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Cancer Prevention and Control Interventions Using Social Media: User-Generated Approaches

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Overview

Rapid increases in the use and functionality of social media (e.g., Facebook, Instagram, and Twitter) have fundamentally changed the way individuals interact online. Unlike traditional websites that provide information to users, social media platforms are designed for the creation and sharing of information by and among users. This “architecture of participation” provides an opportunity for developing innovative, “user-generated” cancer prevention and control interventions that employ participants’ behavior, knowledge, and existing social connections (1-3). These interventions present unique opportunities to test innovative research designs and collect previously unavailable data on real-time social interactions and behavior, calling for new research concerning their impact on health-related knowledge, beliefs, norms, and behaviors.

The proliferation of smart phones, mobile sensing devices, and software applications (“apps”) create additional opportunities for leveraging social media for cancer prevention programs through the automatic sharing of location and contextual data within social media networks. Recent data on the use of social media also supports their potential for health behavior intervention delivery across demographic groups. Seventy-three percent of online adults are using social media and once online, ethnic minorities are more likely to use social media (79% Hispanic, 73% non-Hispanic black) than non-Hispanic whites (72%) (4). In

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addition, almost one-quarter of social media users follow their friends' personal health experiences or updates on social media and 15% report getting health information on the sites (5). This article explores how the features and growing use of social media for health-related purposes can be used to design innovative, user-generated cancer prevention and control interventions.

User-Generated Cancer Prevention and Control Interventions

Social media-based cancer prevention and control interventions for behavior change are emerging. One of the most established examples is QuitNet (<http://www.quitnet.com>), a web-based tobacco cessation program that includes social media features (e.g., affinity groups, buddy lists, and the ability to communicate synchronously and asynchronously with other QuitNet members) to promote social support for tobacco cessation among members. Sustained use of QuitNet has been positively associated with smoking cessation (6). More recent studies have used existing commercial social media platforms to deliver behavioral interventions to capitalize on the associated ease and low cost of intervention development and delivery as well as participant familiarity with these platforms. In the Internet Support for Healthy Associations Promoting Exercise (INSHAPE) study, a moderator posted exercise-related questions and aggregated behavioral data collected from participant self-monitoring to an exercise-themed Facebook group created for the study to encourage social support and behavioral modeling among participants (7). Another example is the Mobile Pounds Off Digitally Study (Mobile PODS), in which participants were enrolled into small weight-loss groups using Twitter and were encouraged to provide social support to other followers (8). Neither the INSHAPE nor Mobile PODS studies reported improved outcomes versus controls, and although positive associations between social media use and outcomes were found in the Mobile PODS study, questions still remain about the overall efficacy of using these platforms to change behavior (9, 10). In all of these studies, social media was used to encourage interaction between individuals who were assigned to or joined a group but generally did not have a prior relationship.

An alternative approach is to leverage individuals' existing online social networks. This approach was recently employed in a sexual health intervention: in addition to using Facebook as a platform for content delivery and social interaction, participants were asked to recruit their Facebook friends into the intervention (11). A recently published study protocol targeting tobacco cessation describes automating this process by providing participants non-monetary incentives for distributing an app allowing other participants to join the study (3). Barring limitations on potential reporting errors and sampling biases, recruiting via existing social networks could be cost-effective, and could reach a critical mass of participants quickly, and may be more advantageous when intervention effectiveness depends on familiarity among participants. An additional strategy for leveraging existing online social networks now commonly used by commercial marketers is to enlist social media users to promote products through apps, videos, and liking and sharing their product information (12). This strategy could also be used to facilitate advocacy for beneficial cancer prevention and control policies and funding (13). Additionally, users could be prompted to share their personal stories (e.g., experience with a cancer screening test) and ratings of providers with their online networks as a strategy for encouraging others. Despite

the enthusiasm for user-generated discussion of health topics via social media, further research is needed to examine the accuracy of such messages and their impact on health behaviors (14).

Enhancing User-Generated Interventions with Other Emerging Technologies

New technologies in mobile-sensing and global positioning systems (GPS) can be combined with social media to automate many functions, creating novel intervention approaches. For example, users of [mapmyfitness.com](http://www.mapmyfitness.com/) (<http://www.mapmyfitness.com/>) can share GPS-recorded running routes and physiological data with their social media connections who can then comment or later use the same routes (15). Such real-time data-sharing could model instances of positive behavior and elicit social support or reinforcement from friends. Another opportunity for intervention is to use GPS-enabled apps to automatically notify participants of health promotion resources (e.g., a local YMCA) at a time they have previously indicated they are most apt to exercise. If the participant subsequently engages in the behavior, that information could be automatically pushed out to the participant's online social network in a defined geographic area. The development of algorithms that predict future behavior (e.g., tobacco use) from mobile sensors could prompt online social connections to provide support at optimal times (16).

Unique Methodological Opportunities in Social Media Research

Social media and mobile technology-based interventions present novel opportunities for study design, data collection, and analysis. Digital technology allows the potential to rapidly iterate intervention design elements through real-time changes in the intervention across the entire sample or select subpopulations. This type of control in the delivery of intervention components (e.g., turning on or off the sharing of self-monitoring data) coupled with the ability to collect real-time behavioral data could increase the feasibility of emerging research designs, such as fractional factorial, interrupted time series, and single case designs that are congruent with iterative development and multiple time points of data collection (17-19). These designs have been specifically recommended for technology-based interventions, as they allow for greater flexibility and less lag time, thus improving the ability to accommodate rapidly changing technology (20). The ability to automatically alter intervention components in a random manner for participants also allows for "A/B testing", a method commonly used in commercial website evaluation that tests different versions of website features with users to determine those that elicit desired participant actions (21).

In addition, these characteristics may expand research focused on individual-level analysis to network-level effects, which have proven difficult to assess in previous intervention research (22, 23). Traditionally, studies of the influence of social network-level factors on health (e.g., network size, network density, tie strength) are limited by an inability to capture comprehensive network data for individuals and to establish a temporal sequence of social interactions in networks. Online social networks consist of large structures with time-stamped data on social connections and behavior, providing a potential solution to these limitations. This could lead to the discovery of previously unknown relationships between

social connectivity, behavior, and health outcomes, as well as provide innovative real-time methods for detecting trends in health knowledge and attitudes. Early examples of these research approaches include examining the network properties of existing health-related social network platforms, and creating and comparing the effects of different network characteristics on health behavior (24, 25).

Limitations of User-Generated Interventions

Several factors must be addressed to conduct effective cancer prevention and control interventions using social media. By harnessing the power of user contributions, there is an inherent loss of control over intervention dose and fidelity. For example, participants may provide and reinforce erroneous information through their social networks. Based on previous difficulties in encouraging group peer-to-peer communication in health interventions, it is also possible that the amount of interaction required for effecting behavior change will not be produced organically (9). Potential strategies for addressing these limitations include providing robust structure to user-generated interventions, such as automatic prompts or accessible communication templates. Researchers will need to proactively address privacy and confidentiality concerns brought on by the collection of behavioral and relationship data. Specifically, obtaining the consent of study participants and de-identifying participants and their social networks may require novel approaches not currently used in intervention research (23). Moreover, although the digital divide may be narrowing with mobile access, low-socioeconomic status (SES) populations continue to have less access to broadband Internet (26). Intervention programs may need to subsidize smart phone use or provide mobile devices as part of their intervention efficacy trials in low-SES and limited health literacy populations in the near term. Capitalizing on the unique methodological opportunities previously outlined also will require changes in the acceptability of alternative research designs and analytic models by funding agencies, which have traditionally considered randomized controlled trials the gold standard of behavioral intervention research. Without stronger partnerships with commercial social media platform providers (e.g., Facebook, Twitter), it may be too difficult to access and analyze network data essential to understanding behavioral phenomena in user-generated interventions.

Next Steps in User Generated Intervention Research

User generated interventions are predicated on robust participant involvement; however, most existing interventions have failed to reliably produce such engagement. In order to advance this line of research, it will be critical to identify design features at the individual and network level that encourage participation. As a first step, the cancer prevention and control research community should partner more closely with commercial technology companies to rapidly and iteratively test strategies for increasing and sustaining engagement. Once identified, successful engagement strategies can be employed in more traditional randomized behavioral intervention trials. If efficacy is established for this approach, the research agenda should turn toward using the unique features of social media and other emerging technologies for dissemination. In addition, there should be a focus on managing the potential negative consequences outlined previously as well as ensuring the reach and engagement with underserved groups.

Conclusion

Social media technology provides the ability to design, disseminate, and evaluate novel user-generated cancer prevention and control interventions. These interventions could produce efficacious behavior change strategies, lower costs, and increase reach (including underserved communities). Despite this potential, the basic principles of how to fully harness the participatory features of social media at the individual and network levels in intervention design are yet to be established (27, 28). To advance this line of research, stronger partnerships with commercial social media companies are needed, as well as increased acceptance and funding for user-generated intervention research.

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