Ethical Considerations When Using Social Media for Research

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Because of its adaptation across age groups and populations, social media is being used as a venue for the conduction of research studies. The implications for use of social media to streamline data collection and analyses to understand epidemiologic effects of disease are intriguing. Public access to personalized Internet-based searches and conversations for patients with or at risk for cancer can potentially allow providers to target individuals for earlier interventions and improved outcomes. Although publicly posted, the use of personal information to solicit research participants, implement interventions, or abstract information for research studies raises questions regarding maintaining the ethical conduct of research.

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About 25% of the 7.5 billion people on the planet use social media (Chaffey, 2017). To put this number into perspective, today's social media users outnumber the entirety of the planet's population in 1900. Specific to the United States, about 80% of the population uses social media, which has become a rich platform for research data. Social media includes the contribution of materials posted on the Internet by public consumers that is accessible to others, such as that posted to Facebook, Twitter, LinkedIn, and numerous other platforms (Casañas, Comabella, & Wanat, 2015). Using posted data from social media sites for research has led to the creation of the terms *infodemiology*, which is evaluation of Internet-based health data, and *infoveillance*, which is surveillance of Internet use (Bragazzi, Dini, Toletone, Brigo, & Durando, 2016). Social media is also used frequently as a venue to solicit research participants and contribute to interventions. With the amount of data generated daily through social media, the potential to answer research questions that would take considerably longer through traditional means is tremendous. From an ethical lens, what does use of social media mean in terms of confidentiality, biased samples, and equality? In addition, what are the implications for the translation of social media–based findings to oncology healthcare practices?

Confidentiality

In health care, confidentiality pertains to patients' rights to prevent the sharing of clinical or health information (Harman, Flite, & Bond, 2012). When using data from social media, confidentiality is often maintained when large-scale infodemiologic studies are conducted. For example, the Internet has provided a means to globally track infectious disease outbreaks and pandemic situations (Bragazzi et al., 2016; Freifeld, Mandl, Reis, & Brownstein, 2008). One resource, HealthMap (www.healthmap.org), uses algorithms that process posted information to search for media and World Health Organization postings about disease outbreaks and maps them geographically (Freifeld et al., 2008). This type of data collection and evaluation is global, public, and informative without compromising individual health information. Other platforms, such as online social networks that patients may use as a forum for information and/or support, can also track how many individuals are affected and where they are located (Bragazzi et al., 2016). Without the participants' knowledge, contributing to a social media conversation can place them into a research study that they may have declined if approached by the research team.

Another example is the use of posts on Twitter to conduct quantitative and qualitative content analyses. Qualitatively, words, phrases,

and underlying meanings of the content are analyzed for themes (Hamad, Savundranayagam, Holmes, Kinsella, & Johnson, 2016) like they would be from transcribed interviews. One challenge is interpretation of shorthand terms posted, which can have multiple meanings (Weeg et al., 2015). Quantitatively, variables of interest can be put into numeric form and analyzed. In traditional research, potential study participants would be approached, introduced to the study, proceed through the informed consent process, and agree to provide the information for the purposes of the study. Gathering posted information on social media bypasses all of these steps, including the individual's knowledge that his or her information is being used for research purposes. Under the tenets of ethics, this is questionable. However, those posting information do so knowing it is an open public forum; therefore, researchers may conclude that consent is implied for the use of the postings for any purpose. Regardless, such conclusions are questionable.

Biased Samples and Equality

Social media is becoming a frequent venue for recruiting research participants of all ages. The notion that older adults are less likely to use social media is shifting as these "silver surfers" adapt to the technology (Casañas et al., 2015). With the largest percentage of patients with cancer being aged older than 65 years (Howlander et al., 2016), the use of social media is feasible for oncology research studies that include this age group. Advantages of using social media for recruitment are that it is much more far-reaching than the geographic parameters of an in-person study, the timing is at the convenience of the (potential) participant without having to coordinate schedules, and it is more economic (Casañas et al., 2015).

There may be variability, however, in the study information reaching individuals within the study population of interest, particularly those with limited or no Internet access (Morrissey, Kinderman, Pontin, Tai, & Schwannauer, 2016). In addition, self-selection may bias the sample, possibly to a greater degree than a potential participant being approached by a member of the study team (Morrissey et al., 2016). Self-selection is inherent in Internet-based studies and is dependent on the geographic location of the targeted study sample, access to the Internet, use of social media platforms (e.g., Facebook, Twitter) by the researchers, and potential participants' search and/or interest in the health condition under study. Researchers can also target specific individuals through their own networks and ask participants to share the study information to those networks, creating a snowball sampling effect. As with all studies, it is important to remember to disclose sampling bias when disseminating findings. If the targeted population is one that predominately has robust Internet access with a high use of social media, such as within the United States, studies may reach a more representative sample of the target population than traditional methods of recruiting. With the pace at which social media is becoming a mainstream research tool, it may soon be a traditional approach.

Data Sharing

The Internet has been a source of health information for consumers for more than two decades. Differentiating accurate information from misinformation has been challenging for healthcare professionals whose patients may seek treatments based on unreliable information found on the Internet. However, the Internet has also become a platform for providing robust discussions within and between

researcher and clinician groups (O'Leary, Zaheer, Redmond, & Corrigan, 2016). Conducting literature searches using the Internet also saves time; historically, searches were done through hours of combing through library stacks of journals and making forest-sized collations of photocopied articles. Current literature searches using the Internet allow for the most up-to-date peer-reviewed articles. In addition, the Internet has become a resource for researcher data sharing and a venue for creating large datasets through which numerous research questions can be answered (Lau et al., 2011). One widely used area is the open sharing of tumor-based genomic data compiled from multiple studies with consenting patients (O'Leary et al., 2016). These big datasets contribute to multiple subsequent time-efficient, cost-effective studies.

Data sharing on a more personal level without patient knowledge is becoming a more common source for answering research questions. Health-related social networks have even become a resource for researchers to obtain patient-reported outcomes, including effects of pharmacologic therapies, without patients enrolling in such studies (Lau et al., 2011). The implications for this are interesting. Through an ethics lens, patient information is used without consent. From a clinical lens, however, it is possible that information posted is more accurate than enrolled patients responding to questions, which may be influenced by fear of reporting side effects that can truncate therapies. Researchers could elucidate this by conducting a two-armed study comparing outcomes between enrolling patients and following side effects to similarly matched patients posting to health-related social networks.

Translation to Practice

In oncology, the primary goals of research are to improve the lives

of patients with cancer and to ultimately prevent cancer from occurring. Information exchanges between members of the healthcare team and patients through social media is termed *digital engagement* (O'Leary et al., 2016). The use of digital engagement through mobile applications to foster dialogue, serve as health-related task reminders, and monitor patient activity has the potential to streamline clinical activities and may produce more robust data that can be analyzed to further improve protocols and outcomes (O'Leary et al., 2016). Digital engagement as part of clinical practice has infinite implications for healthcare management, but the potential for exposing personal health information is increased even with protective mechanisms. Clear definitions for timing of data evaluation need to be established because data are continuously being generated.

Conclusion

The use of social media for observational and interventional studies is likely to become a standard method for healthcare research in the future. Methods for the collection of valid and reliable data through social media have yet to be established (Mamlin & Tierney, 2016). Reaching populations with poor access to social media is a challenge. In addition, upholding the tenets of the ethical conduct of research needs to be examined and updated to meet the advancements this technology provides. Internet-based technology is evolving so rapidly that it may become a challenge to maintain consistency in research methods.

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