

# **Social Media and Medicine**

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## **Introduction**

In the United States, Medicine is a field dominated by technology. When you enter a hospital, you march to the rhythm of a chorus of beeping machines, chattering keyboards, and informative overhead pages. Even when a patient is visiting the physician, a computer is often a key component of the interaction. However when it comes to communication, physicians are reluctant to use social media, web based and mobile technology created solely for the purpose of intercommunication and exchanging ideas.

This reluctance is understandable, since physicians face many barriers towards the use of social media including potential HIPAA violations, liability, and costs. Yet these concerns don't necessarily dissuade patients from seeking out information from online sources. Patients seem to be flock towards online medical sites like WebMD, or MedicineNet to an extent that has coined the term cyberchondria. There is an obvious gap between what physicians feel comfortable providing and what patients would like provided on social media today. The question is how can we merge medicine and social media so we are satisfying the patient's requests and needs, while still balancing the physician's responsibility to do no harm.

Our group views social media as a tool still in its infancy that can be performed on several different levels to share knowledge. Our goal is to explore the current and potential impact that social media has on healthcare through the patient-patient, patient-physician, and the physician-physician interactions that it fosters.

## **Social Media and Patient to Patient Communication**

Every patient tells a story. Their paths and course in a disease are different as are their hopes and aspirations. Their disease course, however, continues to just be a story until we have the ability to draw data from their experience. The immense value of social media in patient-patient interactions is rooted in the fact that patients find comfort, solace and trust in those who know exactly what they are going through. It is this premonition that has inspired the establishment of multiple patient-centric social networking sites where patients share their experiences, concerns and disease-course with other patients. Such websites have received bad press in the past for being sources of bad, and sometimes dangerous, information. Whether or not such patient-patient interactions improves health outcomes, has not been elucidated in any major study. In recent years, however, physicians have come to see the potential of such websites to be a rich source of data.

The most popular of such forums is the website "Patientslikeme.com". This website has shown the power of social networking in patient-patient interactions. The website has over 40,000 users representing a number of life-altering diseases. Patients use the website as a platform to provide support to one another, describe what worked for them and what did not and a multitude of other information. The website has been running for the last 6 years and since its establishment, physicians have learnt of the abundance of information that they can draw from a well structured social networking site such as this one. For example, a few years ago there was a small case series published by a group of Italian researchers reporting that Lithium Carbonate slowed down the progression of ALS in a study involving 16 patients<sup>1</sup>. Shortly after this study, the website was buzzing on their

ALS forum with patients that were trying Lithium Carbonate off-label. On the website, they reported the progression of their disease on Lithium, along with other variable such as blood Lithium levels, side-effects and perceived efficacy. While this is not a surrogate for a randomized clinical trial, the website provided physicians with valuable preliminary data from 149 ALS patients. Most importantly, this data was available well before recruitment even began for a larger formal follow-up study. This data is not bound by HIPAA as patients self report details about their medical history.

Multiple patients have also reported that the website serves as their “medical diary”. They are able to report news symptoms, change in disease course etc. in real time and are thus able to give their healthcare providers accurate information during scheduled visits. Patients on the website also report that they are able to track the progression of a multitude of other patients who are further along in the course of a disease than they are. Patients feel that this helps them manage their expectations and know what to possibly expect in the future.

Though this data has to be controlled for potential bias, patients who use this website are extremely open in their posts. In fact, a poll conducted by the website revealed that 29% of patients have withheld some aspect of their medical information from their doctors from fear of being lectured or made to feel bad. Thus the data from this website is unfettered and possibly more complete than can be gleaned from an actual office visit. In fact, the only source of revenue for Patientslikeme is that generated from sale of this anonymous data. Another great application of this website is to monitor for the effects, side-effects and patient perceptions about medications. For example, users of SSRIs on the website reported reduced libido in 24% of Lexapro users (n = 149). This was much higher than in the original clinical trial for Lexapro which reported reduced libido in only 3% (n = 715) of users. This discrepancy fueled a new study by Landen et al. who found that the actual rates of sexual side effects from among their study group was significantly higher at 41 % (n = 119)<sup>2</sup>. They account for this discrepancy from the original clinical trial in that the questions used were too open-ended.

We know that social networking sites helps connect people who were otherwise geographically isolated, but we now have come to see such sites as a requiem for patients who feel isolated by their disease. Future studies could help fully flesh out the impact of social networking on health outcomes based on quality of life, impact from good information and misinformation. Additionally, these candid patient-patient interactions serve as a catchment for data that though unstructured and potentially biased, provides a wealth of information to healthcare providers.

## **Social Media and Patient to Physician Communication**

The emergence of social media has changed how patients and physicians interact. Once thought of us an individual relationship in which communication occurs primarily in-person, new technology including blogs, instant messaging platforms, video chat and social networking has provided new avenues for communication. Furthermore, social

media has provided an outlet for physicians to communicate with larger audiences and thus influence the health of the general public.

Social media allows for new and innovative ways for physicians to interact with individual patients. While similar to telemedicine in some aspects, instant messaging (IM) and video chat provide a new avenue for physicians to evaluate patients. An example of this is "Hello Health," a primary care medical practice located in Brooklyn, New York.<sup>3</sup> Hello Health is a concierge practice in which patients can sign up for a monthly fee of \$35 and can be evaluated by a primary care physician over a secure social network. Video-streamed cyber visits with physicians cost anywhere from \$50-\$100, while individual e-mails to physicians are free. In addition to consultation via the Internet, patients have the option of seeing their physician in the office or having their physician make a home visit. Unlike telemedicine, however, this new system of physician-patient interaction affords patients increasing control of their health information through a system that allows patients to schedule appointments, send instant messages to their providers, and view electronic health records.

Whether or not the model of Hello Health will be the future of healthcare in America is yet to be seen; however, many medical groups have already begun to incorporate aspects of social media within their respective health systems. For example, Kaiser Permanente utilizes physician profile pages similar to that of Facebook as well as e-mail messaging between patients and physicians. Electronic Health Records (EHRs) are rapidly overtaking paper records as the primary means of patient health documentation. Sometimes integrated within EHRs are social media tools including secure messaging and chatting. While social media has been embraced differently by various medical providers and practices, its presence alone has the potential to forever change how healthcare is delivered.

With this new technology, however, arise new concerns. One of the main fears regarding the use of social media in the setting of individualized physician-patient encounters is the potential for disclosure of protected health information to third parties and subsequent legal implications for physicians. This concern though is not specific to social media in medicine as it has been a long standing issue regarding EHRs. A second concern regards the regulation of health care entities partaking in the delivery of health care through social media. Current medical practices are regulated by federal and state specific government entities. Furthermore, individual physicians are certified by the state in which they work. Social media transcends geography and physical space adding complexity to the issue of medical oversight and regulation. A third concern regards the issue of physician training. Social media is a relatively new phenomenon in which primarily younger physicians are acquainted with. The widespread use of new technology would require new training for older physicians, thus serving as a roadblock to the embracement of this new technology. Finally, some may question the suitability of technology as a substitute for a face-to-face interaction with a patient, especially with regards to performing a physical exam.

Despite several key concerns regarding the suitability of social media for the delivery of personalized health care to individual patients, there is tremendous potential for the use of social media in affecting the health of larger groups of people. For instance, health blogs

serve as a means in which physicians can disseminate information to a larger audience. Often this can be as simple as using Twitter to highlight current wait times at emergency departments or a family practitioner using a website to host information pertaining to preventive health screenings. Social media can also be used to correct misinformation pervasive on the web. One of the drawbacks and realities of social media is the potential for spread of false information. An example of this is the anti-vaccination movement based on falsely held beliefs that vaccinations cause autism. Dr. Ben Betancourt, a pediatrician and guest writer on the KevinMD blog, comments regarding unproven information pertaining to vaccinations on the internet: “If pediatricians would take the time to create content, link to scientific data, give their perspective, and post it all online, when someone would search on a topic relating to pediatrics, they’d get balanced results.”<sup>4</sup> Ultimately, social media plays an important role in the way physicians can shape the health of the public.

It is our position that current and future physicians should embrace social media; however, to do so with caution. Considering the individual physician-patient relationship, social media may serve as a means to deliver care in unique ways, but should not serve as a substitution for direct, physical interaction. Nevertheless, new messaging platforms including video chat provide a unique platform for the delivery of care and can serve to supplement existing healthcare delivery methods. Government agencies should consider guidelines for appropriate regulation of healthcare delivered via social media as internet-based technology and healthcare continue to intertwine. Regarding the use of social media to affect change on a larger scale, it is our position that physicians should actively embrace technology to affect public health. The use of social media to deliver and digest information is only expanding. Many people depend on the internet as their primary source of health information. In an effort to educate the public and in turn positively affect the health of the general public, physicians must not be afraid to embrace social media in some capacity.

### **Social Media and Physician to Physician Communication**

Social media has the potential to expand physician-physician interactions by allowing providers to share anecdotes, experiences and insights – in a convenient format that bypasses IRB regulations and the conventional medical publication processes.

Today’s physicians are more familiar and engaged with social media information technologies, and this has influenced physician-physician interactions– most notably with the development of online physician-only communities. Websites like Ozmosis.com and Sermo.com create online professional networking communities for U.S. licensed physicians. Ozmosis.com was launched in 2008 to promote peer to peer interactions for the community of MDs and DOs and advocate for collaboration among clinicians, educators and practice owners. Using these platforms, physicians are encouraged to present research findings and challenging cases in hopes of promoting virtual communication between providers who are geographically isolated. These websites

provide us with a virtual doctor's lounge of sorts – where expertise and opinions can be freely exchanged.

Physician online networks are evolving with multiple safeguards to limit physician liability and ensure that these tools create a safe and private environment for collaboration. Orthomind.com is the only online social network exclusively accessible to validated licensed orthopedic surgeons. On this site physicians are frequently reminded to avoid disclosing personal identifiable patient information and all forums are monitored to ensure compliance with HIPAA in the protection of confidential patient information. Because the site is a closed platform with restricted membership, it has the benefit of allowing members to remain anonymous – creating what the site calls “anonymity with accountability.”

Going beyond opinions and commentary, video sharing Internet platforms such as YouTube allow physicians to rapidly share video webcasts of new procedural techniques. Similarly, Medtube.net is a video sharing platform, exclusively broadcasting medical media. Created by two surgeons, this site features videos of numerous surgical procedures and even allows users to watch live surgeries.

With the proliferation of online physician communities and websites, it is clear that social media has found a place among health care providers -- and perhaps in the future we will see additional virtual tools began to supplant traditional medical networking.

## **Conclusion**

New technology always comes with its own set of benefits and risks, and we are still figuring how to best utilize social media. With time and investigation, we can fully appreciate the support and information as well as the liabilities and costs that this technology brings to both patients and physicians. However, there is no denying that social media plays an important role in our lives, and we should embrace its promise as tool that can better serve our patients and enhance our knowledge.

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