

Social media use in hearing loss, tinnitus, and vestibular disorders: A systematic review

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31 **Conflict of Interest**

32 The authors declare that the research was conducted in the absence of any commercial or
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Abstract

Background: People are increasingly using social media outlets for gathering health-related information. There has also been considerable interest from researchers and clinicians in understanding how social media is used by the general public, patients, and by health professionals to gather health-related information. Interest in the use of social media for audio-vestibular disorders has also received attention, although published evidence synthesis of this use is lacking. The objective of this review was to synthesize existing research studies related to social media use concerning hearing loss, tinnitus, and vestibular disorders.

Method: Comprehensive searches were performed in multiple databases between October and November 2020 and again in June 2021 and March 2022 with additional reports identified from article citations and unpublished literature. The review was presented using the PRISMA guidelines.

Results: A total of 1,512 articles were identified. Of these, 16 publications met the inclusion criteria. Overall, social media offered people the platform to learn about hearing loss, tinnitus, and vestibular disorders via advice and support seeking, personal experience sharing, general information sharing, and relationship building. Research studies were more common on information and user activities seen on Facebook pages, Twitter, and YouTube videos.

Misinformation was identified across all social media platforms for each of these conditions.

Conclusions: Online discussions about audiovestibular disorders are evident, although inconsistencies in study procedures make it difficult to compare these discussion groups. Misinformation is a concern needing to be addressed during clinical consultations as well as via other public health means. Uniform guidelines are needed for research regarding the use of social media so that outcomes are comparable. Moreover, clinical studies examining how exposure to

and engagement with social media information may impact outcomes (e.g., help-seeking, rehabilitation uptake, rehabilitation use, and satisfaction) require exploration.

Keywords

Social media, Hearing loss, Tinnitus, Vestibular disorders, Systematic review

Introduction

Within the past decade, the use of social media platforms has increased dramatically (Auxier & Anderson, 2021). “Social media” can be defined as internet-based tools that facilitate the creation and dissemination of user-generated content, including the exchange of text-, photo-, and audio/video- information (Kaplan & Haenlein, 2010). It builds on the ideological and technological foundations of Web 2.0 enabling individuals and communities to participate in social networking. Social media is not limited to websites, such as Facebook and YouTube, but includes platforms such as blogs, business networks, collaborative projects, enterprise social networks, microblogs, photo sharing, product/service reviews, social bookmarking, video sharing, and virtual worlds (Aichner & Jacob, 2015). Social media has been widely used in health contexts by health information consumers from all social groups regardless of age and gender (Xiong & Liu, 2014). While social media was once considered a personal resource emphasizing self-expression and connecting with others, its increasing popularity provides new avenues for interaction and care highlighting a more user-centric, engaged, and collaborative experience (Hesse et al., 2011). Consequently, patients are now more likely to seek and share health information, including clinical news and treatment options, than in previous decades (Chou et al., 2021).

Chronic audiovestibular conditions such as hearing loss, tinnitus, and Meniere's disease have profound impact on quality of life of patients (Miura et al., 2017; Mueller et al., 2014; Shield, 2006). Hearing loss has adverse consequences on interpersonal communication, psychosocial well-being, and economic independence (Olusanya et al., 2014). It can impede speech and language development in children, which can lead to social and learning difficulties (Olusanya et al., 2014). Untreated hearing loss in adults is associated with a greater risk of developing dementia, performing cognitive tasks, and following instructions (Jayakody et al., 2017; Loughrey et al., 2018). There are several interventions for hearing loss including hearing aids, medical treatment, assistive listening devices, cochlear implants, and aural rehabilitation. Bothersome tinnitus can be debilitating causing symptoms such as depression, anxiety, sleep disturbances, and pain (Bhatt et al., 2017; Møller, 2007; Salazar et al., 2019; Trevis et al., 2018). Current evidence reveals that there is no cure available for tinnitus and hyperacusis, but there are several management strategies, such as tinnitus retraining therapy (TRT; Nemade & Shinde, 2019) and cognitive behavioral therapy (CBT; Aazh & Moore, 2018; Beukes et al., 2018). Disorders of the vestibular system can cause symptoms of vertigo, dizziness, and imbalance leading to a greater risk of falls. The impact of vestibular disorders is significant due to limitations on physical activities and social engagements (Agrawal et al., 2014). Therapies are designed to alleviate problems caused by vestibular dysfunction, such as vestibular rehabilitation and canalith repositioning therapy for benign paroxysmal positional vertigo (Sulway & Whitney, 2019). Due to the chronic nature and impact of these audiovestibular conditions, it is important for individuals experiencing symptoms to receive appropriate care and high-quality information.

As the global prevalence of audiovestibular condition rises (Davis & Hoffman, 2019), the awareness of such conditions has consequently increased, partly due to the technological advances and increased use of the internet and social media. With roughly 70% American adults using the internet, it is evident that people are currently exposed to social and digital media (Auxier & Anderson, 2021). Contemporary discussions in the healthcare domain have established that social media offers a vast amount of health-related information to which laypeople (i.e., patients) and healthcare professionals (i.e., doctors) contribute (Moorhead et al., 2013). Recent research reveals that social media is an important source of health information for patients with chronic diseases, including audiovestibular impairments (Zhao et al., 2021). It allows users to connect with others, and to share comments or recommendations regarding care services (Berard & Smith, 2019; Moorhead et al., 2013; Smailhodzic et al., 2016). Virtual communities found on social media platforms, such as online support groups on Facebook, provide emotional support while allowing users to share their experiences (Hwang et al., 2010). Users can learn from other individuals' experiences and improve their health outcomes. Consequently, healthcare providers utilize social media platforms to discuss healthcare policy, facilitate patient-patient dialogue, and share information (Abadi et al., 2015; Heldman et al., 2013; Khan et al., 2021). Moreover, healthcare providers may improve health outcomes by utilizing social media to harness support (Smailhodzic et al., 2016).

In light of the booming popularity of social media, it is important to address the changes in how information is disseminated, publicized, evaluated, and utilized. A few of these changes are positive, such as the rapid distribution of information, rapid uptake of resources, and instant access to health-related information (Kroll et al., 2021; Ventola, 2014). However, undesirable

outcomes from social media adoption, such as rampant dissemination and influence of fake news and dis-/misinformation are challenges faced by healthcare providers (Finn, 2019; Suarez-Lledo & Alvarez-Galvez, 2021). Misinformation involves information that is inadvertently false, lacks peer-reviewed evidence, and is shared without the intent to cause harm (Wardle & Derakhshan, 2017). On the other hand, disinformation is the intentional sharing of false information, with some ulterior motive in mind, be it economic, political, or to instigate people (Lazer et al., 2018). Due to the difficulties of determining the intention of social media users, we use the term misinformation in this study to indicate information that is inaccurate, false, or lacks peer-reviewed evidence. Such misinformation may lead to patient noncompliance to undergo evidence-based treatments, unwarranted skepticism about medical guidelines and policy statements, rumors about disease outbreaks, antivaccine messages, and exposure to inaccurate information (Chou et al., 2018; Gentile et al., 2018; Merchant & Asch, 2018). For instance, in times of crisis, social media platforms, such as Facebook, have facilitated important conversations about the coronavirus and the pandemic, while at the same time allowing misinformation to spread in which most users are unlikely to fact-check what they see on the internet with their healthcare providers (Ahmed et al., 2020). Social media users with audiovestibular conditions, such as tinnitus and hyperacusis, must remain vigilant of potential misinformation. Further, healthcare professionals, including audiologists and hearing health professionals, should be aware of online information pertaining to audiovestibular conditions to provide only evidence-based information that is precise and understandable to the public.

Current evidence suggests that there are both positive and negative effects of social media use. It is important to identify these effects in the field of hearing and balance healthcare because social

media platforms hold considerable potential value, such as real-time access to and sharing of information. A growing interest in understanding the internet and social media use regarding audiovestibular-related aspects is evident in research. Smith et al. (2020) explored the use of fifteen internet websites using the single search term *hyperacusis* but did not specifically focus on social media. Their study revealed a wide disparity in the quality and content of hyperacusis information across websites. Similarly, Henshaw et al. (2012) investigated computer and internet use among older adults (aged 50-74 years) in the United Kingdom suggesting that elderly adults experiencing slight hearing difficulty have increased odds of greater computer skills than individuals reporting no difficulty. However, the researchers did not review social media platforms. Kožuh and Debevc (2020) explored the utilization of social media by D/deaf and hard-of-hearing users. They found that social media communities allowed D/deaf and hard-of-hearing users to be connected through writing language and availability of captions/subtitles in a more efficient manner through Facebook. However, peer-reviewed publications regarding social media users included in the D/deaf community were excluded to ensure that audiological deafness is differentiated from prelingual deafness (Prudans-Smith et al., 2019). These studies highlight individuals with such disorders often use digital media for audiovestibular-related health information. However, although individual studies have been conducted, knowledge of the overall effects of social media use on audiovestibular healthcare is required.

Despite the growing evidence of social media use in communication science and disorders, there is no systematic review on social media use regarding audiovestibular conditions to our knowledge. Given the rapid development of digital technology and social media, little is known about how to best use these tools for users' interest, especially concerning auditory and

172 vestibular healthcare. Health-related social media use systematic reviews do exist. They have,
173 however, not been specific to discussions regarding audiovestibular impairments on social media
174 platforms but have focused on wider applications. These include social media use in the general
175 healthcare environment (Moorhead et al., 2013; Smailhodzic et al., 2016; Ventola et al., 2014)
176 and among specific conditions, such as Crohn's disease (Zhao et al., 2021), anxiety, and
177 depression (Keles et al., 2019; Kim et al., 2021) and mental health disorders (Wongkoblap et al.,
178 2017). Moreover, this narrative is comprehensive and up to date. Although there are no relevant
179 audiovestibular-related publications concerning social media usage during the COVID-19
180 pandemic, the topic is relevant in today's scenario because of the increasing use and adoption of
181 social media and the internet worldwide, especially in the healthcare industry. For purposes of
182 this review a systematic review was selected as this provides higher-level evidence in
183 comparison to scoping reviews. A systematic review would furthermore provide the opportunity
184 to identify, retrieve, and synthesize evidence that is relevant to our particular research questions
185 using a structure protocol (Munn et al., 2018). Systematic reviews are considered the pillar of
186 evidence-based healthcare (Munn et al., 2014) and results from this review may result in further
187 research in social media use amongst individuals with chronic conditions, including audio
188 vestibular disorders, and aid in the development of social media guidelines amongst healthcare
189 professionals, particularly in the field of hearing and balance healthcare.

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191 A review on this topic will provide the opportunity to compile and collate findings from different
192 studies for a better understanding of the potential benefits and challenges of social media use in
193 relation to auditory and vestibular conditions. The findings presented in this review have strong
194 implications in the provision of audiovestibular healthcare, such as utilizing social media

platforms to aid in easing the burden of chronic audiovestibular conditions by providing support and credible information . The aim of our review was to investigate audiovestibular-related content (conditions i.e., hearing loss, tinnitus, and vestibular disorders as well as their treatments) on social media websites. The specific aims were to (a) identify who participates in social media discussions, (b) examine what kind of conversations they engage in, (c) determine how frequently different social media platforms are used, and (d) evaluate the extent of misinformation present on these platforms.

Method

Protocol

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009; see Supplementary Material File 1) and utilized a systematic approach to retrieve relevant research studies.

Eligibility Criteria

Eligibility was determined to address the research questions with reference to Participant, Intervention, Comparison, and Outcomes (PICO) tool as shown in Table 1 (Schardt et al., 2007). The population of interest included the general public (e.g., individuals with audiovestibular conditions, family members and friends of patients, and professionals; Abadi et al., 2015; Heldman et al., 2013; Khan et al., 2021; Zhao et al., 2021) and organizations (e.g., non-profit, commercial, and for-profit; Griffis et al., 2014) participating in social media. There were no age, gender, or origin restrictions. Studies that examined social media utilization patterns, identified consumers' behaviors and/or perceptions on social media platforms, analyzed the content on

social media networks, or identified the advantages and disadvantages of social media use related to audiovestibular disorders were included. Only peer-reviewed English-language publications were included with no restrictions on publication date. As the PICO tool does not currently accommodate terms relating to qualitative research or specific qualitative designs, we adapted the tool to “PICOS” with the “S” referring to the Study design. All studies, irrespective of the study design, were included but systematic reviews were excluded as systematic reviews as this is a secondary source of information and systematic reviews focus on original research to avoid repetition. Articles were excluded if they were: a.) not published in peer-reviewed journals, b.) described social media use in a general context rather than a health context, c.) did not investigate at least one specific social media website, d.) examined social media marketing for professionals, or e.) investigated participation in social media for discussion regarding prelingual hearing loss (Deaf or deafness).

<<Table 1 near here>>

Information Sources

A systematic search was undertaken in October and November 2020 and again in June 2021 and March 2022 by two authors (AU and AP). The following electronic research databases were used: Academic Search Complete, CINAHL, Psychology and Behavioral Sciences Collection, and PubMed (including MEDLINE). Additional searches included manual searches within key journals, reference lists from the included studies, gray literature on Google Scholar, and contacting stakeholders and research experts in the field.

Search Strategy

A peer-reviewed search strategy was developed using Boolean operators, combining comprehensive terms for contemporary social media (Moorhead et al., 2013) by targeting two domains: the condition (e.g., hearing loss, tinnitus, vestibular disorder) and the mode of delivery (e.g., social media and social networking). The search terms were adapted from similar systematic reviews exploring wide audiovestibular topics from Beukes et al. (2019) and Moorhead et al. (2013). The search strategy was developed together with a librarian at Lamar University. The use of search terms and their Boolean combinations were adapted for each search engine to suit its requirements. To identify articles, capturing condition of interest (e.g., hearing loss, tinnitus, and vestibular disorders) and (b) the mode of delivery (e.g., social media, social networking), the following search terms were selected:

- a) (“social media” OR “social networking” OR “Facebook” OR “Twitter” OR “YouTube” OR “Instagram” OR “Reddit” OR “Web 2.0”) AND (“hearing loss” OR “hearing impair*” OR “hard-of-hearing” OR “hearing disability”)
- b) (“social media” OR “social networking” OR “Facebook” OR “Twitter” OR “YouTube” OR “Instagram” OR “Reddit” OR “Web 2.0”) AND (“tinnitus”)
- c) (“social media” OR “social networking” OR “Facebook” OR “Twitter” OR “YouTube” OR “Instagram” OR “Reddit” OR “Web 2.0”) AND (“vertigo” OR “dizziness” OR “vestibular*” OR “balance*” OR “Ménière*” OR “benign paroxysmal positional vertigo” OR “Neuritis”)

The search strategy was piloted for the hearing loss category to ensure it was effective.

Study Selection

Two authors (AU and AP) independently screened the search results using the Rayyan software to identify studies that met the inclusion criteria by reading the title and abstract. The Rayyan software was used to read titles, abstracts, remove duplicates, and read full texts (Ouzzani et al., 2016). The authors then read full texts of articles to determine eligibility. Disagreements were resolved based on discussions with a third author (VM).

Data Extraction

Data from included studies were manually extracted using Microsoft Excel spreadsheets. One author (AU) extracted information about the author(s), year of publication, condition of interest(s) (e.g., hearing loss, tinnitus, or vestibular disorders), study design, type of data collected (e.g., video or text), search terms used, methods used for data collection and data analysis, and key findings of each study included in the systematic review to aid comparison and synthesis of the studies. Another author (AP) cross-checked and verified the data extraction. The completed extraction forms were provided to all authors for cross-checking. All necessary data were obtained from the published studies.

Quality Appraisal and Level of Evidence

Quality assessment was conducted independently by two authors (AU and AP) using the Appraisal Tool for Cross-Sectional Studies (AXIS) for cross-sectional studies (Downes, et al., 2016) and the Critical Appraisal Skills Programme (CASP) tool for qualitative and mixed-methods studies (Critical Appraisal Skills Programme, 2013). The AXIS tool was utilized to assess the risk of bias, quality of design, and quality of reporting of selected full-text articles. AXIS is composed of five main components: objective, methods, results, discussion, ethics, and

funding. It includes 20 questions, and each question is judged as yes, no, or I don't know. A 20-point scale considers studies with <10 points as low quality, 10-15 as moderate quality, and 16-20 as high quality. The CASP tool for qualitative studies, recommended by the Cochrane Collaboration for qualitative literature, was used to assess the risk of bias for included studies with a mixed-methods design. CASP contains 10 questions about the study goals, methodology, bias, ethics, data analysis, and result reporting. An overall risk of bias judgment was made as low risk of bias, moderate risk of bias, or high risk of bias for each domain based on criteria defined by authors. A 10-point scale considered studies with <5 points as high risk, 5-7 as moderate risk, and >7 as low risk of bias. Disparities were resolved through a third reviewer (VM) for all quality analyses conducted for each included publication.

Synthesis of Studies and Presentation of Results

A descriptive analysis of the characteristics of the included literature was conducted. Included articles were described according to the publication date, type of social media, and targeted condition studied (e.g., hearing loss, tinnitus, vestibular disorder). Due to the variation in studies included in this systematic review, three themes were identified, which included social media use surrounding topics of hearing loss, tinnitus, and vestibular disorders. Given the substantial heterogeneity within the included studies, formal meta-analyses could not be attempted.

Results

Study Selection

Figure 1 shows the search results and included studies. The initial search identified 1,512 publications, of which 1,311 records were screened after removing duplicates. Of these, 1,284

records were excluded based on title/abstract review. Five additional records were identified through a manual search. Full texts of the remaining 26 studies were assessed for eligibility. Seven studies were excluded either as the study outcomes were not relevant to the scope of this review (Ma et al., 2021; van Wier et al., 2021; Wong et al., 2016; Giordano et al., 2021; Oh et al., 2022) or the non-peer-reviewed publications (Choudhury & Renken, 2018; O'Brien et al., 2019). Thus, a total of 19 studies were included in the present systematic review. Of these, nine studies were related to hearing loss, six studies were related to tinnitus, and four studies were related to vestibular disorders. All included studies were published in English from 2012 to 2022.

<<Figure 1 near here>>

Study Characteristics

The 19 selected studies are summarized in Table 2 based on the social media platform (e.g., YouTube, Facebook) and medium (e.g., text, video, questionnaire) being examined, the scope of the study, and the associated audiovestibular disorder evaluated. A total of 226,532 social media search results and 1,570 questionnaire responses were analyzed across the studies. More specifically, hearing loss-related searches returned 51,643 results, tinnitus-related searches returned 174,753, and vestibular-related searches returned 136 results. Among the included publications, all used or described at least one specific type of social media. Several audio-vestibular conditions were reviewed among the included studies. Of the 19 studies, fourteen focused on social media use for audiovestibular conditions while five focused on treatments for audiovestibular conditions (e.g., Epley maneuver, hearing aids, cochlear implants). Audiovestibular conditions discussed among studies included hearing loss, hyperacusis, tinnitus,

auditory processing disorder (APD), Meniere's disease, and vestibular disorders (e.g., vestibular migraine, bilateral vestibular hypofunction). Moreover, only text data were analyzed in seven studies (e.g., Twitter tweets, Facebook posts, and blog posts), followed by video and text data in five studies, and only video data in four studies. The remaining studies analyzed self-reported questionnaire data (Manchaiah et al., 2020b; Manchaiah et al., 2020b; Vanstrum et al., 2021).

<<Table 2 near here>>

Description of the Included Studies

The summaries of the nineteen studies included in this review can be seen in Tables 3-5. Two main methodological approaches were observed in the included studies: (1) examining the content and user activity of social media sites or platforms via qualitative or quantitative techniques; and (2) examining the users regarding social media use on various platforms using surveys. Most studies aimed to analyze available information on various social media platforms. This included analyzing the content of social media posts, identifying uploader characteristics, and comparing and evaluating user activity among social media applications.

<<Table 3 near here>>

<<Table 4 near here>>

<<Table 5 near here>>

Of the studies, most researchers performed qualitative analyses of data obtained from social media websites (e.g., discussion posts). Data were often manually scraped, collated, and

analyzed. For instance, studies evaluated the social media information using tools such as the Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-AV; The PEMAT and User's Guide, n.d.; Manchaiah et al., 2020a; Manchaiah et al., 2020c) and modified DISCERN criteria, modified Journal of the American Medical Association (JAMA) benchmark criteria, and Global Quality Scores (GWS; Yildiz & Toros, 2021). Manual categorization of data was also performed. For example, Manchaiah et al. (2020a) evaluated the YouTube content on hearing aids and defined eleven content categories: hearing mechanism, information about hearing loss, hearing aid type, hearing aid features and functionalities, handling and maintenance of hearing aid, benefits of hearing aids, limitations or side effects of hearing aids, cost of hearing aid and reimbursement, hearing aid purchasing process, featuring a celebrity with hearing aids, and the purpose of the video. The purpose of the videos was further categorized into general information about hearing aids, personal experiences about hearing aids, and promotional information to sell a product or a service.

Quantitative analyses of data were also conducted in most studies (e.g., Crowson et al., 2017; Manchaiah et al., 2018; Ni et al., 2020). For instance, tweet volumes were tabulated and mapped to assess gross longitudinal trends over the study period in Crowson et al. (2017). However, most of the quantitative data were presented in a descriptive format (Choudhury et al., 2017; Deshpande et al., 2018; Deshpande et al., 2019b; Manchaiah et al., 2020a; Manchaiah et al., 2020b; Manchaiah et al., 2021; Ni et al., 2020; Saxena et al., 2015). Automated text analyses of social media data were performed in a few studies using methods such as cluster analysis and/or the Linguistic Inquiry and Word Count (LIWC; Tausczik, & Pennebaker, 2010; i.e., Kimball et al., 2019; Manchaiah et al., 2021; Manchaiah et al., 2022; Ni et al., 2020;). LIWC is a text-

analysis computer software that produces results similar to qualitative content or thematic analysis by using topic modeling, which involves text mining algorithms to identify patterns within the data (Nunez-Mir et al., 2016). Such techniques may aid in the understanding of results amongst hearing healthcare professionals as they are familiar with qualitative analysis techniques. The remaining studies that conducted surveys performed quantitative analyses by using descriptive statistics to examine survey responses (Manchaiah et al., 2020b; Manchaiah et al., 2020d; Vanstrum et al., 2021).

Characteristics of Social Media Users

As shown in Tables 3-5, the characteristics of social media users in the included studies were diverse. Account owners were identified as users with the targeted condition, service providers/professionals, or commercial/for-profit organizations. Crowson et al. (2017) reported the top 100 most active Twitter accounts belonging to organizations (67%) rather than individual users (33%) for Twitter posts about hearing loss. In another study exploring online hearing aid discussions, professionals accounted for most of the videos (n=80 out of the top 100 most viewed videos) (Manchaiah et al., 2020a). Similarly, Saxena et al. (2015) found that Twitter was dominated by cochlear implant manufacturers. Kerber et al. (2012) revealed that providers accounted for more than half of the 33 videos, and patients, patient acquaintances, vendors, others, or unknown accounted for the remaining videos. Yildiz and Toros (2021) also identified YouTube video sources comprising of universities/occupational organizations, medical ad/profit-oriented companies, independent users, and others (news/media/state institutions). The main video source was medical ad/profit-oriented companies (60.2%).

Kimball et al. (2019), Manchaiah et al. (2020d), and Vanstrum et al. (2021) presented demographic data regarding study participants who completed the study survey (e.g., geographic location, age, and gender). Kimball et al. (2019) reported participants being 18 years or older, which was determined by viewing Facebook profiles. Researchers further categorized users into four distinct categories considering the condition (i.e., tinnitus and hyperacusis) and the type of post (i.e., “initial” posts being comments initially posted by a member and “reply” posts being responses to an initial post). For the tinnitus group, 165 language samples (male=94) were collected in the form of ‘initial’ posts and 142 (male=67) were collected as ‘reply’ posts. For the hyperacusis group, 68 language samples (male=28) were collected in the form of ‘initial’ posts and 72 (male=24) as ‘reply’ posts. Similarly, Manchaiah et al. (2020d) presented demographic information reporting the age range of Meniere’s disease survey respondents being less than 35 years old to over 63 years. Most respondents were retired from their occupation (n=216), while students represented the smallest group (n=6). In addition, more than 60% of respondents were professionals and/or university educated. Females accounted for most of the survey responses (74.4%), and the duration of Meniere’s disease was evenly distributed among respondents. Lastly, Vanstrum et al. (2021) analyzed two online support communities on Facebook that provide support for patients with general vestibular symptoms. The cohort of 549 participants consisted of primarily educated middle-aged (median = 50, interquartile range 40–60), non-Hispanic white (84%), and female (89%) participants. Almost half of the cohort saw five or more providers before receiving a primary diagnosis. The most common primary diagnoses included vestibular migraines (26%), vestibular neuritis (15), and Meniere’s disease (9%). The most common secondary diagnoses included VM (23%) and benign paroxysmal positional vertigo (14%). About eight percent of participants reported that they did not have a diagnosis yet.

Moreover, respondents saw a mean of 4.6 medical providers (SD 2.58) before receiving a diagnosis, most often by an otolaryngologist. Most participants received their primary diagnosis between >1 and 5 years previously (45%). Vanstrum et al. (2021) also identified the presence of online support communities on Facebook with over 250,000 cumulative members and 10,000 posts among seventy-three online support communities. The remaining studies analyzed the general social media environment without restrictions on populations. For instance, Manchaiah et al. (2022) analyzed Reddit discussions regarding tinnitus. However, user characteristics could not be described as Reddit does not provide demographic data on the site's users.

Domain of Research

Although hearing loss, tinnitus, and vestibular-related conditions were being evaluated, there was a variety of discussion topics investigated among social media communities (Table 2). Hearing loss-related studies focused on sudden sensorineural hearing loss (Manchaiah et al., 2021), unspecified hearing loss (Crowson et al., 2018; Manchaiah et al., 2020b; Manchaiah et al., 2020c), cochlear implants (Saxena et al., 2015), auditory processing disorder (APD) (Deshpande et al., 2019b), and hearing aids (Choudhury et al. 2017; Manchaiah et al., 2020a). Tinnitus was investigated by Basch et al. (2018), Deshpande et al. (2018), Manchaiah et al. (2018), Manchaiah et al. (2022), and Ni et al. (2020). Kimball et al. (2019) investigated tinnitus and hyperacusis. Deshpande et al. (2019a) investigated hyperacusis. Both studies were reviewed as tinnitus-related social media studies because hyperacusis is often associated with tinnitus. There were only four vestibular-related social media studies included in this review. Manchaiah et al. (2020d) investigated Meniere's disease. Kerber et al. (2012) explored the Epley maneuver for benign paroxysmal positional vertigo (BPPV). Vanstrum et al. (2021) investigated online support

communities on Facebook regarding a variety of vestibular disorders (e.g., vestibular migraine, vestibular neuritis, Meniere's disease, BPPV, persistent postural perceptual dizziness). Fourth, Yildiz and Toros (2021) analyzed YouTube videos regarding vestibular rehabilitation.

Social Media Uses for Audiovestibular-Related Communication

As reported in Tables 3-5, there were many uses for social media regarding audiovestibular conditions. Most studies categorized uses of social media into functional categories/themes performed manually and defined by authors, ranging from 4 to 10 categories. The classification of categories was inconsistent. However, common themes were reported.

The most frequently reported categories of online discussion around hearing loss were sharing advice and support (e.g., Choudhury et al., 2017; Deshpande et al., 2019b; Saxena et al., 2015), sharing information (e.g., Choudhury et al., 2017; Deshpande et al., 2019b; Manchaiah et al., 2020a; Manchaiah et al., 2020c), and sharing personal experiences (e.g., Deshpande et al., 2019b; Manchaiah et al., 2020a; Manchaiah et al., 2021; Saxena et al., 2015). For instance, a child wearing a hearing aid for the first time had 14 million views and the highest number of likes (41,545) on YouTube (Choudhury et al., 2017). Content analysis also identified social media as a source for company/brand discussion and/or product promotion (Deshpande et al., 2019a; Manchaiah et al. 2020a; Manchaiah et al. 2020c; Saxena et al., 2015). Facebook was used by patients to connect with parents of children with CIs, to share accessories (e.g., CI clothes, accessories, and retention aids for kids and adults), to work on aural rehabilitation for CIs, and to connect with CI researchers (Saxena et al., 2015).

It was noted that the tinnitus community engaged in social media for various purposes, such as sharing services/products (Choudhury et al., 2018; Deshpande et al., 2018; Manchaiah et al., 2018; Ni et al., 2020), providing support (Choudhury et al., 2018; Deshpande et al., 2018; Ni et al., 2020), and sharing information (Basch et al., 2018; Choudhury et al., 2018; Deshpande et al., 2018; Ni et al., 2020). More specifically, social media use regarding tinnitus included the sharing of services among audiologists, medical doctors, or other related professionals and institutions, the advertisement of tinnitus management applications, and fundraising for organizations or events seeking financial support for tinnitus research (Deshpande et al., 2018). For instance, hyperacusis-related products were endorsed particularly through Twitter accounts (20%) followed by Facebook pages (5.1%; Deshpande et al., 2019a). Moreover, Manchaiah et al. (2022) identified 16 unique clusters belonging to two topics discussed amongst tinnitus-related conversations: 1) tinnitus causes and consequences and 2) tinnitus management and coping. The *causes and consequences* topic included discussions regarding medical triggers and modulators of their tinnitus, dietary effects of tinnitus, tinnitus perception (e.g., pitch, loudness, maskability), sleep-related issues, association between tinnitus and attention/concentration, discussions around the onset of their tinnitus as well as how long it may last, and also music listening and hearing protection. The *management and coping* topic was largely defined by discussions regarding users' interactions with their hearing health care providers, general discussions around social media posts about tinnitus, hoping for a cure, dietary supplements and alternative therapies, hearing research, interactions with people who do not experience tinnitus and their limited understanding of tinnitus, mental health issues and coping, as well some appreciation toward the online community for answering their questions or concerns and for being supportive.

494 There were two main uses of social media in vestibular disorders: (1) to gather information and
495 (2) to share information. For example, YouTube videos revealed demonstrations of the Epley
496 maneuver through guided treatments (e.g., a person guiding a patient through the maneuver;
497 n=22) or self-treatments (n=11; Kerber et al., 2012). Complete diagnostic information about
498 BPPV was not found in any of the videos. Moreover, there were a total of 424 comments from
499 349 unique identifiers. Of the comments, two themes emerged regarding the use of the videos.
500 The first theme was that of patients self-treating with the Epley maneuver after reviewing the
501 videos. For instance, most users commented about their dizziness symptoms and others reported
502 that they performed the Epley maneuver as a result of viewing the video. Other users reported
503 that self-treatment with the Epley maneuver was highly beneficial and expressed appreciation,
504 even describing it as a “miracle.” Some patients also expressed disappointment with prior
505 medical encounters that had not resulted in utilizing the Epley maneuver as a treatment. Some
506 users provided extensive descriptions of their symptoms (e.g., auditory symptoms or prolonged
507 or constant dizziness) suggesting diagnoses other than BPPV. Furthermore, some patients also
508 requested more details about the Epley maneuver treatment, particularly, identifying the effected
509 side and how often the maneuver must be performed. Researchers also identified the theme of
510 providers utilizing YouTube videos as a prescription for patients or for educational purposes. For
511 example, some comments revealed that providers instructed patients to use the videos to guide
512 them with self-treatment. On the other hand, some providers commented that some videos were
513 useful as educational tools for themselves and for teaching others. Similarly, Yildiz and Toros
514 (2021) identified YouTube videos related to vestibular rehabilitation practical education for
515 patients. Manchaiah et al. (2020) also identified that respondents with Meniere’s disease
516 frequented social media to gather more information about their health conditions. Lastly,

Vanstrum et al. (2021) identified that most survey respondents were motivated to join a vestibular online support community was to hear from others with the same symptoms or diagnosis (89%). Other initial motivations for joining a vestibular online support group included to learn about treatments, to provide support for others, to find support for mental health, to learn about medical professionals, and to access research and publications.

Frequency of Social Media Use

Due to the study designs of social media-related publications, there was a lack of information regarding the frequency with which social media users utilized platforms/websites for audiovestibular-related information. Among the studies, only four publications discussed information regarding the frequency of social media use, reported in Table 2 (Manchaiah et al., 2018; 2020b; 2020d; Vanstrum et al., 2021). Manchaiah et al. (2018) analyzed tinnitus-related trends over time revealing that users sought information on Facebook regarding tinnitus diagnoses, social support, and challenges – more significantly during the years 2013, 2014, and 2015 (data extraction period during 2010-2016). Next, in a survey study, Manchaiah et al. (2020b) revealed that over 40% of the respondents discussing hearing loss used Facebook and YouTube “most of the time” or “sometimes,” whereas less than 10% of the respondents used other sources (i.e., Twitter, LinkedIn, and Instagram). Similarly, in another survey study, Manchaiah et al. (2020d) revealed that Facebook, YouTube, Instagram, and Twitter were used by 65.8%, 46.5%, 26.2%, and 5.4% of the participants discussing Ménière's disease, respectively. Notably, researchers also compared the time spent weekly among the social media platforms revealing that Facebook and Instagram were used more than one hour by 73% and 34% of the respondents, respectively, whereas YouTube and Twitter were used more than one

hour by less than 30% of the respondents (Manchaiah et al., 2020d). Lastly, frequency of support group engagement was also analyzed by Vanstrum et al. (2021) revealing that among respondents, 198 participants (36%) utilized the support group daily followed by multiple times week for 173 participants (32%). Other users participated on online support communities weekly (15%), monthly (8%), once every few month (8%), and other (1%).

Extent of Misinformation

Various degrees of misinformation were found across all social media platforms. Misinformation was defined as information that was inaccurate, questionable, or lacking peer-reviewed evidence. Misinformation was identified on all investigated social media platforms regarding discussions about tinnitus (Deshpande et al., 2018) and hyperacusis (Deshpande et al., 2019a). More specifically, Deshpande et al. (2018) identified that among the social media platforms investigated, Facebook groups yielded the highest amount of misinformation related to tinnitus (44.4%), followed by Facebook pages (42.7%), and YouTube videos sorted by relevance (the default sorting option; 30.9%). In contrast, investigation regarding hyperacusis yielded less misinformation compared to tinnitus, with YouTube leading the platforms with 19% inaccurate information (Deshpande et al., 2019a). Another study revealed that misinformation was not a significant problem in APD-related posts based on analyzing general trends (Deshpande et al., 2019b). Ni et al. (2020) identified one tweet (1%) regarding misinformation about causes of tinnitus linked to electrical signals in the environment. However, the extent of misinformation in the Twitter tweets was not thoroughly examined by researchers. Next, Kerber et al. (2012) revealed inaccurate demonstrations of the Epley maneuver on twelve YouTube videos. This included a nonstandard first step (e.g., incorrect head placement), inadequate head movements,

head lifting during the rollover step, or head not turned downward after the rollover. Lastly, Manchaiah et al. (2020d) did not analyze the content of social media posts but instead found that participants did not find information trustworthy. For example, 55.9% of participants used Facebook to gather information on Meniere's disease problems but only 14% found the information trustworthy. This suggests that respondents were somewhat aware of the issue of misinformation. Vanstrum et al. (2021) also reported that the two online support communities investigated were not scientifically or medical moderated, which raised the possibility the misinformation could be distributed. Lastly, Yildiz et al. (2021) utilized the modified DISCERN criteria, the modified JAMA benchmark criteria, and the GQS completed by independent otorhinolaryngologist reviewers revealing low mean scores from all three objective checklists. Results suggests that online information about vestibular rehabilitation education on YouTube was of poor quality and unreliable. However, videos uploaded by universities/occupational organizations (25.2%) had statistically significant higher modified DISCERN criteria scores, modified JAMA benchmark criteria scores, and GQS values compared with the other groups ($p < 0.001$).

Social Media Tools

Different social media platforms were evaluated among the included studies, the most reported being YouTube, Facebook, and Twitter, respectively. More specifically, social media sources assessed were YouTube ($n = 12$), Facebook ($n = 10$), Twitter ($n = 9$), Instagram ($n = 3$), blogs ($n = 2$), forums ($n = 2$), Reddit ($n=2$), and LinkedIn ($n = 1$). Among the studies included for review, seven studies investigated more than one social media platform/website, and the remaining studies evaluated a single social media platform.

586

587 *Search Terms*

588 Data collection involved utilizing search terms to obtain results. All studies, but two, utilized
 589 search terms. Manchaiah et al. (2020b; 2020d) did not report search terms as they were not
 590 applicable to the study design (i.e., survey results were analyzed rather than social media
 591 content). Moreover, Vanstrum et al. (2021) did not state specific search terms used to identify
 592 online support communities on Facebook. However, researchers created comprehensive list of
 593 vestibular diagnoses to identify online support communities.

594

595 *Quality and Risk of Bias Assessment*

596 Overall, the AXIS quality assessments for cross-sectional studies were of moderate quality, with
 597 common issues identified in several domains as shown in Table 6. None of the studies received
 598 scores <10 (poor), six studies had scores 10-15 (moderate), and three studies had scores >15
 599 (good). No studies met the 20 out of 20 criteria. Where an “unsure” response was assigned, it
 600 was most commonly associated with a lack of clarity in reporting items in the methods. Of the
 601 studies that were not applicable, issues of non-responders and justification were not addressed.
 602 The risk of bias for mixed-methods studies using the CASP tool was low among all the included
 603 studies as shown in Table 7. Of the ten mixed-methods studies included in this review, all studies
 604 adequately addressed all CASP criteria except one question (i.e., Has the relationship between
 605 researcher and participants been adequately considered?).

606

607 <<Table 6 near here>>

608 <<Table 7 near here>>

609

610 **Discussion**

611 To our knowledge, this is the first review to examine studies focusing on the portrayal and
 612 discussion of audiovestibular conditions on social media platforms. All of the studies were
 613 published in the past 10 years, which demonstrates the increase in research in this area. Nineteen
 614 research studies met the inclusion criteria for this review, indicating that there is an online
 615 presence of audiovestibular-related discussion across a variety of social media platforms. Users
 616 can obtain and share information regarding audio-vestibular conditions (e.g., symptoms and
 617 diagnoses), share individual experiences with the targeted conditions, seek support from
 618 individuals who understand the conditions, provide services to manage and treat auditory-related
 619 conditions, and advocate for increased awareness of the targeted conditions.

620

621 **Key Findings**

622 The studies included in the review were diverse, evaluating various social media platforms,
 623 research designs and methodologies, and outcomes. Content analyses among the studies revealed
 624 that individuals used social media for various purposes, including sharing symptoms and
 625 diagnostic information (e.g., Manchaiah et al., 2018), sharing personal experiences (e.g., Basch
 626 et al., 2018), seeking support (e.g., Deshpande et al., 2019a), advocating for awareness (e.g.,
 627 Deshpande et al., 2018), and obtaining information about research (Manchaiah et al., 2018).
 628 However, the review highlighted that there was no consensus among experts on the best form of
 629 social media platform for seeking and sharing health information. The results of this study
 630 revealed varied and fragmented social media use, which shows some promise in the

dissemination of health information that healthcare providers may use to potentially motivate patients and increase personal awareness of news and discoveries (Ventola, 2014).

Social media was used by a variety of individuals including organizations (e.g., commercial/for-profit organizations; Choudhury et al., 2017; Crowson et al., 2017; Kimball et al., 2019) and professionals (Basch et al., 2018; Manchaiah et al. 2020a; Manchaiah et al., 2020b). The account ownership trend highlights how social media can be a beneficial tool for healthcare professionals and companies, such as introducing and advertising services to potential patients (Choudhury et al. 2017). Recent research suggests that social media can enhance organizational visibility and marketing for products and services (Ventola, 2014). Not only does the dissemination of services through advertisements and social media posts attract new patients (Courtney, 2013), it also has a strong influence on consumers/patients, which must be considered and implemented into practices by healthcare professionals and companies. Peck (2014) revealed that 57% of consumers reported that a hospital's social media presence strongly influenced their decision of where to go for services. Consumers also interpreted a strong social media presence as an indication that the hospital offered cutting-edge technologies (Peck, 2014). Healthcare professionals, such as audiologists, must recognize the impact social media has on their businesses and patient health behaviors.

YouTube, Facebook, and Twitter were reported most often among the studies, which is consistent with recent trends regarding social media use in the United States. Auxier and Anderson (2021) reported YouTube and Facebook dominating the online landscape, with 81% and 69%, respectively from a national survey of 1,502 U.S. adults conducted via telephone. Most

platforms have also shown little growth since 2019, except YouTube and Reddit (Auxier and Anderson, 2021). Interestingly, only one study evaluated Reddit data (Manchaiah et al., 2021).

Further, the frequency of social media use was not commonly investigated among the studies. Manchaiah et al. (2018) conducted an analysis of trends over time revealing users seeking information on tinnitus diagnoses, social support, and challenges more significant in 2013, 2014, and 2015, respectively. Investigating trend analyses on social media may help researchers identify recurring patterns that may impact future research or service/product development regarding audiovestibular treatment and management. Additionally, analysis over time may be useful in understanding patterns and the formation of public opinions about tinnitus.

Caveat of Social Media Use

Social media is an internet tool used to diffuse health-related information. The cost of generating and disseminating online information is low, providing opportunities for users to propagate and share unauthenticated information. This results in an abundant amount of misinformation throughout the internet, which is sometimes more popular than accurate information (Wang et al., 2019). In this review, only a few studies assessed misinformation, revealing a presence of misinformation and mistrust across all social media platforms investigated. This is particularly important because individuals with audiovestibular-related conditions may act on potentially harmful or ineffective advice to alleviate symptoms. For instance, accurate demonstrations of the Epley maneuver are essential for the proper treatment of symptoms associated with BPPV. If done incorrectly, the technique may result in insufficient particle movement within the affected semicircular canal, reducing the effectiveness of the treatment.

677

678 Health misinformation is a public health concern and must be further investigated as social
 679 media use continues to grow. Both the general public and health professionals must remain
 680 vigilant of potential misinformation as it can spread unintentionally or intentionally (i.e.,
 681 disinformation). Audiologists and other health professionals play a significant role in correcting
 682 health misinformation. They must be aware of online information about hearing loss, tinnitus,
 683 and vestibular disorders to provide and share accurate information regarding these conditions on
 684 social media. For instance, ‘miracle cures’ for tinnitus that are promoted through social media
 685 outlets may attract users with tinnitus as this condition may be debilitating and perplexing.
 686 Health professionals can also be active contributors on social media platforms to generate good
 687 content and to correct misinformation. For example, Bautista et al. (2021) presented a two-
 688 phased conceptual model showing how professionals can aid in authenticating and correcting
 689 health misinformation on social media. There are various correction strategies, such as public
 690 rebuttal, private rebuttal, public priming, and private priming, that health professionals may
 691 utilize to dispel health misinformation on social media.

692

693 **Limitations and Future Directions**

694 The current study has several limitations that should be considered. Firstly, the search strategy
 695 employed in our study may not have captured the terminology used by others despite efforts to
 696 define the targeted conditions and subject. There are many related conditions under the umbrella
 697 term *vestibular disorders*. Contemporary social media terms also vary among health-related
 698 systematic reviews and information seekers. Limiting our search strategy to specific
 699 audiovestibular conditions and/or social media platforms (e.g., Twitter) may have impacted

search results, inappropriately excluding articles from review. For instance, there is some disagreement regarding whether or not a forum is a form of social media. This needs to be further investigated. Similarly, searches performed on specific databases may have inappropriately excluded articles from review. It is furthermore possible that the pilot searching conducted to evaluate the effectiveness of the search terms was not sufficient as it only focused on the hearing loss category. Moreover, although misinformation was a theme that was identified in our review, we did not include terms related to misinformation to expand the number of records retrieved. Next, we utilized an expanded PICO tool to aid in the development of an effective search strategy. Future studies may consider alternative search tool, the SPIDER (sample, phenomenon of interest, design, evaluation, research type) tool, as it may be more applicable particularly for qualitative syntheses with potential to identify qualitative and mixed-methods studies due to its greater specificity (Methley et al., 2014). Furthermore, a limitation of every systematic review is the variability in objectives, study methods, and means of interpretation to reach conclusions. For instance, most studies included in the review did not discuss specific user demographics due to the lack of variability among study designs. Lastly, the exclusion of relevant articles published in non-English languages may have omitted relevant research.

Despite the popularity of social media platforms evident in research, future studies should explore the online activity across various social media platforms to identify patterns and presuppositions patients may have regarding various health aspects. Since little is known about the quality of information circulating through social media, content-analyses may aid in analyzing the extent to which authentic information is shared via social media, specifically

related to audiovestibular conditions. Additionally, future research could investigate the impact of social media use on health outcomes, specifically related to audiovestibular conditions. For instance, during the coronavirus pandemic, there was a significant increase in the average time users spent on social media (Statista, 2021). Social distancing efforts and state mandates influenced the shift, increasing the amount of time with social media platforms to stay connected on new platforms (e.g., TikTok) and old platforms (e.g., Facebook). The shift and uptake of social media urges exploration of online health-related discussion and the spread of information to investigate social media use after the coronavirus pandemic (e.g., formation of presuppositions regarding audiovestibular conditions, onset and exacerbation of audiovestibular conditions following the diagnosis of COVID-19). Next, it would be useful to examine how information from social media contributes to the self-management of individuals with various audiovestibular conditions and their health outcomes.

Conclusions

Overall, the ubiquity of social media, the internet, and smartphones have shifted the healthcare landscape, and individuals are turning to online platforms for access to health-related information and discussions. The current review is the first to provide insight into the current use and impact of contemporary social media on diseases related to audiovestibular dysfunction. Results indicate that there is an online presence of audiovestibular discussion across social media platforms among a variety of users. The proliferation of social media tools in recent years reveals that users seek advice and support, find providers, and share information and personal experiences. Due to the chronic nature of some audiovestibular conditions, it is important that information uploaded to the internet and social media are appropriate and relevant. These

findings highlight the need for stakeholders (e.g., clinicians, web developers) to be aware of some pitfalls to using social media, including misinformation. Audiologists and other health professionals play an important role in identifying and correcting health misinformation, especially in times of crisis. Despite the current limitations of social media, online platforms have the potential to become dominant communication channels for hearing and balance care. Clinicians can use this information to understand the current climate of social media discussions regarding audiovestibular conditions and treatments and to potentially be prepared to address them. Moreover, the internet and social media could be leveraged to deliver evidence-based interventions and research to reduce condition-related distress and improve patient outcomes. Clinicians must have high-quality data before investing in digital technologies such as social media. Future research is warranted to identify the gaps and limitations of social media.

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1008 **Tables and Figures**

1009 Table 1: Eligibility criteria using PICOS framework

1010 Table 2: Summaries of included studies

1011 Table 3: Summary of hearing loss studies on social media

1012 Table 4: Summary of tinnitus studies on social media

1013 Table 5: Summary of vestibular disorder studies on social media

1014 Table 6: Quality analysis for cross-sectional studies

1015 Table 7: Quality analysis for qualitative and mixed methods studies

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1017 Figure 1: PRISMA flow diagram of studies included/excluded