



Challenges and Opportunities in Social Media Research in Gastroenterology

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Abstract

In recent years, social media has transformed how we as gastroenterologists communicate with each other and has grown into an arena of knowledge and peer support for patients. Gastroenterologists commonly use social media for education networking, patient populations use social media for peer support and advocacy, but little is known about how gastroenterologists can use social media to conduct thoughtful and rigorous patient-centered research. Therefore, we aim to introduce the scope of social media research, highlight prominent examples in gastroenterology, and review innovative opportunities and unique challenges to using and studying social media for research.

Keywords Internet · Social media · Methods · Patient communication · Ethics

Introduction

Over the last decade, the rapid growth and influence of social media have permeated academic medicine and changed how we as physicians connect with colleagues, patients, and healthcare organizations. In gastroenterology, social media platforms such as Facebook, Twitter, LinkedIn, YouTube, Instagram, and Pinterest have become widely popular arenas for professional development, networking, disseminating education, and patient engagement [1, 2]. With the rise of social media in academic medicine, several online GI communities (#GITwitter, #LiverTwitter, @MondayNightIBD, @ScopingSundays, #TracingTuesday) have become popular sources of communication and engagement for trainees and junior faculty [3–7]. Simultaneously, patients seek out ubiquitous online resources for education, advocacy, and peer support via these same social media platforms, online health forums, and advocacy group sites [8]. As this virtual

space becomes pervasive and inescapable in our professional spheres, it raises questions of if, when, and how we should and can harness social media as a mechanism to conduct rigorous and meaningful research, including in the field of gastroenterology. In the wake of the recent controversial study on social media content of vascular surgery trainees and the #MedBikini backlash [9], how can we take a step back to ensure that our work is well-motivated, ethically sound, and rigorous in design and execution?

Opportunities and Strengths

Social media research includes any research using data from social media sources and/or social networking sites (e.g., Facebook), blogs (e.g., Twitter, Reddit, Wordpress), content communities (e.g., Instagram, YouTube), and collaborative projects (e.g., Wikipedia). Social media can be leveraged as both an effective tool to collect data in the form of online surveys and polls or as the research subject when the content or the activity of social media is under study. As social media and the internet offer a rich source of data and a valuable means of conducting research, there are many noteworthy strengths that these platforms offer.

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Diversity of Study Designs

Given the diverse forms of data, social media data lend itself to various study designs and research methodologies. User demographics (age group, gender, geographic location), volume (number of retweets or views, followers, rates of interaction), and keyword content or hashtags from posts can be collected for retrospective or prospective quantitative analysis to examine social media use and the potential impact of online social support. Extraction of internet and social media data, or web scraping, can be performed manually or via automated tools such as a software program or browser extension. To conduct patient-focused research, various platforms can be used to conveniently deliver and facilitate surveys, online polls, interviews, and focus groups [10]. To date, social media interactions have been used to conduct multiple randomized control trials on the use of social media on self-management behaviors such as diet and exercise, immunization, and smoking cessation [11–14]. Qualitative approaches include using virtual ethnography to study online communities and thematic analysis of text content or images can be used to understand perspectives and attitudes, semantics, and the effects of online social or peer support [15]. For example, to gain patient insights on inflammatory bowel disease knowledge and treatments, Martinez et al. identified 1,598 posts from Twitter and electronic forums and performed a qualitative analysis to identify prominent themes around risks and/or benefits of the use of biologics [15].

Participant Recruitment

Adopting the Internet as a medium through which to target a diverse sampling pool, social media offers advantages to broaden subject recruitment. Particularly in the study of rare diseases or specific populations (e.g., subspecialty providers and caregivers of patients), social media may allow the researcher access to numerous potential participants without geographic limitations. Snowball sampling whereby study subjects can recruit other participants can be easily deployed via social media through reposts or retweets to enrich the sample. We have used this approach to recruit adult patients and caregivers of pediatric patients with eosinophilic esophagitis (EoE) and other rare eosinophilic gastrointestinal disorders to describe barriers to care, treatment preferences, and perspectives on shared decision making. Recruitment via disease-focused Facebook groups allowed us to reach considerably greater responses than in-person single-center recruitment would have permitted [16, 17]. Social media can also be an

effective means to recruit and communicate with cohort members as in the case of the Autoimmune Hepatitis Research Network, in which Facebook advertisements were used to invite patients to complete epidemiologic surveys and collect saliva DNA to study the genetic and environmental risks of AIH [18].

Organic or “Naturally Occurring” Data

With the rise of online health and peer support communities, social media outlets can be valuable sources of unfiltered, user-generated data. Rarely created for the purpose of research, social media content can be an untapped source of “organic” data. Advantages to mining these existing sources include reducing participant burden, researcher bias, and participant recall bias. As this content is publicly available and easily accessible to many, collection and analysis of real time data can be faster and more affordable compared to acquiring large datasets. Digital analytics programs such as Google Analytics can be used to collect information on social media use/habits, including site traffic, user demographics, interactions, and online conversations. In their study of reproductive health and medication concerns of IBD patients, Keller et al. utilized a social media data mining service to index online content from patients and caregivers from over 3000 social media sites and health forums for qualitative content analysis [19].

Patient Engagement and Communication in Research

At the heart of patient-centered research is understanding relationships between multiple stakeholders in the health-care system to communicate with and engage patients. Using social media, researchers can form efficient collaborations with patient groups to learn about timely and relevant patient healthcare needs and concerns. As physicians are increasingly using social media for networking and staying up to date in their clinical practices, patients and caregivers are doing the same to seek peer support and education. Partnering with patients and patient advocacy groups (PAGs) can open the doors for community-based participatory research methods and increase patient engagement in research. Additionally, PAGs can be involved as research partners, not only to help with patient recruitment, but also with study design, research protocol review, and generating relevant and patient-focused research questions [20, 21]. A microcosm of social media in gastroenterology research is IBD Partners, a collaborative research network of over 15,000 patients with inflammatory bowel disease (IBD). Together with researchers, patients within this online community interact with researchers by proposing and discussing research ideas, completing surveys, reporting disease-related outcomes,

referring friends to the network as “citizen scientists” [22, 23]. Through these collaborations, IBD Partners have conducted patient-centered survey studies on medication adherence and utilization, dietary patterns, quality of life, decision making, social media use and preferences, and created a IBD-specific quality of life patient-reported outcome evaluation [10, 24–28]. This success has served as a catalyst for the development of EGID Partners for eosinophilic gastrointestinal diseases and PSC Partners for primary sclerosing cholangitis. Patient-reported diagnoses on these platforms have also been validated to be accurate, providing the foundation for the validity of this type of research [29, 30].

Challenges and Pitfalls

For similar reasons that social media data offer new opportunities and strengths, social media research presents potential challenges in reliability and ethical considerations. As always, rigorous research methods are necessary to direct meaningful findings.

Noise

Although social media is a rich data source, a potential downside to such abundance is noise, or excess meaningless information, which can make the true signal difficult to detect and compromise the reliability of the findings. Careful selection of the appropriate social media data source can improve the quality of the results. Similarly, care should be taken to screen out information from bots and organizational accounts (e.g., businesses, pharmaceutical companies), which can distort the dataset. Techniques to filter out or remove noise in social media data collection are unique challenges and an area of future investigation.

Generalizability

Although social media can allow for more diverse participant recruitment, data from these platforms may not be representative of all populations. As of 2019, 72% of the American public uses at least one type of social media with the large majority of use in those < 65 years old (90% use in ages 18–29, 82% use in ages 30–49, 62% in ages 50–64), but with nearly uniform use across all race, gender, and income groups [31]. While social media research may not be generalizable to older adults, it can be leveraged to access prevalent users, especially for those whom social media is a primary form of communication. For example, in the wake of actor Chadwick Boseman’s untimely death from colon cancer, colon cancer awareness dominated social media, a medium which could be used to study the uptake of the new screening guidelines in the 45–50-year age-group [32]. In diseases more prevalent in younger people, such as eosinophilic esophagitis and IBD, social media is commonly used and a powerful tool to study patient communication and support, concerns about treatment, and chronic disease management. Leveraging the popularity of social media among IBD patients, an ethnographic study of 14 IBD online communities identified themes of personal appearance, symptoms and disease severity, humor, self-efficacy, and need for awareness [33]. However, since social media data exist across broad social cultural spectrums on the Internet, where users differ by age (e.g., Facebook versus Twitter users), language (e.g., Weibo versus Twitter users), and geography, the findings of online research should also be validated with offline approaches and potential sources of bias should be considered when examining this data (Table 1) [34].

Table 1 Potential sources of bias in social media research

	Example
Self-selection bias	Online survey participants Sampling criteria include characteristics of the data (e.g., including only posts with a specific hashtag)
Participant bias	Subjects are aware of the researchers’ presence during chatroom communication Perception of privacy may affect how or what users share online Subjects by definition have access to internet and a connected device
Behavioral bias	Participants from different populations have a tendency to emphasize certain topics (e.g., patients in rural areas may express challenges in access to care versus those in urban settings struggle with care fragmentation from too many provider choices) How people find and use social media are affected by differences in their needs and interests (e.g., disease severity or prior positive/negative experiences impacting social media sharing)
Temporal bias	Data collected from different periods of time may affect social media use, certain populations, or interactions (e.g., social media use or concerns during the COVID-19 global pandemic)

Ethical Considerations

As the traditional guiding principles for research ethics should continue to inform our work, using social media data for research creates new ethical challenges, particularly with informed consent and threats to privacy [35]. These concerns largely arise from the question of whether social media data are public and universal information or private and subject to protections. Buried deep within our pervasive online world and social media outlets are the terms and conditions that we subconsciously agree to, including how third parties access and use this information. In this sense, one could argue that social media and its data are considered the public domain and fair play for researchers, especially on open social media sites (e.g., Twitter, TikTok, YouTube) and social media monitoring is a commonly used tactic for market researchers, businesses, and organizations to learn more about their consumers and improve products. In a similar vein, social listening, or auditing social media conversations can be viewed as exploratory fieldwork and offer advantages over traditional surveys, but can also be perceived as invasive or unwelcomed in case of sensitive topics. Social media users may assume or expect the shield of privacy when engaging on online settings particularly if a login, password, permission granted by a moderator is required to join (e.g., private Facebook group, LinkedIn, virtual health communities). As a general rule of thumb, researchers interested in using social media data should consult their institutional review boards and carefully consider these ethical considerations prior to embarking on social media research.

As a tenet of clinical research, informed consent involves guiding a competent subject through the study-related information, risks and benefits, potential harms, the right to withdraw, and voluntary participation. For social media research, informed consent emerges as a complex challenge as data from participants can be collected without the user's direct knowledge. The authors recommend that online data may be analyzed without consent only if the data are publically archived, access is not prohibited by the site and does not require a password and does not include highly sensitive content. Even with these precautions, all measures should be taken to collect the bare minimum of personal information as possible. For all other research conducted online or via social media, we recommend that consent is obtained in both observational and interactive studies. When consent is obtained for social media research, the researcher should take caution not to disrupt any online interactions between participants and obtain assent in the case of pediatric or adolescent participants. In the case of interactive social media research, contacting the group moderator or administrator is crucial

to determine the feasibility of the study and establishing transparency as a researcher.

In other forms of clinical research and trials, great care is taken to guarantee subject anonymity often to avoid sources of bias. Depending on the data source, anonymity cannot be guaranteed on social media and nuanced challenges in maintaining participant privacy depend on the particular platform. For example, Twitter requires that all Tweet texts must be displayed with the author's username without modification [36]. When appropriate, social media sources ought to be cited according to standard citation style guides. While aggregate data may be anonymized, because platforms often archive data and metadata, direct quotes can be de-anonymized and tracked to the corresponding participant or author. Alternatively, the risk of participant identification can be reduced by rewording or paraphrasing the content, but at the cost of methodologic rigor and potentially presenting inaccurate data. Additional threats to participant privacy include disclosure of personal identification or protected health information and external access by non-study participants.

Conclusion

As the use of social media continues to expand and infiltrate our personal, professional, and clinical lives, now is the time to examine ways to cautiously approach this resource as a mechanism to enhance patient-centered research. A ubiquitous presence, social media offers valuable opportunities for various study designs, diverse recruitment, and unique collaborations. In gastroenterology, social media has already proven to be a powerful and innovative tool to discover valuable patient-reported insights in the care of IBD and EoE. With the birth of several partnerships between gastroenterology and hepatology researchers, physicians, and patients, social media offers opportunities for participatory research, allows us to hear unspoken patient experiences, holds promise to break communication and geographic barriers for study recruitment. However, as social media research is still in its nascent stages, we must be mindful of the potential challenges and pitfalls in order to conduct and interpret useful and rigorous studies.

Key Messages

- Advantages of using social media to conduct clinical research include applying various quantitative and qualitative study designs, recruiting diverse study participants, and forming partnerships with patients in participatory research approaches.

- When using social media for research, one should take caution to avoid the potential pitfalls by screening out noise and addressing reliability and ethical issues such as consent and anonymity.
- The early use and study of social media within gastroenterology have gained novel and valuable patient-reported insights.

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Declarations

Conflict of interest JWC declares no potential conflicts of interest related to this paper. Dr. Chang has received consulting fees from Takeda. ESD declares no potential conflicts of interest related to this paper. Dr. Dellon has received research funding from Adare, Allakos, GSK, Meritage, Miraca, Nutricia, Celgene/Receptos, Regeneron, Shire/Takeda and has received consulting fees from Abbott, Adare, Aimmune, Allakos, Arena, AstraZeneca, Biorasi, Calypso, Celgene/Receptos, Eli Lilly, EsoCap, GSK, Gossamer Bio, Regeneron, Robarts, Salix, Shire/Takeda, and educational grants from Allakos, Banner, and Holoclara. None of the other co-authors report any relevant disclosures or potential conflicts of interest.

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