study. For example, the most viewed YouTube video to the keyword 'tinnitus' had 7.1 million views, while the most viewed video for 'hyperacusis' had only 400,000 views. Similarly, the Twitter account with the most followers related to tinnitus (72,285 followers) was significantly more popular than the most followed hyperacusis account (1616 followers). Based on these findings, it can be speculated that fewer people are affected by hyperacusis, and therefore the condition has a less significant presence on social media.

Another major difference between our analyses of the portrayal of tinnitus and hyperacusis on social media was that our investigation of tinnitus generally yielded significantly more results categorized as misinformation than hyperacusis. In terms of Facebook pages, our tinnitus investigation yielded 42.7% inaccurate information, while the present study on hyperacusis resulted in only 5.1% misinformation. Although similar amounts of overall misinformation were found on YouTube (21% of videos), both investigations revealed that sorting by Rating (rather than Relevance or View Count) yielded the lowest proportion of misinformation (15.9% and 13.6% found for tinnitus and hyperacusis, respectively). Based on the tinnitus and hyperacusis studies, the authors strongly recommend sorting by rating to obtain relevant results when searching for tinnitus or hyperacusis related information on YouTube.

In terms of the IntQuo for tinnitus videos, personal story videos also had the highest interaction quotient (Mean IntQuo = 0.01868; standard error (SE)=0.005). There was a significant difference between the top three categories in terms of their IntQuo ( $H(2)=8.543$ ,  $p=.014$ ). Surprisingly, misinformation videos had a significantly higher IntQuo than management videos. For our investigations of both tinnitus and hyperacusis, misinformation and

personal story videos consistently had the highest rates of engagement across platforms. The authors speculate that individuals with tinnitus may be drawn to videos expressing inaccurate information, particularly those that engage the user at an emotional level because users are keen to find a cure for their tinnitus [13].

### ***Caveats of using social media platforms and implications for audiologists***

Social media has become widely popular in recent years, but individuals must be aware of caveats about its use. First, although social media platforms are increasingly attempting to monitor online content for appropriateness [20], there are generally minimal gatekeeping mechanisms to monitor the authenticity of information that is shared. As a result, substantial amounts of misinformation are prevalent throughout the internet, as seen in both of our investigations on hyperacusis and tinnitus. Another caveat is that social media platforms often generate targeted results for different individuals. This is achieved through processes like search engine optimization (SEO); use of cross-platform tracking via cookies, caches, internet protocol (IP) address and location access; unauthorized data collection by certain applications [21]; and use of automated 'bot' systems to engage users [13,22]. Due to these mechanisms, internet and social media users are frequently exposed to inaccurate search results. This is particularly significant because individuals with hyperacusis may believe uninformed advice or take potentially harmful measures to desperately alleviate their symptoms. Additionally, novice internet-users may falsely believe that any information obtained on social media regarding conditions like hyperacusis can replace medical advice.

Audiologists should be cognizant that individuals with hyperacusis frequently turn to social media platforms to obtain information and support. The results of the present investigation can better prepare audiologists and hearing health professionals to counsel patients with hyperacusis (for instance, sorting options on YouTube). Further, audiologists who are aware of the current climate of hyperacusis portrayal on the internet and are sensitive to the views of the hyperacusis community may be more successful at building rapport with this clinical population. Finally, clinicians who actively spread accurate health information on social media platforms (for instance, engaging with patients on online forums, commenting on public posts, dispelling myths about hearing

disorders) can potentially minimize the spread of misinformation.

### Study limitations and future considerations

The present investigation had some limitations, many of which could not be avoided. First, the authors may have received targeted results during this investigation on Facebook, Twitter and YouTube. Although efforts were made to prevent this occurrence, it is possible that IP addresses, cookies and personal social media accounts previously logged onto the three platforms could have impacted the results. Secondly, the internet and social media are changing, growing, and evolving, often by the minute. Data from our investigation on hyperacusis are accurate as of August 2017. Thirdly, because we included closed Facebook groups in our investigation, our categorizations may not be entirely accurate since we relied on page description rather than content analysis. Consequently, our appraisals of closed Facebook groups may have been skewed if content diverged from the groups' descriptions. Finally, although we searched the term 'hyperacusis', it is possible that not all relevant results were displayed for this singular keyword, and therefore our investigation of hyperacusis may not be all-inclusive.

Future investigations in this realm should continue to investigate the online social media portrayal of other audiological conditions, like auditory processing disorders. Additionally, since the current investigation assessed macro-level trends of hyperacusis online, future research should assess micro-level trends, including investigation of #tinnitus and #hyperacusis on Twitter, Facebook, and Instagram. Lastly, the presence, spread and potential mitigation of online misinformation related to tinnitus and hyperacusis should be investigated.

### Conclusions

The present investigation provides a fundamental evaluation of the information content, quantification, quality and accuracy of social media results related to hyperacusis found on Facebook groups, Facebook pages, Twitter and YouTube as of August 2017. The investigation revealed the presence of hyperacusis on social media platforms as it relates to distributing information, sharing experiences, offering support, locating medical providers, dispersing research findings and advocating for increased awareness of the often-misunderstood condition. Additionally, we noted several differences in the portrayal of hyperacusis on

social media compared to tinnitus. Despite the current limitations of social media, these online platforms can be exceptionally impactful for the healthcare industry. The results of the present investigation can be utilized by audiologists and other hearing health professionals to orient themselves to the changing landscape of hearing health and to better serve their patients, including those with hyperacusis.

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No potential conflict of interest was reported by the authors.

### ORCID

Colleen A. O'Brien  <http://orcid.org/0000-0001-8682-8033>

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