

Social Media Utilization in the Cochlear Implant Community

Rajeev C. Saxena, BSE;¹ Ashton E. Lehmann, MD;² A. Ed Hight, MS;² Keith Darrow, PhD;^{2,3}
 Aaron Remenschneider, MD, MPH;² Elliott D. Kozin, MD;² Daniel J. Lee, MD²

¹Tufts University School of Medicine, Boston, MA ²Massachusetts Eye and Ear Infirmary, Boston, MA ³Worcester State University, Worcester, MA

ABSTRACT

Background: Over 200,000 individuals worldwide have received a cochlear implant (CI). Social media websites may provide a paramedical community for those who possess or are interested in a CI. The utilization patterns of social media by the CI community, however, have not been thoroughly investigated.

Purpose: Investigate participation of the CI community in social media websites.

Research Design: A systematic survey was conducted of online CI-related social media sources. Using standard search engines, the search terms “cochlear implant,” “auditory implant,” “forum,” and “blog” identified relevant social media platforms and websites. Social media participation was quantified by indices of membership and posts.

Study Sample: Social media sources included Facebook, Twitter, YouTube, blogs, and online forums. Each source was assigned one of six functional categories based on its description.

Data Collection and Analysis: All online searches were conducted in Feb. 2014. Total counts of each CI-related social media source were summed, and descriptive statistics were calculated.

Results: Over 350 sources were identified, including 60 Facebook groups, 36 Facebook pages, and 48 Twitter accounts, 121 YouTube videos, 13 forums, and 95 blogs. The most active online communities were Twitter accounts, which totaled 35,577 members, and Facebook groups, which totaled 17,971 members. CI users participated in Facebook groups primarily for general information/support (68%). Online forums were the next most active online communities by membership. The largest forum contained approximately 9,500 topics with about 127,000 posts. CI users primarily shared personal stories through blogs (92%), Twitter (71%), and YouTube (62%).

Conclusions: The CI community engages in the use of a wide range of online social media sources. The CI community utilizes social media for support, advocacy, rehabilitation information, research endeavors, and sharing of personal experiences. Future studies are needed to investigate how social media websites may be harnessed to improve patient-provider relationships and potentially used to augment patient education.

CONTACT

Rajeev C. Saxena
 Tufts University School of Medicine
 Email: rajeev.saxena@tufts.edu

INTRODUCTION

Over 200,000 individuals worldwide have received a cochlear implant (CI). Population growth in CI users in the past decade has coincided with an extensive evolution of Internet-based communication patterns, including that of social media. While audiologists and otolaryngologists have traditionally played the primary role in patient education and counseling, the internet is fundamentally changing the patient-provider relationship.¹

In light of the popularity of social media, it is important as medical providers to understand the type of health care information available online. To our knowledge, no previous study has investigated the utilization of social media in the CI community. The role of social media has been studied in ophthalmology, oncology, and psychiatry, but not yet in this specialized community.²

Herein, we aim to:

- (1) Investigate how the CI community shares and exchanges information through social media
- (2) Quantify the utilization of these online sources

METHODS AND MATERIALS

▪ Identification of Social Media Platforms & Websites
 The reviewed sources are indicated in Figure 1 (middle column). “Cochlear implant” was entered as the search term in platforms; “cochlear implant” or “auditory implant” and “forum” were entered to search websites.

Platforms:

- Inclusion criteria: communication centered on CIs as specified by title or description or communication pertaining to a specific CI manufacturer
- Exclusion criteria based on activity: <10 members in a Facebook group, <10 “likes” for a Facebook page, <10 followers of a Twitter account, and <100 views of a YouTube video

Websites:

- Inclusion criteria: returned within the first 10 pages of results and either a forum centered on CIs as specified by title or description or a blog
- Exclusion criteria: institutional websites, research websites, and non-English language sources

▪ Activity on Social Media Platforms and Websites
 Activity was defined by # members of a Facebook group, # “likes” for a Facebook page, # Tweets and followers of a Twitter account, and # views of a YouTube video.

▪ Utilization Categorization

Each source identified from the above searches was assigned to one of six functional categories (Table 1).

Category	Definition	Example
Personal story	Content is generated by or about an individual	• YouTube video about an individual's CI activation
Topic	Communication is centered on a specific topic or question	• Online forum in which conversation is organized in threads titled with a question
General information	Communication is for general information, education, or support	• Facebook page for parents of children with CIs
Rehabilitation	Communication on speech, language, music rehabilitation	• Twitter account about music rehabilitation
Scientific research	Communication is CI-focused and managed by a scientific institution or group	• Facebook page of a scientific laboratory
Company	Communication is managed by a company or content is specific to a CI brand	• Forums sponsored by a medical device company

Table 1. Functional categories Applied to Social Media Sources

RESULTS

- Survey of social media demonstrates >350 CI-related communities
- Content of websites varies based on type of social media
 - Of 60 CI-related Facebook groups identified, 67% offered general information and support related to CI use (Fig. 2)
 - Facebook pages were utilized for many diverse purposes
 - Twitter, Youtube, and blogs were mainly used for personal stories
 - Online forums were designed around specialty topics
- Twitter is most actively utilized by cochlear implant manufacturers
 - 48 CI-related Twitter accounts amassed 35,577 followers
 - The most followed Twitter accounts included Cochlear America's US account, CochlearImplantOnline, and Advanced Bionics
- YouTube videos demonstrate the highest level of activity among social media and are predominately related to implant activations
 - 121 CI-related YouTube videos amassed >36 million views
 - Most popular implant activation had >20 million views
- Cochlear implant forums encompass numerous topics
 - With nearly 2,700 members, Pediatric Cochlear Implant Circle was the largest forum
 - With >9,500 topics and ~127,000 posts, the HearingJourney forum demonstrated the greatest activity

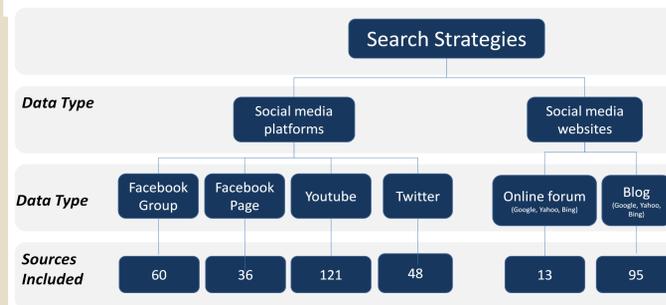


Figure 1. Social media sources included in review

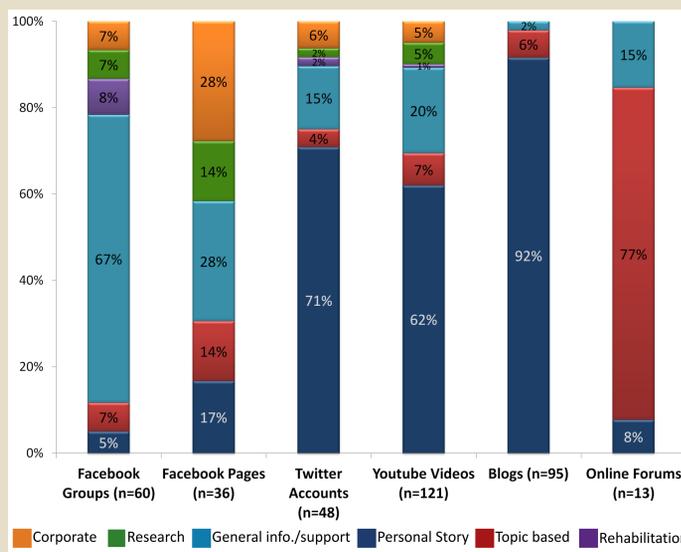


Figure 2. Comparing utilization patterns across different social media sources

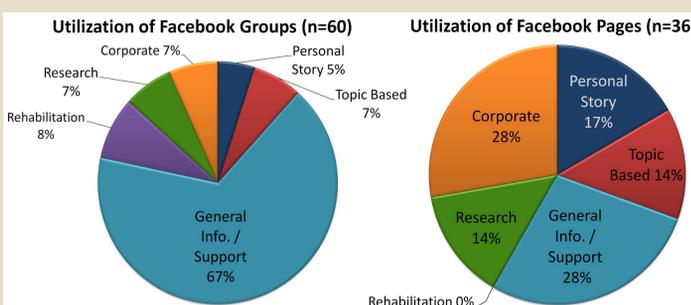


Figure 3. Facebook Utilization Patterns in the Cochlear Implant Community

DISCUSSION

- Our survey reveals a dynamic CI community that engages in a variety of social media sources.
 - Social media platforms and websites create an instantaneous community with all of the potential benefits of peer-to-peer interaction that was not possible as recently as 10 years ago.
- Our data demonstrate that the CI community online is highly diversified and fragmented:
 - No singular site or group serves as the central platform or “voice.” CI manufacturers have attempted to become focal points, hosting online forums and maintaining a strong presence in social media.
- CochlearTM is the most active company. This information may be helpful to clinicians in anticipating what device-related corporate information is most encountered online.
- Social platforms have distinct utilities in the CI community:
 - CI blogs are ideal for patients and families that want to learn more about an individual's experience with a CI.
 - Facebook provides a strong support system in the CI community. If a patient has a question or wants to connect with a CI group, we recommend Facebook.
 - Similar to Facebook, message boards also facilitate specific questions in a community setting.
 - YouTube provides a host of CI activation videos that may provide information as to what a patient and a patient's family may expect during device activation.
 - Twitter is limited in nature. At this time, we do not see direct utility of pointing patients to Twitter.

CONCLUSIONS

The CI community utilizes a wide range of social media sources to access and share information for multiple purposes, including education, support, rehabilitation information, research endeavors, and sharing of personal experiences. Awareness of the presence and extent of CI-related content on social media provides clinicians and researchers better insight into patients' sources of information and support.

Knowledge of social media may enable clinicians to help connect their patients to supportive paramedical communities, may help clinicians provide more focused education, and may serve as a starting point to recognize and address unmet needs in the CI community. Future studies are needed to investigate how social media websites may be harnessed to improve patient-provider relationships and augment patient education.

REFERENCES

1. Steehler, K., Steehler, M., Pierce, M., & Harley, E. (2013). Social media's role in otolaryngology-head and neck surgery: informing clinicians, empowering patients. *Otolaryngol Head Neck Surg*, 149(4), 521-524.
2. McGregor, F., Somner, J., Bourne, R., Munn-Giddings, C., Shah, P., & Cross, V. (2014). Social media use by patients with glaucoma: what can we learn? *Ophthalmic Physiol Opt*, 34(1), 46-52.