

Virtual Mentor

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The Benefits of Online Health Communities

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The number of users of online health communities such as PatientsLikeMe [1] and Inspire [2] is growing. PatientsLikeMe, for example, has approximately 220,000 registered users—about double the number of users it had in 2011 [3]. Although this is far below the numbers of more general social networking sites like Facebook (which has more than one billion registered users) [4], online health communities offer patients the opportunity to interact with others who have been diagnosed with a variety of diseases and conditions, track their health information on the site, and become involved in research. And, at least one online health community—PatientsLikeMe—includes a networking feature and a “real-time research” platform [5].

Some of the disparities in membership between sites like Facebook and online health communities can be explained by the amount of advertising that Facebook does, the media coverage that the company receives, and its general—rather than health care-specific—social networking purpose. In short, people have heard of Facebook, and they can use it to talk about more than just their health.

Benefits of Participation

The American public has realized that it can find an abundance of information online about health and health care. According to a 2013 Pew Research Center report, of the 85 percent of adults in the US who use the Internet, 72 percent (or about 61 percent of *all* US adults) reported using it to find information about their health, whether seeking a possible diagnosis for themselves or others, a recommendation for a clinician, or other information [6]. A 2011 Pew report found that of the 74 percent of adults who used the Internet, 80 percent (or about 59 percent of *all* US adults) looked for information on a specific disease or treatment [7].

Online health communities offer an abundance of information for patients and their caregivers, family members, and friends. More than half of PatientsLikeMe members said that the site was either moderately or very helpful for learning about their symptoms, more than half said it helped them manage symptoms and understand treatments, and almost half said that they connected with another member who helped them learn more about a medical treatment [8].

The opportunity to become a part of a support system is significant. Users of online health communities cited the emotional support received from other members, the accountability the sites provided them for reaching their health-related goals, the

motivation they got from other members, and the advice they received from other members as reasons for their membership in the community [9]. They pointed to advantages of online health communities over other social networking sites—such as Facebook—for achieving these goals because Facebook’s purpose is “to communicate the impression of being interesting people who [are] in control, positive, and not struggling” [9].

In addition to offering information and support, online health communities can serve as the birthplace for beneficial social movements, such as “participant-led research,” in which “participants are the leading force in the initiation or conduct of research projects” [10]. For example, as a group, Inspire members with spontaneous coronary artery disease (SCAD) convinced a researcher at the Mayo Clinic to initiate research that led to the creation of a SCAD registry [11], an important step in conducting more research on this rare disease. Without an online forum, these women might never have been able to connect with each other and galvanize support for such a project.

Drawbacks of Participation

Despite the benefits, there are drawbacks to online health communities that should be acknowledged. It can be difficult to control the quality of the information shared on these sites, causing concern about dissemination of inaccurate information. The FDA, for example, encourages people to carefully evaluate health information found online because of the possibility that it may not be accurate [12].

In the research context, concerns have been raised that clinical trial participants use online forums to try to figure out whether they are randomized to the placebo or study drug [13]. Site users have also encouraged prospective study participants to falsify information provided during screening to appear eligible to enroll or to withdraw from studies early [13]. Such influences could ultimately bias study results and compromise the progress of research.

Potentially inaccurate health information and biased study results, of course, exist outside the online world, but the widespread access to information that the Internet provides essentially guarantees that posted information will reach a large audience.

Despite these drawbacks, I believe that medicine and public health benefit when patients who are willing and able are encouraged to share their health information online. Patients’ ability to receive emotional support is good for their health [14], active and informed patients may have better outcomes [15], and new research results may translate into practice (though that is often easier said than done) [16]. Unfortunately, the US does not yet have a perfect mechanism for reducing or eliminating the risk of sharing such information online.

Potential Privacy Risks

People who only search for health information online face fewer risks than those who provide information about themselves to other Internet users, but many benefits

of online health community membership stem only from fully engaging in the site, which involves sharing information. Out of almost 1,800 people surveyed recently, 30-40 percent said they had used social networking sites to consume health-related information, but less than 15 percent reported posting information online [17]. Admittedly, more research is needed to attempt to explain this discrepancy, but privacy concerns could contribute to it.

Privacy concerns associated with sharing health information online include possible discrimination by the employers, insurance companies, friends, or family of those who post [8]. There are also concerns about “potential ‘data intruders’...with motivations ranging from personal research, genealogy, ancestry, forensic purposes or use in marketing, insurance, or employment decisions” [8]. In the research context, institutional review boards (IRBs) may be concerned about how information from online health communities is being collected and used as they strive to protect research participants from invasion of privacy [18].

Although the Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits employers and health insurance companies from discriminating on the basis of genetic information [19], the act’s scope is limited. People are not protected under federal law from possible discrimination when applying for life, long-term care, or disability insurance, and GINA’s employer and health insurance protections cover genetic test results and family medical history but not the patient’s own medical history. The Affordable Care Act (ACA) now, in most cases, protects against higher health insurance premiums for people with preexisting conditions, but some grandfathered plans will not offer this protection [20]. Neither GINA nor the ACA addresses the problem of social stigma against people with certain diseases or conditions.

Online health communities take measures to protect the privacy and security of the information shared by their members, such as using “commercially reasonable” methods to protect the security of information that users provide and supplying details in their privacy policies about how the information users share with the site may be disclosed to and used by third parties, including pharmaceutical companies [21, 22]. Privacy is never guaranteed, however; any information posted could be redisclosed either within or outside the site, and these sites are careful to remind their users about this possibility [21, 22]. Furthermore, an important purpose of social networking sites is to share information, and online health communities are no exception. Indeed PatientsLikeMe has—in addition to a privacy policy—an openness philosophy that says the company encourages the sharing of information [23].

Conclusions

I offer the following suggestions for encouraging patient use of online health communities. First, physicians should educate themselves about the different purposes for which their patients use—or could use—social networking sites and online health communities in particular. They should pass this information on to their patients to facilitate shared decision making. Second, IRBs should become

comfortable with their researchers using online health communities to recruit participants and collect data, and they should ensure that they have the appropriate expertise on their committees to be able to conduct thoughtful, thorough reviews of studies that use such methods. Third, we should consider enacting new legislation that will provide additional protections beyond what GINA and the ACA currently offer, so that patients and their friends and families can share their information with others and get the support they seek without fear of repercussions. Social stigma surrounding illness is likely to be reduced when information is shared openly and we become more educated about these issues.

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