

Internet Support Groups for Health: Ready for the Affordable Care Act

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Millions of Americans have gained health insurance coverage under the Affordable Care Act (ACA). However, it is presently unclear whether adequate numbers of primary care, behavioral health, and other medical specialists will be available to provide these and millions of other insured Americans with timely and convenient access to care. Approximately half of all U.S. adults have at least one chronic medical illness whose treatment requires long-term adjustments in lifestyle and medical monitoring. Yet physicians typically monitor their patients' conditions via in-person encounters of limited frequency and duration. Attending such visits is difficult for those who are unable to take time off from work, live in rural locations, or have transportation issues. These challenges, coupled with the widespread adoption of online social media, present an opportunity for accountable care organizations (ACOs) to promote the delivery of patient-centered chronic illness care through deployment of moderated Internet support groups (ISGs) that allow member-patients 24/7 access to personalized education, treatment advice, and peer support.

The number of public ISGs that allow users to discuss their health from the convenience of home and wherever they have Internet access has grown rapidly. Perhaps informed by the rise of Facebook and other general online communities, some ISGs have grown into collections of 200,000 or more members who self-organize into various disease-specific forums (e.g., patientslikeme.com), while others focus on a specific disorder or condition (e.g., mylvad.com). Emerging evidence suggests that ISG participants experience greater confidence in knowledge about their health and treatment options, increased control of their illness, reduced social isolation, and decreased psychologic distress.^{1,2} Consequently, this widely available and relatively low-cost technology has critical public health potential to promote patient engagement in self-care activities and improve health at reduced costs to the U.S. health care system.³

FROM THE PRESENT TO THE FUTURE

Many physicians, including at least one Mayo Clinic specialist,⁴ have established Facebook groups associated with their practices that allow highly motivated patients and their caregivers to share and access information through discussion boards, YouTube videos, podcasts, and other educational materials. However, these practice-affiliated ISGs are typically small in membership and reliant on the efforts of individual physicians to maintain these sites in addition to their regular clinical duties. By contrast, the largest ISGs with thousands of members are professionally managed and deployed by for-profit companies independent of any organized health care delivery system, with support from the pharmaceutical and medical device industries.

Numerous hospitals, academic medical centers, and other provider groups are presently using social media to help market their services to the public. We believe the largest and most innovative ACOs among these groups will soon evaluate the impact of deploying their own branded ISGs independent of support from any outside for-profit entities to promote: (1) high-quality chronic illness care and population health; (2) appropriate utilization of often discretionary high-cost medical services (e.g., emergency rooms, radiology imaging, specialty referrals); and (3) membership retention, particularly in competitive regions where individuals may have a choice of providers and insurers. These ACOs are likely to begin by creating ISGs for the most prevalent and high-cost chronic conditions (e.g., cardiovascular disease, diabetes, depression, cancer) and then leveraging their experiences to create ISGs for other conditions (e.g., neurologic disorders, HIV, organ transplant) and population health.

To enroll members into these ISGs, ACOs and their aligned practices will encourage patients to log into the patient portal of their patient-centered medical home's electronic health record (EHR) system. There, the EHR will present the patient with several ISGs they may be interested in joining, selected automatically for them by an algorithm that incorporates information from their EHR ("My Support Groups"). Upon first entering the chosen ISG(s), the patient will be prompted to electronically

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acknowledge its “community rules,” agreeing not to post inappropriate or offensive content or divulge any personally identifying information, and then set up their user profile that will be visible to other members. Other steps ACOs may take to build ISG communities could include: (1) having the site moderator welcome all new patients to the community and guide them through their initial use of the ISG; (2) sending regular e-mail reminders of new activities and information on the site; and (3) sponsoring contests with small financial rewards to promote desired behaviors (e.g., creating most commented-on posts).

ACO member-patients will be able to log into their selected ISGs at any time to pose questions, share treatment and symptom information, and receive insights’ from other members’ experiences through various discussion boards monitored by other ISG members and by trained moderators provided by the ACO to help ensure that the material posted is accurate. We also anticipate that ACO-branded ISGs will direct patients towards sources of trusted, high-quality, consumer health information such as those found on the websites of various government (e.g., National Institutes of Health, Medicare) and professional (e.g., American Heart Association) societies, as well as links to more general resources, including crisis hotlines and local pharmacies that offer \$4 generic medication programs.

PROMOTING SUCCESSFUL ISG COMMUNITIES

Despite their potential, e-health interventions often have low rates of patient utilization that may limit their effectiveness in routine practice. Buy-in from ACO leadership and physician opinion leaders will be critical to promote successful ISG communities. We envision that select physicians will participate in developing ISGs within their areas of expertise by helping to identify clinical content for these sites, and later serve as discussion guides and providers of general advice (e.g., “ask-an-expert”, guest bloggers, chat hosts) in exchange for Relative Value Units (RVUs) or similar support. However, so as not to add to ACO physicians’ daily workload by getting embroiled in time-consuming digital conversations or increase patients’ expectations, we foresee that most ACO physicians will either not have password access to their ACO’s ISGs, or have “view-only” access that allows them to read but not comment or send messages to other member-patients. Instead, we anticipate these ACOs will support: (1) professional writers and marketing experts to help develop site content; (2) nurse-moderators to initiate ISG conversations and monitor patient-members’ comments; and (3) technical staff to maintain the site and implement various iterative improvements in its design and features.

The leading ACO-sponsored ISGs are also likely to incorporate predictive analytic software algorithms capable

of analyzing the “Big Data” captured within the EHR and ISG simultaneously to anticipate users’ needs and interests. Much as these programs have enabled Amazon and Netflix to “personalize” their users’ experiences, they will enable the ISG to present member-patients with proactive information that could direct them to: (1) fellow ISG members who may need or have pertinent health advice to share; (2) nearby in-network medical specialists, imaging centers, and medical equipment suppliers; (3) reminders of due preventive care services; and (4) other useful links that may help address a specific health issue. While there has been considerable hype about “Big Data” analytics,⁵ this ability to mine information contained within the EHR will sharply distinguish ACO-sponsored ISGs from public ISGs that lack access to patients’ health records.

The most successful ACO-sponsored ISGs will be “dynamic” communities that emerge as new features and members are added, users contribute content, and lay leaders come forward to guide discussions and provide peer-support. We believe they are likely to emerge from organizations that routinely collect and review quantitative metrics of engagement, such as: the proportion of ACO members with a given condition who join its condition-specific ISG, their log-in frequency, page views, numbers of posted comments, and time-on-site to inform iterative improvements to the site. They will augment this data with qualitative reviews of topics searched and posted comments to better understand their members’ needs and thereby improve the overall patient experience with the ACO itself. Moreover, as with other successful online communities (e.g., eBay, Twitter), we envision the ISG software platform will allow members to earn and display such visible indicators of status as reputation scores and the numbers of “likes”, “hugs”, followers, and other badges to recognize their contributions and encourage such desired behaviors as log-ins and supportive comments on other members’ posts.

ISGs have the potential, in theory, to reduce health care disparities through delivery of: (1) culturally appropriate and linguistically tailored information, including video clips, podcasts, and discussion boards that can accommodate a wide range of learning preferences; (2) automated reminders of preventive care; and (3) Big Data algorithms capable of presenting relevant and personalized information. Although the “digital divide” has filled in sharply along racial lines in recent years (80% of all adult Americans have home broadband or smartphone access to the Internet, including 79% and 75% of non-Hispanic Blacks and Hispanics, respectively), it continues to persist along the basis of educational attainment and age (93% of college graduates and 95% of those age 18-29 have Internet access, versus 52% of those without a high school diploma and 46% of those age 65 and older).⁶ Still, simply providing patients with access to an ISG is unlikely to reduce health care disparities, particularly if they do not log into the ISG to seek medical information, or have limited health literacy skills.

KEY QUESTIONS

Recent global events have demonstrated the power of social media to promote revolutionary societal change. However, these tools have evolved faster than our ability to test them in National Institutes of Health (NIH)-funded randomized trials.⁷ Relatively rapid quasi-experimental and other methodologically rigorous testing designs are therefore required to keep pace with developments in social media and answer such critical questions as: (1) how best to engage patients in building viable on-line communities; (2) who is likely to become a lay leader and assist other ISG members; (3) the community size required to establish the level of responsiveness needed for successful interactions; (4) the actions and level of effort required from the site moderator to initiate and maintain an effective online community; (5) the sociodemographic groups and medical disorders for whom ISGs are likely to be most useful and effective; (6) how ISGs might impact existing disparities in access to care and health outcomes; (7) the direct costs for an ACO to direct costs to deploy an ISG or suite of ISGs and their business unit(s) responsible for these costs; (8) the potential cost-savings derived by ACOs that deploy these new technologies; and (9) the incidence and severity of potential harms caused by ISGs, including inaccurate peer-provided advice, loss of member confidentiality, cyberbullying, and other malicious behaviors.

CONCLUSIONS

Moderated ISGs deployed by ACOs and other healthcare delivery systems presently experimenting with social media are an innovative and scalable strategy that has the potential to

promote both personalized chronic illness care and population health at an affordable cost. Recent global events have demonstrated the power of these tools to promote revolutionary societal change. Therefore, it is of great interest to explore whether and how ISGs could be utilized to promote revolutionary improvements to the U.S. health care system, and thereby meet the challenges and potential posed by the ACA.

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