Social Media as a Tool in Medicine

Preliminary Experience With Social Media for Community Consultation and Public Disclosure in Exception From Informed Consent Trials

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Each year in the United States, >300,000 individuals suffer cardiopulmonary arrest and >2,000,000 suffer a serious traumatic injury requiring hospitalization.1,2 Clinical advances in these fields have been limited because of the paucity of scientific evidence guiding resuscitation practices. Prospective clinical trials are important for advancing the knowledge base in these areas, but because of the emergent nature of these conditions and the inability of critically ill subjects to provide informed consent, investigators must often conduct clinical trials of cardiac arrest and trauma under federal regulations for Exception From Informed Consent (EFIC).3

Editorial see p 206

The US Department of Health and Human Services and the Food and Drug Administration have issued guidelines for the execution of clinical studies using the EFIC process.3 One of the key steps for EFIC research is community consultation and public disclosure (CC/PD), a process that connotes consultation between the investigative team, the appropriate institutional review boards, representatives of the communities where the research will be conducted, and communities likely to have the condition. However, the regulations provide little guidance on how to accomplish these key goals. Although traditional methods for CC/PD include public meetings and telephone-based surveys, the ability of these modalities to access the target populations, to effectively deliver information, and to elicit useful feedback remains unclear.4 Internet-based social media has emerged as a popular and powerful new modality for communication internationally.

The objective of this study was to describe our preliminary experience using social media to facilitate the CC/PD process for cardiopulmonary arrest and trauma trials using EFIC.

Methods

Study Design

The activities for this study, including the use of social media for CC/PD, were approved by the Institutional Review Board of the University of Alabama at Birmingham. We devised a social media interface to facilitate the CC/PD process for cardiac arrest and major trauma trials conducted at the Alabama site of the Resuscitation Outcomes Consortium (ROC).

Study Setting

ROC is a collaboration of 10 sites in the United States and Canada dedicated to the study of out-of-hospital cardiac arrests and severe traumatic injury.5 The ROC catchment area includes a population of 23.7 million people over a coverage area of 35,500 sq miles and treats ≈11,900 nontraumatic emergency medical services–treated out-of-hospital cardiac arrests per year.6 The Alabama ROC site includes 10 emergency medical services agencies in the greater Birmingham, AL, community, encompassing a population of 650,000 people over 1300 sq miles and served by ≈1400 emergency medical services personnel.

Social media as CC/PD was used for 2 ROC clinical trials. The ROC Continuous Chest Compressions (CCC) Trial is a multicenter, cluster, randomized trial comparing the 2 strategies of delivering cardiopulmonary resuscitation chest compressions to victims of out-of-hospital cardiac arrests: continuous chest compressions and traditional 30:2 interrupted chest compressions.5 The ROC Hypotensive Resuscitation (HYPO Resus) Trial is a prospective, randomized trial comparing standard and limited volume crystalloid fluid resuscitation in victims of hemorrhagic shock.

Intervention–Social Media Interface

We created advertisements using the social media Web site Facebook (www.facebook.com), a leading social networking Web site. Since its inception in February 2004, Facebook has acquired >900 million active users worldwide.7 We developed advertisements for the cardiac arrest and trauma trials for deployment on Facebook (Figure). Each advertisement was ≈110 characters long, appeared on the sidebar of the Facebook Web site of targeted users, and linked to the Web site for the Alabama ROC regional coordinating center of the ROC study (www.uab.edu/arc). The Alabama ROC Web site provided information about the cardiac arrest and trauma trials, methods for opting out of the study, and contact information for the investigators and the Institutional Review Board. We posted the advertisement for the cardiac arrest study from December 14, 2011, through January 12, 2012, and for the major trauma study from February 1, 2012, through April 30, 2012.

Selection of Study Population

Facebook allows advertisers to select a target audience. For the cardiac arrest study advertisement, we targeted individuals >40 years of age with a listed city within a 50-mile radius of Birmingham, AL, a geographic region encompassing 184,520 Facebook users. For the major trauma trial, we targeted individuals 15 to 44 years of age in the same geographic region, encompassing 375,580 Facebook users. The geographic regions coincided with the expected service areas of the
emergency medical services agencies conducting the cardiac arrest and trauma trials.

Methods of Measurement, Outcomes, and Data Analysis

We evaluated the social media interface by examining access statistics for the Facebook and Alabama ROC Web sites. Access statistics for the Facebook advertisement were provided by the company and included the number of advertisement exposures, the number of exposures resulting in redirection to the Alabama ROC Web site, and the age and sex of viewers. Information on the race and ethnicity of viewers was not available. We similarly determined access statistics to the Alabama ROC Web site using Google Analytics (Google, Inc, Mountain View, CA). Google Analytics generates descriptive statistics about the use of a Web site, including the number of visitors to a Web site, the pages visited, and the time spent viewing each page. We analyzed the data using descriptive statistics and compared the Web access characteristics between the cardiac arrest and major trauma advertisements.

Results

Between December 14, 2011, and January 12, 2012, there were 5111678 displays of the cardiac study advertisement (27 displays per target population). A total of 437 individuals selected the advertisement for redirection to the study Web site. Respondents were mostly female and were 40 to 54 years of age (Table 1). Three fourths (75%) of viewers referred from the cardiac arrest study advertisement were new visitors. The trauma study advertisement was displayed from February 1, 2012, through April 30, 2012. During this time, there were 10430948 displays of the advertisement (28 displays per target population). A total of 743 individuals selected the advertisement for redirection to the regional study Web site. Respondents were mostly female and were 40 to 54 years of age (Table 2). Two thirds (66%) of viewers referred from the trauma study advertisement were new visitors.

For both studies, visitor engagement was relatively brief, with 84% of individuals spending <1 minute viewing the cardiac arrest study Web site and 88% spending <1 minute viewing the trauma study Web site (Table 3). The most commonly viewed cardiac arrest Web pages were Q&A About Cardiac Arrest Research and Faculty and Staff. The most commonly viewed trauma Web pages were Faculty and Staff and Training. Of the 16 individuals viewing the opt-out information for the cardiac arrest study, only 1 person requested to opt out of the study (Table 4). Of 21 individuals viewing the opt-out information for the trauma study, none requested to opt out of the study.

Discussion

Social media has emerged as a powerful new tool for international communications. For example, of the 312 million residents in the United States, almost half (49.7%) have a Facebook account. American Internet users devote more time to Facebook

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<th>Table 1. Demographics of Individuals Accessing Information Through the Cardiac Arrest Research Study Advertisement (447 Total Respondents)</th>
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<th>Table 2. Demographics of Individuals Accessing Information Through the Major Trauma Research Study Advertisement (743 Total Respondents)</th>
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Stephens et al  Social Media for CC/PD  269

than any other Web site, spending a total of 53.5 billion minutes a month on Facebook.7 Social media is arguably a favored means of social interaction and has influenced interactions between individuals and their local communities and communities around the world. Social media has even been credited with facilitating recent major political upheavals.8–10 Our observations illustrate a novel approach of using social media to facilitate the CC/PD process in EFIC trials. Through the use of social media, we were able to efficiently reach a large audience.

The original concept of community consultation and public disclosure involved the use of town hall meetings with community members. Although varying in scope, a typical meeting format included a brief presentation of the study in layman’s terms followed by a question-and-answer session. Prior studies suggest that community meetings are often logistically complex, inefficient, and expensive; access a limited audience (often only those who are most interested in the research or research topic); and yield few questions.11 In a prior ROC trial of hypertonic saline for major trauma, we conducted 39 community meetings in the Alabama region; these meetings cost $8000 and garnered a total attendance of only 465 participants ($17.24 per person). In contrast, the cardiac arrest social media campaign described in this report cost $1000, resulting in 5.1 million advertisement views ($0.0002 per view) and 437 visits to the study Web site ($2.29 per visitor). Similarly, the trauma social media campaign cost $1000, resulting in 10.4 million advertisement views ($0.0001 per view) and 743 visits to the study Web site ($1.35 per visitor). Although there are no existing measures or standards to determine the adequacy of CC/PD, compared with traditional approaches, our social media strategy clearly reached a larger audience.

Some studies have used random-digit dialing telephone surveys to augment the CC/PD process, but this strategy is expensive and laborious and may become obsolete as fewer citizens elect to maintain home telephones.12 In addition, many people view uninvited phone calls as intrusive. In the prior ROC hypertonic saline trial, 5 regional ROC sites used a random-digit dialing survey, yielding 505 respondents (range, 272–505).13 There are clearly tradeoffs between social media and traditional methods of CC/PD. Although the advertisement was exposed to a large number of persons, we observed relatively modest rates of advertisement and study Web site access. Respondent characteristics were also skewed, with primarily middle-aged women responding to the cardiac arrest advertisement and teenagers responding to the trauma advertisement. We were unable to ascertain the quality of information uptake or retention by users who viewed the research Web site, which may be modest in light of the relatively short time durations spent on study Web pages. The research Web site used relatively static content with no multimedia content; the latter may have increased or improved user engagement.

Prior reports suggest that up to one third of the US population does not use social media.14 Efforts to leverage social media for CC/PD must account for these demographic gaps. For example, men are less likely to use social media than women (62% versus 71%). Non-Hispanic whites, individuals >65 years of age,
and rural residents are less likely to use social media. Ironically, social media use is lowest in the highest annual household income group (> $75,000). CC/PD efforts must include alternative strategies to target these gap populations.

We note that one fourth of the viewers of the study Web site were repeat viewers; although this observation suggests the presence of selection bias, the ability to provide recurrent information to interested parties is likely an important consideration and feature of social media. Additional research must determine ways to better target the desired demographic groups and to increase the duration and depth of information access.

Prior studies have used social media to facilitate medical research but focused on subject recruitment and follow-up. For example, Bolanos et al.15 examined the utility of using Facebook for locating study participants targeted for follow-up in a longitudinal study of methamphetamine use; that study found Facebook useful for locating hard-to-reach study participants. Fenner et al.16 used Facebook to assess the feasibility of recruiting young women into a health study, finding the method useful and cost-effective for engaging young women in health research. We believe that our effort is one of the first to use social media for CC/PD activities. These examples and our current effort illustrate novel ways to leverage social media to facilitate medical research.

The scale, breadth, and reach of social media are clearly appealing. Social media is arguably a patient-centered approach to CC/PD in that it capitalizes on a favored communication modality in the United States and allows individuals to choose if and how they will respond to solicitations. Further research must elucidate how to optimally leverage this modality for medical research while safeguarding protected health information and the rights of individuals as research subjects. As society’s communication practices migrate to social media and computer-based networks, social media may one day emerge as one of the best ways to interface with research subjects.

Limitations
Our data originate from a single site. Findings may have differed in other regions of the ROC network or the United States. We limited exposure to 2 months to coincide with local CC/PD requirements; we may have obtained additional responses with a longer posting. Although we had Web page exposure and access statistics, we did not have methods for determining the quality of those interactions. We also do not know if the format of the advertisement or regional research Web site may have affected the uptake of information. Furthermore, information on the race and ethnicity of viewers was not available. Independent validation is necessary to determine whether this strategy can be applied in other communities.

Conclusions
In clinical trials using exception from informed consent, social media may provide an additional option for facilitating the CC/PD process.

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Disclosures
None.

References

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