

Review Article

Leveraging Online Communities to Understand Patient Experiences With Hearing Aids and Cochlear Implants: A Scoping Review

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ARTICLE INFO

Article History:

Received July 14, 2025

Revision received September 9, 2025

Accepted October 30, 2025

Editor-in-Chief: Ryan W. McCreery

Editor: Steven Marcum

https://doi.org/10.1044/2025_AJA-25-00167

ABSTRACT

Purpose: Hearing loss impacts 430 million individuals worldwide and is linked to negative outcomes such as social isolation and cognitive decline. While social media offers a valuable avenue for gathering insights into patient experiences with hearing aids (HAs) and cochlear implants (CIs), there remains a significant gap in understanding how to effectively capture and analyze these perspectives. This scoping review aims to map existing literature about online communities, providing a novel approach to exploring and analyzing patient experiences with HAs and CIs that conventional research methods may overlook.

Method: A comprehensive literature search was conducted across several databases to identify studies evaluating HA and CI user experiences with regard to online platforms. Studies were screened and summarized, drawing out themes for user devices studied, digital platforms utilized, and primary analysis methods.

Results: Of 1,752 original studies screened, 16 were ultimately included. Three primary modes of analysis emerged from a review of the literature: (a) manual coding of text, (b) computational text analysis, and (c) audiovisual content analysis. Each approach contributed distinct insights: Manual coding captured nuanced lived experiences and emotional narratives, computational techniques offered scalable assessments of sentiment and usage patterns, and audiovisual analyses highlighted educational quality and content dissemination trends. Findings revealed underlying trends in the utility of online communities as a space for patients with a CI or HA to share personal anecdotes and experiences, as a modality to distribute medical information and decrease barriers to health literacy, and as a unique environment to find peer support.

Conclusions: This scoping review demonstrates promise in the use of online platforms as a resource for evaluating HA and CI user experiences. Evaluating these digital platforms can help inform patients and guide providers with user perspectives, offer support systems for patients, and empower patients with a CI or HA to optimize their medical, communicative, and social engagement throughout their hearing health care journey.

Supplemental Material: <https://doi.org/10.23641/asha.31060957>

Hearing loss affects 430 million people worldwide and is associated with adverse outcomes, including social isolation, cognitive decline, and reduced quality of life (Guntuku et al., 2020; Mener et al., 2013; World Health

Organization, 2025). Understanding real-world experiences of individuals using hearing aids (HAs) and cochlear implants (CIs) is essential for improving delivery of care, reducing stigma, and guiding device design and health policy innovations (Blazer et al., 2016). Other devices, such as bone-anchored hearing aids (BAHAs) and direct-to-consumer hearing devices (DCHDs), represent growing alternatives to HAs and CIs that similarly warrant better insight for understanding patient experiences (Almugathwi et al.,

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Disclosure: The authors have declared that no competing financial or nonfinancial interests existed at the time of publication.

2020; Manchaiah et al., 2019). BAHAs, unlike conventional HAs, use bone conduction and typically require surgical implantation, whereas DCHDs provide nonsurgical amplification and can be obtained without a professional consultation. DCHDs include Food and Drug Administration (FDA)–approved over-the-counter (OTC) HAs, which are intended for adults with mild-to-moderate hearing loss, as well as personal sound amplification products, which amplify sounds but do not treat hearing loss. However, amid the growing diversity and use of hearing technologies, capturing HA and CI experiences remains difficult. Currently, patient opinions are primarily explored using retrospective surveys (Anthony et al., 2024; Bannon et al., 2023; Picou, 2022), but surveys are limited by components of response bias, including low response rate, recall bias, and sampling limitations (Althubaiti, 2016; Groves & Peytcheva, 2008; Wu et al., 2022).

To address survey pitfalls, researchers have begun mining data from online communities, such as digital platforms, social media, and review forums, where users can interact, share experiences, and post content. This work captures perspectives from a diverse population, offering real-time insight into their lived experiences. Social media platforms such as Facebook, Twitter (renamed X in July 2023), and Instagram are playing a growing role in sharing health-related information and influencing health decisions (Iftikhar & Abaalkhail, 2017; Thackeray et al., 2013; Zhao & Zhang, 2017). In prior studies, 90% of adolescents and approximately two thirds of adults use social media (Anderson & Jiang, 2018; Perrin, 2015). With millions of words, pictures, and videos being uploaded every day, there is a wealth of linguistic data to be captured (Kern et al., 2016). Public health researchers have developed methods to harness health-related online information for faster, cost-effective assessments of health concerns (Lane et al., 2023; Paul & Dredze, 2014; Schmidt, 2012; Widmer & Kapa, 2017). Although social media plays a growing role in shaping hearing loss treatment decisions such as hearing device selection (Feier et al., 2023; Huang et al., 2023; Saxena et al., 2015), these public health approaches have only recently been applied to the field of hearing loss with little understanding of the scope of samples, methods, and results gleaned from online communities.

Although some literature has described the promise of extracting patients' opinions about hearing devices from social media since 2013 (Noirjean & Degen, 2013), there remains a gap in understanding how to practically capture patient experiences with HAs/CIs from online forums. Existing studies vary widely in their methodology, platforms analyzed, and the depth of qualitative versus quantitative insight, making it difficult to synthesize findings or apply them to clinical or policy contexts (Choudhury et al., 2017; Williams et al., 2023). As online forum use continues to grow, especially among patients seeking peer

support and information outside of traditional health care settings, the need to systematically map how these platforms have been and could be used to understand HA and CI experiences is becoming increasingly important (Saxena et al., 2015; Southall et al., 2019). This scoping review aims to (a) comprehensively examine literature that utilizes online communities to capture the experiences of patients with HAs and CIs; (b) identify and thematize discussion types emerging from the literature (e.g., positive or negative feedback, general reflections, advice seeking); and (c) discuss limitations, implications, and future directions to guide the effective use of online patient posts in shaping and advancing audiological health care practice. This study's findings may help encourage clinicians to engage with or leverage insights from social media to better understand patients' lived experiences beyond clinical settings so that clinicians can better anticipate patients' needs, address misconceptions, and disseminate accurate information. Attention to online discussions about various topics around HA and CI decision making such as financial, self-image, and cultural factors can enhance holistic, patient-centered audiological care.

Method

A medical librarian was consulted at the inception of the review. A pilot search was performed in the Medline (PubMed) database. Additional search terms were added upon review of the initial results and input from subject experts. The following literature databases were deemed relevant to the topic: Medline (PubMed), EMBASE (Elsevier), CINAHL (EBSCOHost), PsycINFO (ProQuest), Cochrane Database of Systematic Reviews (Wiley), Cochrane Central Register of Controlled Trials (Wiley), and Scopus (Elsevier). Google Scholar was not included in the search strategy, as the selected databases provided broader functionality, reproducibility, and credibility in line with Cochrane Handbook recommendations (Higgins & Green, 2008). Each database was searched with a combination of keywords and corresponding subject headings, if applicable. All searches were limited to journal articles with available English language (whether original or translated). Reference lists and studies by authors from the included full-text article list were also screened. The final Medline (PubMed) search strategy is available in Supplemental Material S2. All references were uploaded into Covidence systematic review software for screening and data extraction (Veritas Health Innovation, n.d.). This study followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews checklist (see Supplemental Material S1), which outlines key components to promote clarity, transparency, and consistency in the conduct and presentation of scoping reviews (Tricco et al., 2018).

Study Selection

Two screeners reviewed and refined initial inclusion criteria before screening. Studies were eligible if they (a) focused on individuals with a HA, CI, BAHA, or DCHD; (b) involved an online community (e.g., social media, review forums); (c) reported outcomes based on user-generated content; and (d) were written in English. The term “users” refers to individuals engaging on platforms, not patients, and the term is not intended to depersonalize patients. Online communities were broadly defined as forums where HA/CI users share experiences and receive interaction (e.g., comments, likes). Broad criteria ensured inclusion of diverse sources. Using the Covidence systematic review software, two reviewers independently screened each article by title and abstract, voting “yes,” “no,” or “maybe.” Dual “no” votes led to exclusion, while all vote combinations that involved less than two “no” votes advanced to full-text review. Disagreements were resolved by a third reviewer voting to reach a majority at this stage. During full-text review, screeners voted for exclusion due to absence of any of the following: online forums, HA/CI focus, first-person patient experiences, or outcome data. Discrepancies were adjudicated by a third reviewer voting to reach a majority. References of included articles were hand-searched, with new articles screened using the same process.

Data Extraction

For each article, the following variables were extracted: authors, publication year, sample, methodology, results, and conclusions. In addition to key study information, screeners categorized each study according to three thematic domains: device, forum, and primary analysis. Studies could include multiple themes within a single domain, indicating that themes were not mutually exclusive (e.g., HA and CI in the device domain).

Results

Overview

Studies screened included 1,157 studies sourced from databases and registers as well as an additional 917 studies identified by searching the included authors and references of the included papers from the original 1,157 studies (see Figure 1). Of the combined 2,074 results, 322 duplicates were removed, yielding a total of 1,752 original entries for our systematic search. During the initial screening, 1,715 results (97.9%) were excluded. Of the remaining 37 articles that underwent full-text review, 16 studies (43.2%) were included (see Table 1). These papers were categorized based on the

analysis methods used: (a) manual coding of text, (b) computational text analysis, and (c) audiovisual content analysis (see Figure 2). Within the papers, these analysis methods were applied to various social media platforms, with some overlap between them.

Manual Coding of Text

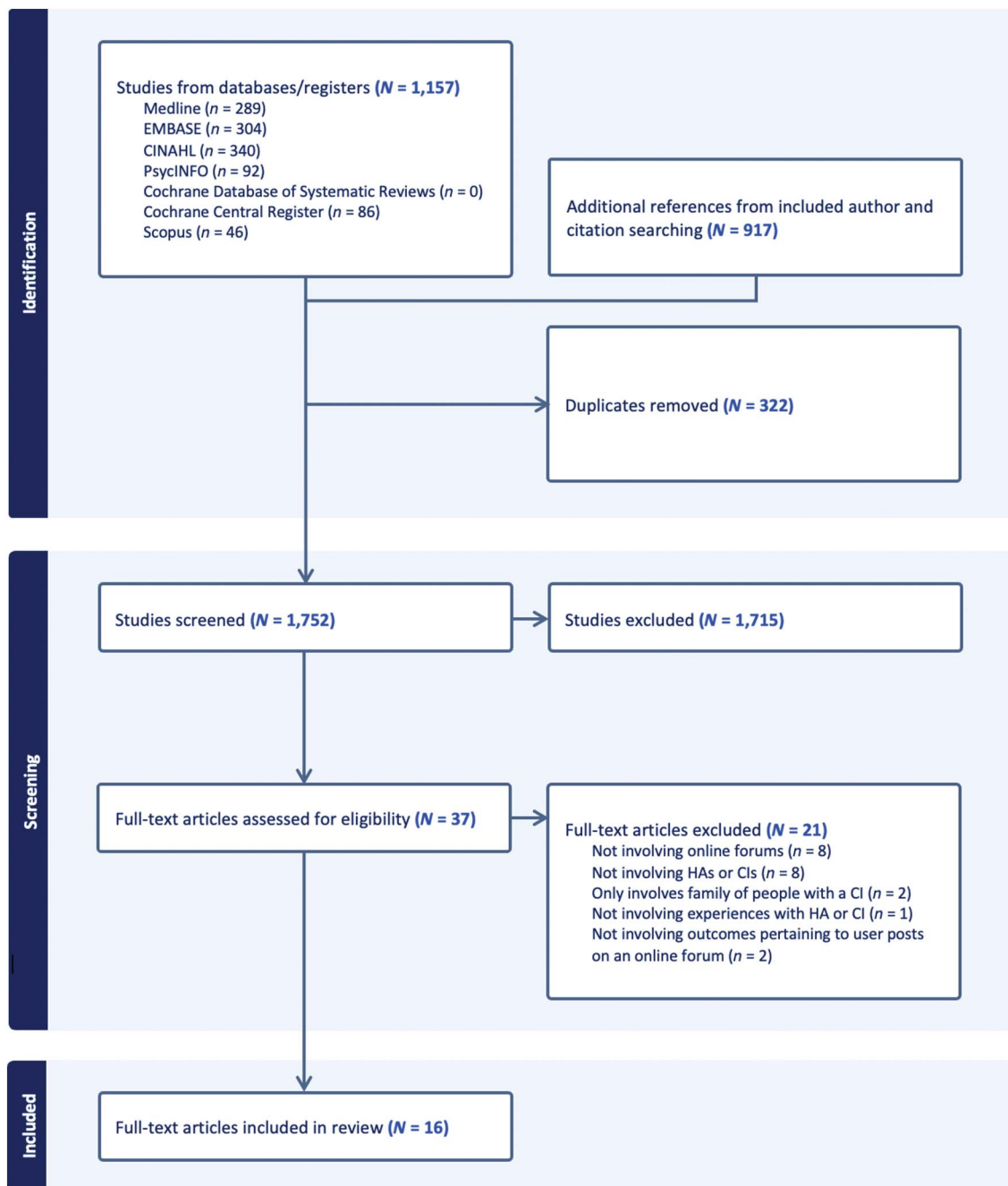
Some studies used reflexive thematic analysis to generate themes into which HA and CI user posts were categorized (Almugathwi et al., 2020; Feier et al., 2023; Heselton et al., 2022; Zabielska & Żelazowska-Sobczyk, 2019). These thematic analyses involve researchers assessing and interpreting the pattern of language and topics discussed in HA and CI user posts (e.g., social media comments) to generate themes and subthemes that capture the essence of the described user posts. Other studies involved coding manuals with predefined themes and subsequently associated posts with those themes (Choudhury et al., 2017; Profita et al., 2018, 2016; Saxena et al., 2015). Manual coding is a technique for evaluating qualitative data—nonnumerical information that captures people’s words, behaviors, experiences, or meanings—in which posts are read and labels (aka codes) are applied to the text to identify specific words, phrases, or passages that are relevant to the research question. This technique was often used as an initial step in some thematic analyses.

Facebook

Thematic analysis of 1,000 Facebook posts in a support group for patients with a BAHA revealed that the main categories of posts included seeking information and support regarding topics such as pre- and postsurgery considerations, concerns about self-image, and potential challenges related to BAHAs (Almugathwi et al., 2020). Furthermore, researchers found that users valued the online forum peer support when in-person support groups were absent. Patients with a BAHA also strongly valued reading about the lived experiences of other patients through these forums. Overall, the posts were positive, detailing how improved hearing enhanced users’ quality of life.

Profita et al. (2016, 2018) investigated 365 posts about decorative customizing of HAs and CIs on Facebook. The posts taught users how to customize their hearing devices, provided advice on which materials to use, and shared decorations others had created. These studies attributed the growth of device customization to online communities due to their ability to foster creativity and collaboration. Interviews with customizers revealed that decorating hearing devices facilitated expression of personal style, empowerment, and reduction of self-perceived stigma of wearing HAs and CIs. Seeing the positive impact of these online discussions, Profita et al. (2018) suggested that device makers could create easily customizable HA and CI devices and accessories to support self-expression.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) procedural flowchart.



Twitter

Feier et al. (2023) used thematic analysis on 19,376 posts on Twitter. Most user posts were positive (53%), 25% of which celebrated implantation success. The negative posts discussed celebrity involvement and controversy within the Deaf community regarding CIs. Despite some complaints about complications and decreased functionality,

most posts reflected positive experiences, messages of support, and optimism with CIs.

Multiple Platforms and Blogs

Saxena et al. (2015) evaluated multiple popular CI-related platforms (e.g., Facebook, Twitter, YouTube, blogs, other forums) using manual coding of text. Most CI-related

Table 1. Summary and themes of included studies.

Study	Sample	Methods	Results and conclusions	Device(s)	Forum(s)	Primary analysis
Almugathwi et al. (2020)	1,000 posts retrieved from a public United Kingdom-based Facebook support group with 270 patients with a BAHA and candidates	Google search engine was queried with terms related to BAHAs and resulted in four relevant Facebook discussion groups, of which only one was public. Reflexive thematic analysis of free-text Facebook posts about BAHAs in this discussion group was performed.	Themes included obtaining information about BAHAs, support for decision making, quality of hearing improvement, and improving quality of life. Challenges when choosing BAHA included fears of surgery and post-implantation infection. Predominantly positive BAHA posts but unclear if sample is representative.	BAHA	Facebook	Manual coding of text
Bennett et al. (2021)	1,378 online consumer HA reviews from HearingTracker	Open-source automated topic modeling software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (IRaMuTeQ) was used to identify themes in online consumer reviews. Findings were compared with quantitative review data.	Six clusters across two domains were identified. Device acquisition included (a) choosing a provider and HA pricing, (b) matching HA to hearing loss, and (c) device management. Device use included (a) smartphone streaming to HAs, (b) HA adjustment via smartphone, and (c) hearing in noise. Concerns about sampling bias since online reviewers are likely tech-savvy and younger, and no demographic data in reviews.	HA	HearingTracker customer reviews	Computational text analysis
Chen et al. (2022)	155 HA-related videos from TikTok using keyword “助听器” (i.e., “hearing aids” in Chinese) from December 2019 to March 2022	Collected video characteristics and assessed understandability/ actionability and reliability using Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-A/V) and DISCERN instruments, respectively.	TikTok videos promote HA features and purchases, with minimal risk information. Health professionals created the most content. Quality of information varied by source: Nonprofit organizations provide the highest quality, and for-profit organizations offer the lowest quality information. Patients should be cautious about HA information from TikTok.	HA	TikTok	Audiovisual content analysis

(table continues)

Table 1. (Continued).

Study	Sample	Methods	Results and conclusions	Device(s)	Forum(s)	Primary analysis
Choudhury et al. (2017)	557 social media sources from popular social media platforms, blogs, and forums in April 2015 using key phrases	Manual collection and analysis of public social media data about HAs. Selected posts above a certain threshold of engagement. Categorized posts into seven types: personal story, advice and support, information sharing, new technology, topic-based, corporate, and service provider.	HA users actively engage on social media, primarily on Twitter and Facebook, for advice, support, and service information. Volume of social media utilization is comparable between HA and CI communities. Service providers dominate HA-related content, while CI forums offer primarily community support. Social media has a growing role in hearing health education and must be adapted to patient needs.	HA	Twitter, YouTube, Facebook, blogs	Manual coding of text
Feier et al. (2023)	19,376 English-language tweets containing “cochlear implant” from 2019 to 2021	Thematic analysis on 100 most negative, 100 most positive, and 100 most “liked” tweets, ranked using Valence Aware Dictionary and Sentiment Reasoner (VADER) and tweet metadata.	Most liked tweets discussed personal experiences with CI, CI activation, and popular news topics. Negative tweets discussed media representation, controversy of cochlear implantation, and unrelated experiences while positive tweets discussed happiness and support, unrelated experiences, and hearing new sounds. Tweets were mostly positive in tone, but others highlighted ongoing challenges and stigma.	CI	Twitter	Manual coding of text
Feng et al. (2023)	95 TikTok videos found with query “cochlear implant” on October 9, 2022	Quality of TikTok videos using Global Quality Scale (GQS) and modified DISCERN tools.	Overall quality scores for the top 100 CI TikTok videos were low according to GQS and DISCERN. No videos featured hearing health care professionals. Social media offers an opportunity for clinicians to raise awareness about CIs.	CI	TikTok	Audiovisual content analysis

(table continues)

Table 1. (Continued).

Study	Sample	Methods	Results and conclusions	Device(s)	Forum(s)	Primary analysis
Heselton et al. (2022)	1378 “open-text” consumer HA reviews published from 2013 to 2019 on HearingTracker	Inductive thematic analysis of “open-text” online consumer reviews.	11 themes within three domains were identified. Clinical processes contained (a) hearing assessment and (b) HA acquisition; the device contained (a) function, (b) performance, (c) physical, (d) device management, and (e) maintenance; and the person contained (a) satisfaction, (b) quality of life, (c) personal adjustment, and (d) knowledge. Patients with an HA shared positive, negative, and neutral descriptions, which may be useful for future product development and service delivery innovation.	HA	HearingTracker customer reviews	Manual coding of text
Manchaiah et al. (2019)	11,258 unique Amazon-verified customer reviews on 62 different DCHDs during the period of September 2017 and December 2017	The quantitative analyses were conducted with the IRaMuTeQ software. Cluster analysis involved the Reinert method. Verbatim Amazon reviews were analyzed using content analysis and constant comparison methods. Each 10th review was entered into the MAXQDA 2018 software, and the reviews were coded into a code book by the two researchers.	The analysis found seven unique clusters focused on issues such as fit and comfort of the DCHD, friends and family recommendations, sound quality, customer service, and affordability. Qualitative content analysis resulted in eight main themes, including related factors, supplemental items, ease of use, support services, reasons for purchase, experiences, and general information. Quantitative analysis did not converge on a predominant theme, but qualitative analysis boiled down to sound quality, praise, and complaints regarding the DCHD.	DCHDs	Amazon customer reviews	Computational text analysis

(table continues)

Table 1. (Continued).

Study	Sample	Methods	Results and conclusions	Device(s)	Forum(s)	Primary analysis
Manchaiah et al. (2020)	100 most viewed English-language videos related to HAs on YouTube	General information, source, and popularity were extracted from each video. Content was sorted into 11 themes using a predetermined fact sheet based on guidelines from American Academy of Audiology, American Speech-Language Association, Hearing Loss Association of America, and National Institute on Deafness and Other Communication Disorders. PEMAT-A/V was used to assess understandability and actionability.	Most YouTube videos were created by health professionals. Clips from television had the most views and likes compared to consumer- and professional-created videos. Videos contained a broad range of topics related to HAs, including types, costs, benefits, and limitations. Professional-created videos have the highest understandability and actionability compared to consumer- and media-created videos.	HA	YouTube	Audiovisual content analysis
Manchaiah, Swanepoel, Bailey, et al. (2021)	1,378 free-text consumer HA reviews published 2013–2019 on HearingTracker	Automated text analysis of reviews, Linguistic Inquiry and Word Count (LIWC) searched for keywords or word stems categorized into 90 language dimensions.	Higher personal and emotional device engagement increased satisfaction, while talk of clinic visits and cost lowered it. Natural language used by consumers demonstrates perceived benefit and satisfaction.	HA	HearingTracker customer reviews	Computational text analysis
Profita et al. (2016)	365 posts from a HA and CI customization Facebook group (September to December 2015)	50 posts were reviewed to generate a coding manual with 11 themes. Coding manual was used to assign themes to all posts and images.	Community members promote wearing HAs or CIs through customizations. Customizing HA or CI compensates for limited aesthetic qualities of commercial devices, expresses one's personal style and interests, forms relationships, and manages stigma surrounding hearing loss.	HA, CI	Facebook	Manual coding of text

(table continues)

Table 1. (Continued).

Study	Sample	Methods	Results and conclusions	Device(s)	Forum(s)	Primary analysis
Profita et al. (2018)	365 posts and 10 interview transcripts from a HA and CI customization Facebook group (September to December 2015) and interviews with a panel of 10 HA and CI customizers	50 posts were reviewed to generate a coding manual with 11 themes. Coding manual was used to assign themes to all posts and images. Reflexive thematic analysis of interview transcripts and field notes performed to assign themes.	Customizing one's HA or CI compensates for limited aesthetic qualities of commercial devices, expresses one's personal style and interests, forms relationships, and manages stigma surrounding hearing loss. Individuals rely on online communities to support HA and CI customization.	HA, CI	Facebook	Manual coding of text
Rossi et al. (2023)	1,400 Instagram and 542 TikTok posts from search terms #cochlearimplant, #cochlearimplants, #cochlearimplantkids, #cochlearkids, and #cochlearfamily (March to September 2021)	Posts were subclassified into (a) media type, (b) author, (c) topic, (d) setting, (e) depiction, and (f) popularity. Non-English and posts unrelated to CI were excluded.	Patients with a CI were the most common authors of CI social media posts, followed by companies and patients' family members. Physicians and hospital/academic institution posts were less common. Topics of posts included lifestyle, advertisements, informational/educational posts, and inspirational posts. Most posts were positive, followed by neutral and negative (of which most were made postoperatively).	CI	Instagram, TikTok	Audiovisual content analysis
Saxena et al. (2015)	373 sources: 60 Facebook groups, 36 Facebook pages, 48 Twitter accounts, 121 YouTube videos, 13 forums, and 95 blogs (February 2015)	"Cochlear implant" was searched on Facebook, Twitter, and YouTube. On Google, Yahoo, and Bing, "cochlear implant" or "auditory implant" and "forum" or "blog" were queried. Websites in first 10 pages of results were included. Posts were assigned categories: (a) personal story, (b) topical information, (c) general information/support, (d) rehabilitation, (e) research, and (f) company/brand.	The internet provides an extensive set of CI communities that help patients with a CI share support, advocacy, rehabilitation information, research endeavors, and personal experiences.	CI	Facebook, Twitter, YouTube, blogs	Audiovisual content analysis, manual coding of text

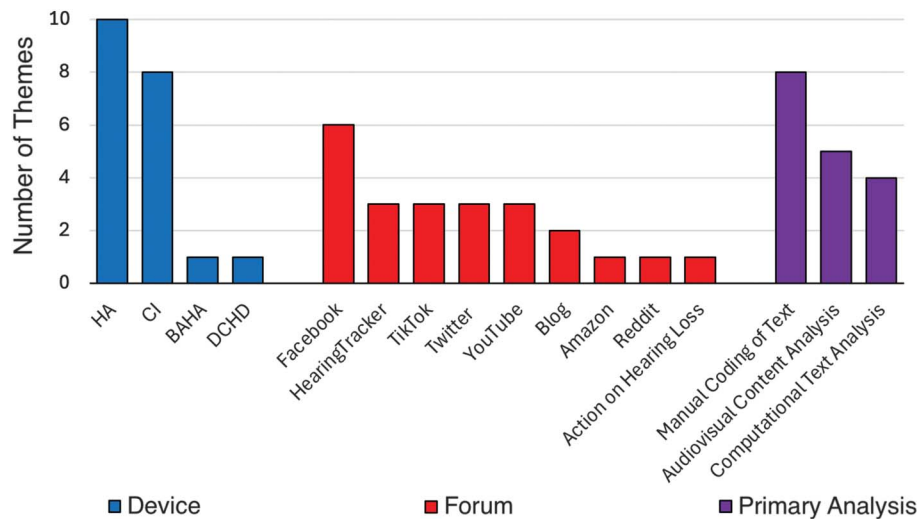
(table continues)

Table 1. (Continued).

Study	Sample	Methods	Results and conclusions	Device(s)	Forum(s)	Primary analysis
Williams et al. (2023)	987 posts from subreddit r/CochlearImplants	Used Pushshift Multithread API Wrapper (PMAW) to access Reddit API and extract posts from the r/CochlearImplants subreddit. Natural language processing using BERTopic automated topic modeling technique identified 16 topics, which was manually increased to 23 topics.	Popular topics related to CI included connectivity, considering CI, surgery-related posts, and day-to-day living. Discussions about CI brands received the highest number of comments, showing the need for greater medical support for patients choosing CI. Posts from adults considering CI and supporting CI users received many comments.	CI	Reddit	Computational text analysis
Zabielska & Żelazowska-Sobczyk (2019)	151 posts from three Action on Hearing Loss forums and two Facebook groups	Analyzed posts, identifying emotionally charged discussions through linguistic cues. Ungerer's model determined emotional content and intensity in user posts. Themes included personal experiences, advice requests, and expressions of support or opinion.	Users discuss their issues from first- or second-person perspective. Brief posts include requests for information/advice or expressions of support/anxiety while long posts include experiences. Professionals who wish to know patients' values, sources of anxiety, and presentation of anxiety inducers should read these posts.	HA, CI	Action on Hearing Loss, Facebook	Manual coding of text

Note. BAHA = bone-anchored hearing aid; HA = hearing aid; CI = cochlear implant; DCHD = direct-to-consumer hearing device.

Figure 2. Number of device, forum, and primary analysis themes of included studies. BAHA = bone-anchored hearing aid; CI = cochlear implant; DCHD = direct-to-consumer hearing device; HA = hearing aid.



Facebook groups (community spaces for user discussion) offered general information about CIs, while Facebook pages (official profiles for businesses or organizations) were split between general information and brand-specific content, with 71% of CI-related Twitter accounts and 92% of CI-related blogs being used for sharing personal CI experiences. Moreover, 77% of posts on CI-related forums (e.g., Pediatric Cochlear Implant Circle, HearingJourney) focused on CI-specific topics and questions. Similarly, Choudhury et al. (2017) studied popular HA user posts across various social media platforms (e.g., Facebook, Twitter, YouTube, blogs): Patients with an HA and their families use social media to seek information, advice, and support. Twitter accounts often advertised HA and CI products, while YouTube and Facebook posts focused on advice. Facebook pages also listed HA service providers and clinicians. They compared their findings with Saxena et al., noting that HA posts are less focused on personal experiences, possibly because HAs exhibit fewer medical risks and lower costs.

Beyond major media platforms, Heselton et al. (2022) collected 1,378 consumer reviews on HearingTracker, an online HA platform providing expert and consumer-generated reviews (HearingTracker, n.d.). Inductive thematic analysis found reviews ranging from positive to negative on device performance, management, and satisfaction. Zabielska and Żelazowska-Sobczyk (2019) analyzed Action on Hearing Loss (and Facebook groups) using a modified Ungerer's emotional inferencing system, a method developed to interpret the emotional character of news articles (Ungerer, 1997). This study found that forums are stress-free environments where patients with a CI or HA share

their perspectives and that online communities provide information about their daily lives that may benefit health professionals.

Computational Text Analysis

Unlike manual coding analyses, where humans interpret social media posts and categorize them into codes or themes, computational text analysis uses algorithms and software to process text and detect patterns, topics, sentiment, or linguistic features. Four studies employed computational text analysis of online user posts regarding HAs and CIs (Bennett et al., 2021; Manchaiah et al., 2019; Manchaiah, Swanepoel, Bailey, et al., 2021; Williams et al., 2023). Despite disparate approaches, each study illustrated complementary themes underlying user experiences with HAs and CIs.

Tools Commonly Used for Computational Text Analysis

Various automated analysis tools were used across the four studies. Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (IRaMuTeQ) is an open-source software that extracts themes from data (Ratinaud, 2025). Linguistic Inquiry and Word Count (LIWC) is a text analysis program that examines the linguistic aspects of data (Pennebaker et al., 2015). BERTopic NLP is a natural language processing topic modeling technique—based on Bidirectional Encoder Representations From Transformers (BERT) developed by Google—that identifies and creates classifications and themes from data (Grootendorst, 2022).

Amazon

Manchaiah et al. (2019) studied DCHDs and analyzed 11,258 verified Amazon reviews utilizing IRaMuTeQ with a Reinert method approach for cluster analysis (Reinert, 1983). Excluding FDA-regulated HAs and products with fewer than 10 customer reviews, 62 DCHDs were identified with costs spanning \$9.95–\$635. Clusters included fit/comfort issues, friend and family recommendations, sound quality issues, listening and conversation, general usage/customer service, and cost/affordability. Interestingly, reviews varied by DCHD price. Customer reviews of DCHDs priced between \$0 and \$50 often discussed issues with fit/comfort or sound quality and lacked discussion on cost/affordability. Customer reviews of DCHDs priced between \$201 and \$500 frequently discussed cost/affordability as well as general usage/customer service, while fit/comfort and friend and family recommendations were not often discussed.

HearingTracker

Bennett et al. (2021) employed the same IRaMuTeQ software with a Reinert approach to analyze 1,378 HearingTracker reviews. Two themes emerged: device acquisition (provider/device selection and price, device suitable for hearing loss, and fit/management) and device use (smartphone streaming, HA adjustment on smartphone, and hearing in noise). Reviews highlighted diverse user experiences throughout rehabilitation. Free-text comments often revealed device shortcomings that conflicted with positive survey responses.

Manchaiah, Swanepoel, Bailey, et al. (2021) evaluated the same 1,378 HearingTracker reviews as Bennett et al. (2021), utilizing LIWC to better understand emotional content. This revealed a negative satisfaction correlation with negative emotions and money but positive satisfaction correlation with first-person pronouns (e.g., “I,” “me”) and references to health, home, positive emotions, and social processes.

Reddit

Reddit is a social media platform where people can create text and image posts within topic-focused discussion communities called subreddits. Williams et al. (2023) studied 987 posts from Reddit users on the online r/CochlearImplants forum and created topical categorizations using BERTopic and manual coding of text. In total, 21 topics were created, and analysis illustrated the popular themes within the community. Popular topics included CI connectivity, obtaining a CI, surgery, and day-to-day living with a CI. Users most frequently commented on posts about the CI selection process, which demonstrated wide-ranging options.

Audiovisual Content Analysis

Audiovisual content analysis from platforms such as YouTube, TikTok, and Instagram involves posts that

primarily rely on photos or videos to convey their information. Thus, the five included studies using this analysis differed from the text-based content of the other two categories—manual coding of text and computational text analysis—and were grouped separately (Chen et al., 2022; Feng et al., 2023; Manchaiah et al., 2020; Rossi et al., 2023; Saxena et al., 2015).

Tools Commonly Used for Audiovisual Content Analysis

Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-A/V) is an instrument that grades audiovisual materials based on understandability and actionability (Shoemaker et al., 2014). The quality of the video as a patient education tool is rated out of 100, with a higher score denoting a more efficacious resource. DISCERN is an instrument consisting of 15 questions and a quality rating (scored out of 5) used by researchers to assess the validity and quality of health-related videos (Charnock et al., 1999). The Global Quality Scale (GQS) is a 5-point scale used to evaluate websites based on factors such as quality, flow, relevance of information, and usefulness to patients (Bernard et al., 2007).

TikTok and Instagram

Chen et al. (2022) studied a sample of 155 TikTok videos in China and found that most videos about HAs were created by health professionals and for-profit organizations, names of which were not listed in the paper. As a result, the topics of focus included HA features, purchasing, fitting, and maintenance. Science communicators, general users, and nonprofit organizations posted fewer videos. PEMAT-A/V and DISCERN analyses found that videos published by health professionals and nonprofit organizations exhibited higher quality than those published by for-profit organizations.

Similarly, Feng et al. (2023) reviewed 95 English-language TikTok videos related to CIs. Videos were evenly distributed across all age groups. Posters were predominantly patients with a CI or parents of pediatric patients with a CI (93.7%). A small percentage of videos were posted by health care professionals (none of whom were otolaryngologists or audiologists) and organizations. Nearly half of the videos discussed personal experiences of CI users, and about one quarter of them focused on educating viewers about CIs and the Deaf community. These TikTok videos were found to have low GQS and DISCERN tool scores. It was hypothesized that the absence of sources in the anecdotal posts contributed to these lower scores on quality assessment.

Rossi et al. (2023) used manual coding on images and videos in 1,400 Instagram posts and 542 TikTok videos. These posts were primarily from patients with a CI, companies,

and patient families. Only a handful of posts (1.1%) were made by health care professionals and organizations. The four main categories of topics found in both TikTok and Instagram were lifestyle, advertisements, information/education, and inspiration. Over 90% of advertisements and educational posts were from Instagram. Regarding the emotional character of these posts, 53.5% were positive, 41.9% were neutral, and 3.7% were negative.

YouTube

Manchaiah et al. (2020) evaluated the top 100 English-language videos related to HAs on YouTube. Of these videos, the majority were created by professionals (e.g., physicians) and the media (e.g., news outlets), but a small proportion were from consumers. These videos provided information on various kinds of HAs and their maintenance. The content of consumer videos primarily included information about hearing loss, navigating the process of HA acquisition, and personal experiences. Professional and media-generated videos focused on HA types and general information. Using PEMAT-A/V, the authors found that videos made by professionals had higher understandability and actionability scores, while media-based videos received more likes and engagement.

Additionally, Saxena et al. (2015) found that most YouTube videos were personal CI stories, followed by activation videos. Moreover, the top 10% of videos accounted for 91% of total views.

Discussion

This scoping review aims to map existing literature about online communities, providing a novel approach to exploring and analyzing patient experiences with HAs and CIs that conventional research methods may overlook. Among the 16 studies meeting inclusion criteria, three primary analytic approaches were performed: (a) manual coding and thematic analysis, (b) computational text analysis, and (c) audiovisual content analysis. Thematic analyses revealed that patients with a CI or HA used social media to seek support, share lived experiences, and express personal identity through device customization. Computational methods further quantified user sentiment and identified thematic clusters related to device acquisition, use, and satisfaction, particularly across platforms such as Reddit, Amazon, and HearingTracker. Audiovisual content analyses, primarily on TikTok and Instagram, demonstrated variable educational quality, with higher quality content more frequently produced by health care professionals and nonprofit organizations.

Comparing Content Platforms

Various online forums exist for hearing health or HAs and CIs specifically (HearingTracker, n.d.; Tinnitus

Hub, n.d.). Along with popular platforms (e.g., Reddit, Facebook) that host online HA/CI communities, there are forums dedicated solely to patients with a CI or HA. For instance, HearingTracker hosts an independent HA review forum that allows patients to post and compare reviews to choose the right HA for them (HearingTracker, n.d.). The Lexie Hearing database consists of data about patients who purchased OTC HAs from Lexie Lumen online and use their app for performing hearing tests and customizing environment settings (hearX Group, n.d.). Additionally, researchers have aimed to create an online platform to improve communication between patients with CI and their families with providers (Marinac et al., 2018).

Broadly, both text-based (Facebook, X, blogs, and forums) and video-based platforms (TikTok, Instagram, and YouTube) demonstrate that posts related to everyday HA/CI experiences are the most common. Due to the nature of text-based platforms more easily fostering groups, such as those on Facebook (Almugathwi et al., 2020; Profita et al., 2018, 2016; Saxena et al., 2015; Zabielska & Żelazowska-Sobczyk, 2019), there is more space for forming community and talking about personal experiences within the subgroups. Additionally, there is a focus on analyzing the quality of medical information when it comes to video-based platforms as opposed to text-based platforms. This may partly be due to how video scoring tools are organized (such as PEMAT-A/V, DISCERN, and GQS), but videos may also make it easier to digest new information about HAs/CIs compared to text. Thus, we also see a substantial number of posts related to educational content in the video format compared to text-based platforms.

Value of Personal Experience

Health care professionals are well trained to inform patients about care and complications, but many have not had personal experience with hearing devices. Almugathwi et al. (2020) describe thematic analysis of presurgery information seeking and postsurgery support, finding that people wanted to supplement professional advice with current advice for patients with a BAHA. While health care professionals can reassure patients with data that the risks are low to dispel those fears, interacting with others who have similar medical experiences may allow them to feel more supported (McFarland et al., 2021). Additionally, consumer reviews can be helpful for patients who are unsure about obtaining hearing devices, since they can be expensive and have unique features (Manchaiah et al., 2019; Williams et al., 2023). Heselton et al. (2022) notes that there are often new HAs being developed due to rapid technological advances, so it can be difficult for health care professionals and prospective HA users to keep up with finding the best device for them. Bennett et al. (2021)

builds upon this, suggesting that consumer reviews can help patients choose their preferred device by offering individualized information on physical fitting, smartphone streaming, and matching the level of hearing loss. Thus, patients can use social media to help them decide on a cost-effective, personalized device.

Role of Health Care Professionals on Social Media

While this review focused on patients with a CI or HA, many studies about YouTube and TikTok videos included posts involving health care professionals. Chen et al. (2022) and Manchaiah et al. (2020) used PEMAT-A/V on TikTok and YouTube, respectively, and found that videos made by health care professionals had the highest scores for reliability and actionability. Health care professionals and organizations may use social media to share accurate information about CIs/HAs to supplement patient experiences and to correct misinformation (Choudhury et al., 2017).

Health care professionals may also use social media to better understand and improve patients' experiences. For example, the power of hearing device decoration described by Profita et al. (2016, 2018) is one nonmedical avenue of making a positive impact on patient experience and confidence that the provider might not think to discuss during a patient visit. Reading consumer reviews can inform providers about device cost, smartphone streaming, and sound quality—all of which are important to the patient's experience (Bennett et al., 2021; Heselton et al., 2022; Manchaiah et al., 2019; Manchaiah, Swanepoel, Bailey, et al., 2021). Additionally, health care professionals can use knowledge from Feier et al. (2023) about patients with CI receiving disapproval from the Deaf community to understand areas where they can counsel patients and obtain greater cultural understanding. However, health care professionals may not have sufficient time to browse social media in depth.

Lowering Barriers to Health Information

As health care professionals increasingly engage with social media, they have an opportunity to improve access to accurate medical information—especially for patients who lack access to a provider and cannot receive personalized advice through clinic visits, calls, or messages (Feng et al., 2023). Additionally, device costs were commonly discussed on Reddit, Amazon reviews, and HearingTracker reviews (Bennett et al., 2021; Manchaiah et al., 2019; Manchaiah, Swanepoel, Bailey, et al., 2021; Williams et al., 2023). Readily available online information allows individuals to learn about devices that match their needs in price and quality. However, it is important to guide patients in verifying online information credibility through reliable sources or professional advice.

Improving Self-Confidence

The widespread usage of social media may inform individuals and destigmatize hearing loss. As Profita et al. (2016, 2018) showed, the Facebook community about personalizing HAs and CIs through decoration led to improved self-perception and confidence. Additionally, with millions of views amassed by TikTok and YouTube videos (Feng et al., 2023; Manchaiah et al., 2020; Saxena et al., 2015), people without a HA or CI may gain insight into the lives of individuals with hearing loss that potentially contributes to destigmatization (Carlson et al., 2023).

Almugathwi et al. (2020) revealed similar findings with BAHAs: Users shared concerns regarding appearance and self-image on forums involving both new and experienced patients with a BAHA. These stories can be encouraging to individuals who might share similar concerns, especially during decision making. (Almugathwi et al., 2020) While fear may be common during hearing device decision making, online communities offer an anonymous space to share fears and help patients improve self-confidence by reading how others overcame similar emotions (Almugathwi et al., 2020).

Differences Between HA and CI Experiences on Social Media

As with Saxena et al. (2015) and Choudhury et al. (2017), the distribution of content varied across multiple social media platforms depending on CIs or HAs. Choudhury et al. note a smaller percentage of posts related to personal stories for HAs compared to CIs, and they partially attribute it to the medically complex nature of CIs. This idea has merit because many posts for CIs are about the surgical procedure itself and medical complications (Saxena et al., 2015; Williams et al., 2023; Zabielska & Żelazowska-Sobczyk, 2019), whereas many posts for HAs are related to general advice and service providers (Bennett et al., 2021; Chen et al., 2022; Choudhury et al., 2017; Manchaiah et al., 2020). Additionally, Almugathwi et al. (2020) showed that BAHA-related posts largely focused on pre- and postsurgical experiences, supporting the idea that surgical factors may contribute to prospective patients sharing or seeking personal experiences.

Related Work

Several analytical approaches did not meet inclusion criteria for this scoping review but were related. Some studies involved surveys of people's use of the internet (Barak & Sadosky, 2008; Simpson, Clarke, et al., 2018; Thorén et al., 2013), and some used online forums for survey distribution (Knoetze et al., 2024; Mothemela et al., 2023). Other studies leveraged online resources for hearing health

interventions (Malmberg et al., 2018; Paglialonga et al., 2018) and telemonitoring (Soares & de Almeida, 2023). Rather than from patients, some work on online information from providers and corporations analyzed content, stigma, and accessibility (Champlin et al., 2024; Simpson, Le, & Malicka, 2018; Thomas et al., 2021). Additionally, some studies about online communities centered around families of CI users (Huang et al., 2023; Scharp et al., 2018) or people identifying as Deaf or hard of hearing that included some discussion without specific hearing devices (Crowson et al., 2018; Shoham & Heber, 2012). Rather than reviews of hearing devices, one study assessed consumer reviews of hearing health care clinics (Manchaiah, Swanepoel, & Bennett, 2021).

Ethical Considerations

Conducting research using online community data on HAs and CIs requires consideration of informed consent, privacy, and minimizing harm (Conway, 2014; Gliniecka, 2023; McKee, 2013). Although online posts are publicly accessible, users often do not anticipate their content being used for research (Stommel & de Rijk, 2021). Researchers should consider user expectations, potential identifiability, and community impact. Maintaining anonymity, avoiding direct quotes, and preventing cross-platform identification are essential privacy safeguards (Benton et al., 2017; Gliniecka, 2023). Researchers must also consider how findings (especially when highlighting dissatisfaction) might unintentionally reinforce stigma, influence decision making, or alter community dynamics (David & Werner, 2016). Study findings should preserve individual dignity and reflect the complexity of patient experiences (Stevie et al., 2019). While online communities offer valuable insight into patient experiences, the potential for misinformation or miscommunication from nonexpert sources may be harmful. Ethical research should therefore balance the benefits of patient expression with the need to contextualize and clarify potentially misleading content. In summary, ethical research should respect community autonomy, minimize harm, and contribute meaningfully to understanding patient experiences with hearing technologies (Fiesler et al., 2024; Proferes et al., 2021).

Limitations

This scoping review exhibits some limitations. Some relevant studies and gray literature might not have been captured, despite our broad search and screening of 1,752 unique results. Additionally, subjective judgment during screening and thematic categorization may have introduced bias, but we accounted for this by performing initial screening and full-text review independently with two reviewers

and adjudication for discrepancies. Moreover, the inclusion criteria were intentionally broad to capture diverse internet sources, allowing for heterogeneity in platform types and study quality. The inclusion criteria were also restricted to English-language manuscripts. Consequently, included studies predominantly evaluated social media content in English, omitting potentially valuable information and insight from non-English posts. Furthermore, although there was some overlap between analysis themes such as using a computational approach to select posts for thematic analysis (Feier et al., 2023), we chose the primary analysis that best informed the conclusions of each study. Included studies involved communities solely of people with HAs/CIs or combined with more general populations (e.g., people with hearing loss) that also included the target population, which might make findings difficult to generalize. However, there is a strong precedent for leveraging data from online communities with more general populations and filtering for only those posts relevant to the subject of interest (Saxena et al., 2015). More generally, unstructured social media data could be viewed as unreliable for capturing patient experiences, but many studies have highlighted the public health utility of social media data (Correia et al., 2020; Giorgi et al., 2024, 2022; Lane et al., 2023; Levanti et al., 2023; Murray et al., 2024).

Implications and Future Directions

Several studies examining the use of social media to understand patient experiences with hearing devices have been limited by their scope, for example, by analyzing only the top 100 English-language YouTube videos. This restriction has prevented capturing the full range of patient experiences. Given the infeasibility of conducting extensive analyses manually, future research should integrate manual and computational methods to create larger, more representative data sets that yield in-depth, actionable insights. Currently, analyzing social media data for patient experiences necessitates specialized knowledge of various platforms and advanced analytical techniques. Therefore, subsequent efforts should focus on developing methodologies that are more accessible to clinicians, researchers, and innovators, facilitating broader participation in studying patient perspectives.

Furthermore, investigating health care professionals' perceptions of social media could reveal critical insights into physician–patient relationships. It would be valuable to understand health care providers' motivations behind their use or avoidance of social media and whether their posts positively impact patient engagement and comfort. Additionally, quantitative studies examining the role of social media in patients' decision-making processes regarding hearing device purchases could enhance marketing strategies and patient education. Comparative studies evaluating patient perceptions of health information reliability versus established metrics such as

DISCERN or PEMAT-A/V would further elucidate gaps between patient trust and content quality. Exploring patients' perceptions and preferences regarding video-based versus text-based platforms, search engines, or direct medical provider consultations for obtaining health information would help optimize communication strategies. Research into the comparative effectiveness of online versus in-person support groups could also inform best practices in patient support. Finally, assessing whether social media reduces barriers to health information access and aids patients in managing stigma or discrimination related to hearing loss could substantially improve patient outcomes and well-being.

Conclusions

This scoping review identified three main analytic approaches for extracting HA and CI user experiences from online communities, each with unique insights. Manual coding revealed emotional narratives, computational methods scaled sentiment and usage patterns, and audiovisual analysis assessed educational content and dissemination. The range and richness of online discussions highlight how users increasingly rely on digital platforms for support and decision making when offline communities are limited or inaccessible. These findings emphasize social media's role as a valuable extension of patient support, with potential to inform clinical care, device design, and public health. Future research should standardize analytic techniques and explore ethical integration of patient-generated content into hearing health care.

Data Availability Statement

Data include research works publicly available online.

Acknowledgments

This article is published Open Access under a read and publish agreement between Vanderbilt University and the American Speech-Language-Hearing Association.

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