



Published in final edited form as:

J Am Acad Audiol. 2015 February ; 26(2): 197–204. doi:10.3766/jaaa.26.2.8.

Social Media Utilization in the Cochlear Implant Community

Rajeev C. Saxena^{*}, Ashton E. Lehmann[†], A. Ed Hight[‡], Keith Darrow^{‡,§}, Aaron Remenschneider[‡], Elliott D. Kozin[‡], and Daniel J. Lee[‡]

^{*}Department of Otolaryngology, Tufts University School of Medicine, Boston, MA

[†]Department of Otology and Laryngology, Harvard Medical School, Boston, MA

[‡]Department of Otolaryngology – Head and Neck Surgery, Massachusetts Eye and Ear Infirmary, Boston, MA

[§]Department of Communication Sciences and Disorders, Worcester State University, Worcester, MA

Abstract

Background—More than 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—The purpose of this study was to investigate participation of the CI community in social media Websites.

Research Design—We conducted a systematic survey 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.

Intervention—No intervention was performed.

Data Collection and Analysis—We conducted all online searches in February 2014. Total counts of each CI-related social media source were summed, and descriptive statistics were calculated.

Results—More than 350 sources were identified, including 60 Facebook groups, 36 Facebook pages, 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 roughly 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 uses 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.

Keywords

Cochlear implant; social media; Facebook; blog; otolaryngology

INTRODUCTION

More than 200,000 individuals worldwide have received a cochlear implant (CI) (NIDCD, 2013). As the age range and indications for CIs broaden, the population of CI users is rapidly growing (Russell et al, 2013). 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 (ComScore, 2011). Although audiologists and otolaryngologists have traditionally played the primary and often sole role in patient education and counseling regarding CIs, the Internet is fundamentally changing the patient-provider relationship. As a result of new communication patterns online, CI users and individuals interested in obtaining a CI may increasingly look to social media for medical information and as a complementary paramedical community.

The Internet has shifted from static Web pages, providing the unidirectional flow of information from site owners to readers into dynamic pages, which are dedicated to bidirectional communication and the generation of multiparty content (Adams, 2010; Kietzmann et al, 2011). This shift in online communication has been met with the growth of social media Websites designed for this bidirectional flow of information. A multitude of mobile and Web-based technologies, commonly referred to as *social media*, now offers interactive platforms through which individuals and communities can co-create, share, discuss, or modify user-generated content (Grajales, et al, 2014; Kietzmann et al, 2011).

Social media available to CI users include large platforms such as Facebook, Twitter, and YouTube. For example, popular CI activation videos on YouTube provide a glimpse into both CI technology and personal medical stories. Among social media Websites, smaller-scale channels for communication exist in the form of online forums and blogs (Grajales et al, 2014). CI manufacturers have sponsored a few forums, including Cochlear Community (Cochlear), HearPeers (MED-EL), and HearingJourney (Advanced Bionics), which are often organized by topic to facilitate a question-and-answer method of interaction. Blogs are traditionally maintained by a single individual and offer a diverse array of options for posts and commentary to generate and share content (Adams, 2010).

In light of the booming popularity of social media, it is important for medical providers to understand the type of information related to health care available online. Social media

provide opportunities to address patient expectations, offer education, receive feedback, and communicate on topics that may appeal to a wider audience of patients and families (Steehler et al, 2013). The role of social media in health care and the patient experience has been studied in the oncology (Dizon et al, 2012; Simmons et al, 2014; West, 2013) and psychiatry literature (Afsar, 2013; Landoll et al, 2013; Livingston et al, 2014). Moreover, to CI users and individuals considering CIs, social media provides an abundance of information concerning the CI placement operation, brand options, and life after implantation. Furthermore, social media enables an instantaneous real-time connection with CI users. Rather than traditional phone or e-mail conversations that are potentially communications between two individuals, social media enables communication directly to groups of individuals.

To our knowledge, no previous study has investigated the utilization of social media by the CI community, which we define as individuals who already possess a CI or are interested in a CI, as well as those individuals' friends and family members. Herein, we aim to (1) investigate how the CI community shares and exchanges information through social media and (2) quantify the utilization of these online sources.

METHODS

Institutional review board approval was obtained from the Massachusetts Eye and Ear Infirmary Human Studies Committee. To survey online social media, we used the systematic approach detailed below. As analysis of social media is still in its infancy in health care, and especially in otolaryngology, we drew from studies in other disciplines for the methodological basis of our study, notably a study by McGregor et al (2014), which investigated the use of social media by patients with glaucoma. All online searches were conducted in February 2014.

Identification of Social Media Platforms

Social media platforms reviewed in this study included Facebook groups, Facebook pages, Twitter accounts, and YouTube videos. The search term *cochlear implant* was entered within each listed platform. The inclusion criteria for sources returned in these searches consisted of (1) communication centered on CIs as specified by *cochlear implant* or *CI* in the title or description of the social media Website or (2) communication pertaining to a specific CI manufacturer as specified by *Cochlear*, *MED-EL*, or *Advanced Bionics* in the title or description. Exclusion criteria were based on activity level of the source: (1) less than 10 members in a Facebook group, (2) less than 10 "likes" for a Facebook page, (3) less than 10 followers of a Twitter account, and (4) less than 100 views of a YouTube video. As this type of study has not been previously performed, we chose these criteria to maximize analysis of popular Websites, those which a CI community member may reasonably encounter online.

Identification of Social Media Websites

In addition to the social media platforms listed above, social media Websites consisting of blogs and online forums were also reviewed. On the standard search engines of Google,

RESULTS

Survey of Social Media Demonstrates Numerous CI-Related Social Media Communities on the Internet

More than 350 CI-related social media sources were identified (Fig. 1). Of large social media platforms, 60 Facebook groups, 36 Facebook pages, 48 Twitter accounts, and 121 YouTube videos met inclusion criteria. In terms of social media Websites, 13 online forums and 95 blogs met inclusion criteria.

Facebook Is a Predominant Social Media Platform for the CI Community

The 60 CI-related Facebook groups identified together amassed nearly 18,000 members. Facebook groups were nearly evenly distributed between closed-access groups (53%) and open-access groups (47%) with no significant difference in access ($p=0.10$). Of the reviewed CI-related Facebook groups, the top 10% of groups by membership ($n = 6$ groups) accounted for 57% of all CI-related Facebook group members. The two groups with the highest membership were “Cochlear Implant Experiences” and “Parents of Children with Cochlear Implants” with 3,232 and 2,390 members, respectively.

The 36 CI-related Facebook pages identified had a total of 89,329 “likes,” a value equivalent to the number of aggregate subscribers. Of the CI-related Facebook pages reviewed, the top 10% of Facebook pages in order of the number of “likes” received ($n = 4$ pages) accounted for 71% of the total number of “likes.” These top four consisted of the Cochlear India, Cochlear US & Canada, Cochlear Implant, and Cochlear Asia Pacific page.

Twitter Is Dominated by Accounts of CI Manufacturers

The 48 CI-related Twitter accounts identified amassed a total of 35,577 aggregate followers. Of the CI-related Twitter accounts identified, the top 10% of Twitter accounts as based on the number of followers ($n = 5$ accounts) made up 38% of the total number of followers. The most followed Twitter accounts included the Cochlear America @Cochlear US account, the Cochlear Implant Online account, and the Advanced Bionics account. An estimated 71% of the Twitter accounts were used for personal stories (Fig. 2).

YouTube Videos Demonstrate the Highest Level of Activity among Social Media and Are Predominately Related to Implant Activations

The 121 CI-related YouTube videos identified together amassed a total of more than 36 million views. Of the CI-related YouTube videos included, the top 10% of videos by number of views ($n=12$ videos) accounted for 91% of the total number of views. The most popular video at the time of review had more than 20 million views.

CI Forums Encompass Numerous Topics

Because of the differences among the 13 CI-related online forums identified, a universal metric of activity to compare across these forums was not available. With nearly 2,700 members, the Pediatric Cochlear Implant Circle forum appeared to be the largest forum based on the number of members. With more than 9,500 topics and ~127,000 posts, the forum HearingJourney demonstrated the greatest activity. Because of the heterogeneity of

blog formats in the 95 CI-related blogs identified, a standardized metric for activity was not available.

Content of Websites Varies Based on the Type of Social Media

Of the 60 CI-related Facebook groups identified, 67% offered general information and support related to CI use (Fig. 3). The 36 Facebook pages identified were used for many diverse purposes, and equal proportions of these pages were used for general information/support (28%) and company/brand discussions (28%). Given these findings, Facebook pages are currently the most frequently used social media source for company/brand discussion.

The majority of Twitter accounts (71%) and YouTube videos (62%) identified were primarily used for sharing CI-related personal stories. CI activation videos made up 41% of the included YouTube videos. CI-related forums most often hosted discussions centered on specific topics and questions related to CI use (77%). Of the 95 CI-related blogs identified, 92% were used for sharing personal stories (Fig. 4).

DISCUSSION

Our study of CI-related social media engagement is the first such study to investigate how and to what extent individuals with CIs and those who are interested in CIs use social media to share and obtain CI-related information. Our data demonstrate that the Internet currently provides an extensive CI-related paramedical community, which can offer connection, support, information, and discussion. Facebook appears to be a predominant and robust social media platform for the CI community. In particular, Facebook groups were the most frequently used of all social media sources for discussion of speech, language, music rehabilitation, research endeavors, and CI brand options.

In addition to Facebook, numerous CI-related mentions on YouTube, Twitter, blogs, and online forums demonstrate a strong online presence of the CI community. The popularity of uploaded videos of CI activations on YouTube highlights how social media can capture and share a significant medical and technological experience with an extensive community of interested individuals. As with CI-related YouTube videos, posts on Twitter and online forums tend to be limited in terms of the functional categories encompassed. CI-related Twitter accounts tend to be dominated by CI manufacturers and have nearly double the number of followers as CI-related Facebook pages. Despite the industry presence on Twitter, the majority of Twitter posts (71%) concerns personal stories. In terms of CI-related blogs, these Websites typically represent a medium for individuals to share their personal experiences regularly. Individual bloggers may add links on their blogs to other blogs, thereby creating a CI-related “blogosphere,” or a network of CI-related content generated by interlinked members of this community. Online forums tend to be set up as question-and-answer venues organized by topic, through which inquiring members of the CI community can pose questions about CI use.

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.” This fragmentation may be reflective of the diverse patient population or simply the result of the nature of social media,

which provides all individuals with the ability to post messages and form groups. In many respects, the CI manufacturers have attempted to become focal points for the community, hosting online forums and maintaining a strong presence in social media sources. Of the three major device companies, Cochlear has the most active presence in social media. This information may be helpful to clinicians in anticipating what device-related corporate information is most encountered online through social media.

Several lessons may be gleaned from our survey to help guide clinicians. First, there is a strong online presence of CI users and individuals interested in CIs who engage with a variety of different social media sources. These 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 few as 10 yr ago. Social media sources host discussions ranging from selection of device manufactures and the implant operation to CI activation and hearing after implantation. Although the study was not designed to quantify posts from individual users, there are clearly cohorts of vocal “veteran” CI users and newly implanted CI users who host and maintain these social media Websites. In many respects, veteran CI users provide mentorship for individuals and families considering CIs.

In terms of utility of current sites, CI blogs are ideal for patients and their families who want to learn more about an individual’s experience with cochlear implantation. Many of these blogs describe in detail the medical evaluation for a CI to postimplantation. Facebook is a strong source for communication with groups of individuals 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 allow for questions in a community setting. Message boards have the added benefit of anonymity; however, they appear less popular than Facebook. 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. Finally, Twitter is limited in nature. At this time, we do not see direct utility of pointing patients toward Twitter. Clinicians should be aware that patients might come to the office with mixed expectations given close-hand knowledge of other individuals’ experiences as ascertained from social media.

Second, unlike vetted static Web pages written and often peer-reviewed by medical professionals, such as WebMD or UpToDate, social media allows for individual interaction, which may or may not result in the communication of accurate medical information. It is important for clinicians to know that the CI community may receive detailed yet rarely vetted medical advice online on a host of CI-related topics. This concern, however, should not greatly detract from the potential for patients to find a supportive and often reassuring community through social media. Finally, individuals posting messages online are quite diverse, ranging from parents of infants with CIs to octogenarians with CIs. In order to connect patients with additional resources, it may be useful for clinicians to recommend specific social media sites or active individuals online who appear trustworthy and a good match for patients from different backgrounds.

Our study also raises questions about the biomedical ethics regarding social media. On the topic of CIs, social media meets at the intersection of private medical information, business,

and technology. Given the popularity of these Websites and platforms, should clinicians be intimately familiar with them? Should clinicians provide corrections to misinformation? Should clinicians advertise through these sites or solicit individuals for research? Finally, how does social media function differently from standard patient support groups that meet in person? These questions are difficult to answer and require further consideration beyond the scope of this study. As is evident from our study, social media Websites and platforms are highly used by the CI community and are unlikely to be replaced anytime soon. Therefore, regardless of the answers to these specific questions, clinicians should be acutely aware that social media act as a paramedical community through which patients may now receive highly detailed medical advice outside the traditional walls of the clinic.

Although limited, a few studies in the literature have investigated social media utilization in regards to specific patient populations. Most of the available studies demonstrate that patient focus is based on the particular medical issue. For example, McGregor et al (2014) found glaucoma patients' engagement in social media most commonly involved discussions of treatment, health care experience, promotional material, and support. The observed difference in topics between patients with glaucoma and the CI community demonstrates the flexibility of social media content to be driven by the community generating and subscribing to it. Thus, social media content is shaped by discrete diagnoses or patient experiences.

Our study had several limitations. Quantification of a system as dynamic as the Internet is fraught with difficulty: within a matter of hours to days, a new Website or group may emerge and rapidly transform the social media landscape. Our search was limited, as we could not quantify every CI-related social media site on the Internet. Furthermore, we did not collect data on sites that were excluded for review. We recognize that this may have introduced bias into our study. Nevertheless, our study does provide a meaningful and contemporary estimate of what an individual in the CI community may find online within social media platforms and Websites. Additionally, some platforms and Websites had "closed-access" memberships, and thus, the content of these sites could not be investigated in the present assessment and could not be easily accessed by many members of the CI community. Finally, engagement in social media is certainly not limited to CI users. Posts or visits made by non-CI users were purposefully included, as these individuals were considered contributory to the CI-related social media community.

CONCLUSIONS

The CI community uses a wide range of social media sources to access and share information for multiple purposes, including support, advocacy, 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. This 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 potentially used to augment patient education.

Abbreviations

CI cochlear implant

References

- Adams SA. Revisiting the online health information reliability debate in the wake of “web 2.0”: an inter-disciplinary literature and website review. *Int J Med Inform.* 2010; 79(6):391–400.10.1016/j.ijmedinf.2010.01.006 [PubMed: 20188623]
- Afsar B. The relation between Internet and social media use and the demographic and clinical parameters, quality of life, depression, cognitive function and sleep quality in hemodialysis patients: social media and hemodialysis. *Gen Hosp Psychiatry.* 2013; 35(6):625–630. [PubMed: 23948575]
- ComScore. Social report: Facebook leading, microblogging growing, world connecting. 2011.
- Dizon DS, Graham D, Thompson MA, et al. Practical guidance: the use of socialmedia in oncology practice. *J Oncol Pract.* 2012; 8(5):e114–e124. [PubMed: 23277774]
- Gold J, Pedrana AE, Sacks-Davis R, et al. A systematic examination of the use of online social networking sites for sexual health promotion. *BMC Public Health.* 2011; 11:583. [PubMed: 21777470]
- Grajales FJ 3rd, Sheps S, Ho K, Novak-Lauscher H, Eysenbach G. Social media: a review and tutorial of applications in medicine and health care. *J Med Internet Res.* 2014; 16(2):e13.10.2196/jmir.2912 [PubMed: 24518354]
- Kietzmann JH, Hermkens K, McCarthy IP, Silvestre BS. Social media? Get serious! Understanding the functional building blocks of social media. *Bus Horiz.* 2011; 54(3):241–251.
- Landoll RR, LaGreca AM, Lai BS. Aversive Peer Experiences on Social Networking Sites: Development of the Social Networking-Peer Experiences Questionnaire (SN-PEQ). *J Res Adolesc.* 2013; 23(4):695–705.
- Livingston JD, Cianfrone M, Korf-Uzan K, Coniglio C. Another time point, a different story: one year effects of a social media intervention on the attitudes of young people towards mental health issues. *Soc Psychiatry Psychiatr Epidemiol.* 2014; 49(6):985–990. [PubMed: 24401914]
- McGregor F, Somner JE, Bourne RR, Munn-Giddings C, Shah P, Cross V. Social media use by patients with glaucoma: what can we learn? *Ophthalmic Physiol Opt.* 2014; 34(1):46–52. [PubMed: 24325434]
- Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. *J Med Internet Res.* 2013; 15(4):e85. [PubMed: 23615206]
- NIDCD. Cochlear Implants. 2013. <http://www.nidcd.nih.gov/health/hearing/pages/coch.aspx>
- Russell JL, Pine HS, Young DL. Pediatric cochlear implantation: expanding applications and outcomes. *Pediatr Clin North Am.* 2013; 60(4):841–863. [PubMed: 23905823]
- Simmons C, Rajmohan Y, Poonja Z, Adilman R. Social media in cancer care: opportunities to improve care in locally advanced breast cancer. *Curr Opin Support Palliat Care.* 2014; 8(1):77–82. [PubMed: 24270751]
- Steehler KR, Steehler MK, Pierce ML, Harley EH. Social media’s role in otolaryngology-head and neck surgery: informing clinicians, empowering patients. *Otolaryngol Head Neck Surg.* 2013; 149(4):521–524. [PubMed: 23959818]
- West HJ. Practicing in partnership with Dr. Google: the growing effect of social media in oncology practice and research. *Oncologist.* 2013; 18(7):780–782. [PubMed: 23814045]

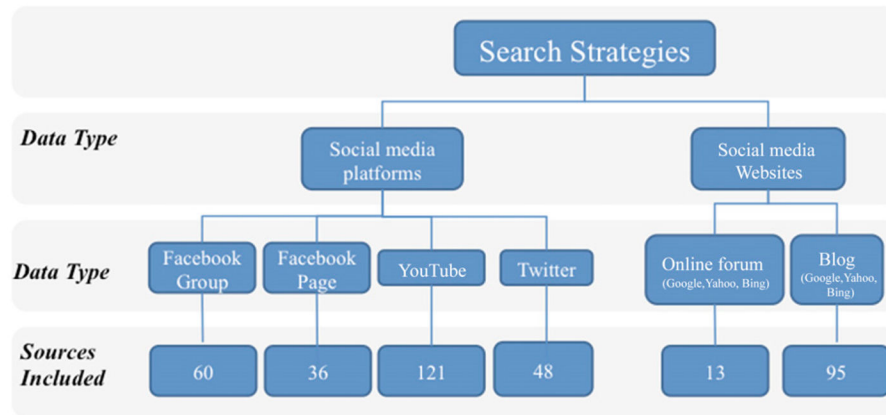


Figure 1. Social media Websites meeting inclusion criteria.

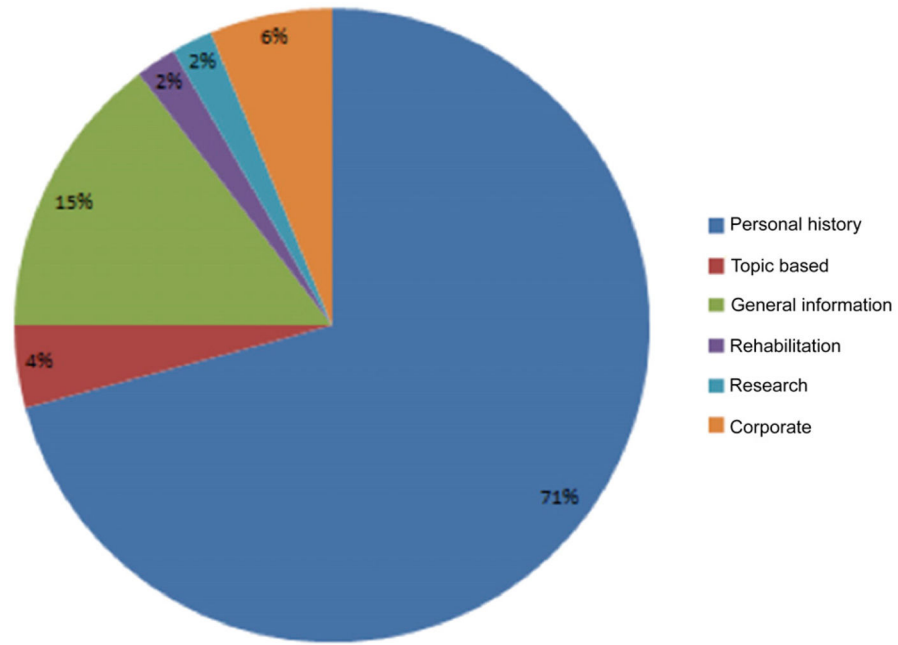


Figure 2. Twitter utilization patterns in the CI community. N = 48.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

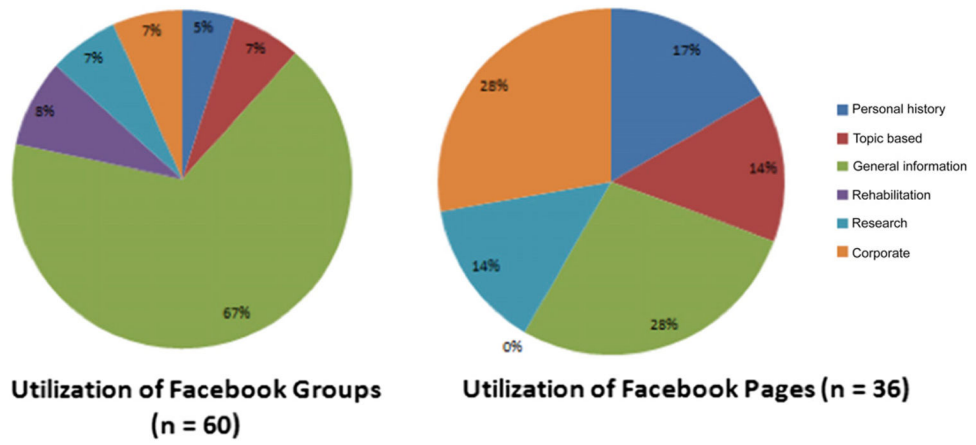


Figure 3. Facebook utilization patterns in the CI community.

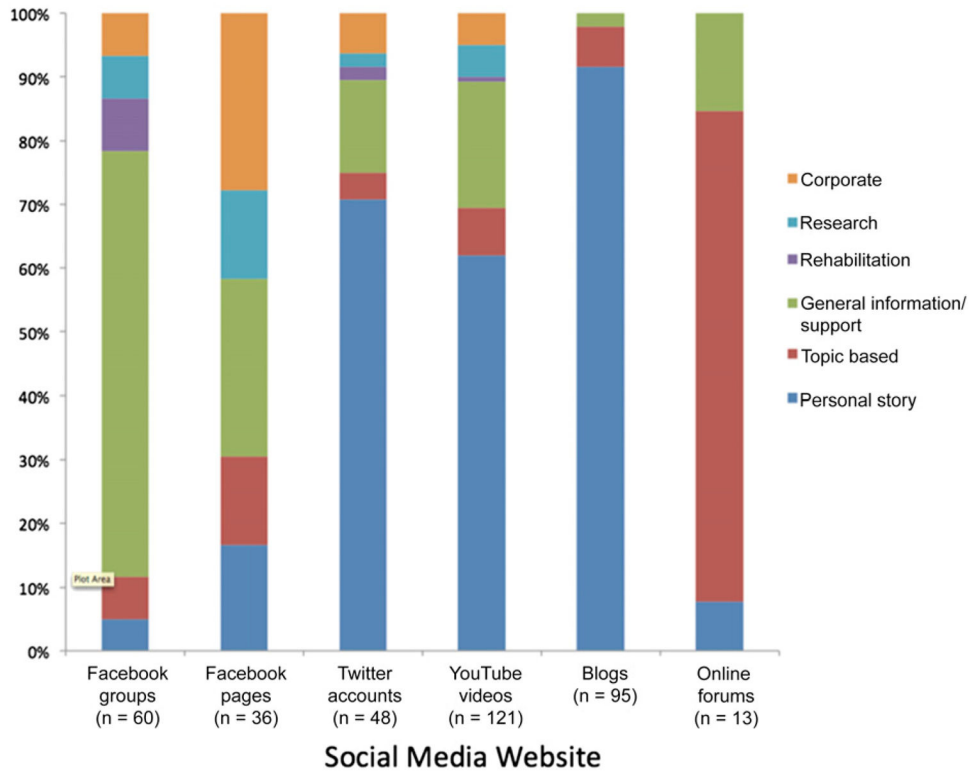


Figure 4. Utilization patterns across different social media platforms in the CI community.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1

Functional Categories Applied to Social Media Sources

Category	Definition	Examples
Personal Story	Content is generated by an individual or about an individual	<ul style="list-style-type: none"> • Blog or Twitter account telling an individual's CI story • YouTube video about an individual's CI activation
Topic	Communication is centered on a specific topic or question	<ul style="list-style-type: none"> • Online forum in which conversation is organized in threads titled with a question • Facebook page about a specialty topic such as fashion accessories for CIs
General Information/Support	Communication is for general information, education, or support	<ul style="list-style-type: none"> • Facebook page for parents of children with CIs • Twitter account about educational resources for CI users
Rehabilitation	Communication is focused on speech, language, or music rehabilitation	<ul style="list-style-type: none"> • Facebook group about CI daily rehabilitation • Twitter account about music rehabilitation for CI users
Scientific Research	Communication is CI-focused and managed by a scientific institution or group	<ul style="list-style-type: none"> • Facebook page of a laboratory specializing in CI research • YouTube video by a research group showing advances in CI technology
Company/Brand	Communication is managed by a company or content is specific to a CI brand	<ul style="list-style-type: none"> • Forums or Twitter accounts sponsored by a medical device company • YouTube video by medical device company of how a CI works