

Social media for patients: benefits and drawbacks

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Abstract

Purpose of review Social media is increasingly utilized by patients to educate themselves on a disease process and to find hospital, physicians, and physician networks most capable of treating their condition. However, little is known about quality of the content of the multiple online platforms patients have to communicate with other potential patients and their potential benefits and drawbacks.

Recent findings Patients are not passive consumers of health information anymore but are playing an active role in the delivery of health services through an online environment. The control and the regulation of the sources of information are very difficult. The overall quality of the information was poor. Bad or misleading information can be detrimental for patients as well as influence their confidence on physicians and their mutual relationship.

Summary Orthopedic surgeons and hospital networks must be aware of these online patient portals as they provide important

feedback on the patient opinion and experience that can have a major impact on future patient volume, patient opinion, and perceived quality of care.

Keywords Social media · Social networking · Web 2.0 · Internet · Patient-patient relations

Introduction

The Internet has completely changed the way people access information and since several years now represents the first source of information for many patients [1]. The impact of this phenomenon was so important for the publishing industry that someone has defined this phase the greatest revolution since Gutenberg's printing press [2]. This trend has been further boosted by the inner evolution of the Web 1.0 toward the so called Web 2.0. This term was first used in 2004 and overlaps with both social network sites and social media [3]. It was introduced to indicate the contrast between the previous era, namely the Web 1.0, and the new one, the Web 2.0, in which content and applications are no longer created and published by individuals, but instead are continuously modified by all users in a participatory and collaborative fashion [4].

The term social media (SM) generally refers to Internet tools that allow individuals and community to gather, communicate, and share information, opinions, photos, videos, and other contents within Internet applications [3]. SM include various kinds of platforms such as blogs (i.e., Tumblr, Blogger), social networks (i.e., Facebook, Twitter, MySpace, Google+), professional networks (i.e., LinkedIn), media sharing (i.e., YouTube, Flickr), collaborative projects (i.e., Wikipedia), and virtual gaming or social worlds (SecondLife, HumanSim) [5–7].

Patients are increasingly active online, and they are frequent SM users for health purposes. In 2015, it has been estimated that

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62% of entire adult population of the USA uses Internet and 72% of adult Internet users use Facebook [8]; in a previous survey, 72% of Internet users say they looked online for health information within the past year [9]. Different SM attract different age groups, and for example, blogging has become less popular among teens and young adults since 2006 and more popular within older adults [10, 11]. Similarly, there are differences in SM use depending on gender, race/ethnicity, education, and income characteristics [12].

Motives and expectations from SM use can be diverse. Health-related SM use by patients is usually due to the need for increasing the knowledge on their disease, expressing their emotions, sharing their experience on their disease and its treatment, being in touch with doctors, finding answers for additional and forgotten questions, getting advice, receiving education, and checking their progress and goals. Patients can tell their story and exchange ideas and feelings so that they themselves create a real community on a specific topic.

Recent data from Pew Research Center [13] shows that nowadays nearly two thirds of the American adults use social networking sites, and if compared with data from 10 years ago, the rise is nearly tenfold with a stable upward trend. The same source provides trends for different demographic groups. Although young adults are the predominant users of SM, usage among older people has more than tripled in the last 5 years. There are not notable differences by gender, racial, or ethnic group while, unlike the past years, differences between a socioeconomic group and communities are gradually vanishing.

Despite there are not many studies analyzing this topic for the specialty, orthopedic patients seem to be big SM users. In a survey of 139 gynecologic patients, Antheunis et al. found that almost all of them (99.3%) used SM, while just about one third of them (31.7%) used SM for health-related reason [14]. The figures for orthopedics are different. Several years ago, 45% of orthopedic patients already searched online for information about their condition prior to consultation [15]. Curry et al. reported a survey of 752 orthopedic patients [16] showing that 51% of all patients involved used SM; the majority of patients which told not to use SM were over 40; furthermore, sports medicine patients were higher SM users relative to other services, and this association was statistically significant when compared to the joints/tumor service. The same authors reported that the biggest indicator predicting SM usage in the orthopedic population was age, with older patients less likely to be SM users; non-doctorate patients and those who lived far from the hospital were more likely to be SM users. Patients who researched their condition prior to their appointment were also SM users. These data confirm the findings of Rozental et al. [17] who, some years before, distributed questionnaires among upper extremity outpatients and showed that about a half of them used social networks; younger age, computer ownership, and higher education were an independent predictor of social networking use. Sadah et al.

have extracted data directly from SM showing that male users in drug review websites mainly talk about back pain [18].

Patient-centered e-health

Patient-centered e-health (PCEH) has been defined as Internet-based technology that engages patients as the major actors in the delivery of health services through an online environment [19]. PCEH systems rely on three major elements: (1) patient focus; (2) patient participation, and (3) patient empowerment [19]. These socially enabled systems facilitate consumer-centered healthcare and permit patients and caregivers to play an active role in providing and consuming health information related to them. Despite the benefits offered by these patient-centered SM, there are concerns about the security, privacy, and confidentiality of the personal health-related information shared on these social platforms; the quality and accuracy of the information shared; and the credibility of individuals who post medical advises and tips [20].

Social media categories

Social media for patients can be classified into two generic categories: general-purpose online social networks (OSNs) and virtual health communities (VHCs) [21]. General-purpose OSNs are Facebook, Twitter, Instagram, and YouTube. They are the most used SM platforms for health information. VHCs are SM platforms that are designed for individuals to facilitate online interaction around specific health topics. VHCs are mostly used by online community groups, like Inspire.com and ask-a-doctor websites, such as MDTalks.com.

OSNs are mostly used in the communication between physician and consumer (P2C). Through these sites, physicians and health-care organizations can communicate with individuals helping them to learn more about their health-related problem and make better future decision on their health and health care. OSNs can also be used to enhance the communication among patients (C2C) around a specific medical topic. So patients can share their opinions and experiences in order to empower themselves and play an active role in their health care processes and education [22].

VHCs are mostly used in the communication between consumers (C2C). These SM platforms are typically built upon mass collaboration on health-related topics, favoring social interactions and social support among patients. Health discussion boards and forums are the most used platform in the C2C collaboration. The discussion boards and forum are typically topic-oriented platforms to discuss about a specific disease or health-related topic [23]. Usually, patients can initiate discussion threads on a topic, asking a question or seeking support from others on the platform, and in response to the thread initiator, other patients can post their comments and provide their experience, information, sympathy, and thoughts about the thread

topic. Another form of collaboration among patients (C2C) is the user review. Patients can rate medicines, physicians, and health-care organizations expressing their personal experiences in order to help other patients who potentially need them in the future. Physician rating platforms are among the fastest growing user reviews in the context of health-related SM [24, 25]. Physician-rating websites represent a different type of communication (C2P) where patients can post their reviews for the advantage of other patients. Health care organization can learn from patients' opinions about the physicians with the scope of improving the quality of care that they provide for the patients [21]. Currently, the most commonly visited physician-rating websites include Healthgrades.com, vitals.com, ratemds.com, zocdoc.com, and GoogleReviews. Patients who use these websites to determine the quality of a physician should do so with some caution as there is no verification process to substantiate the reviews listed for each physician. The benefit of these websites is that they do provide immediate feedback to other patients and the physician on the quality of care received.

Bonesmart.org is a comprehensive virtual health community focusing on patients undergoing hip and knee replacement surgery. The online forum is divided into the preoperative area and the postoperative recovery. This online forum provides a comprehensive resource for people who share hip or knee pain and are interested in potential treatments, what to expect prior, during, and after surgery. These online patient forums provide an invaluable source of online information for patients.

Non-physician-generated social media education for patients

Some patient content is generated by physicians in order to increase practice volume. This educational content, while hopefully valid, is also somewhat biased as it is designed to encourage patients to make an appointment with that practitioner. Health care organization and large hospital networks offer a more neutral source for acquiring reliable orthopedic information for patient consumption. The AAOS (www.orthoinfo.aaos.org) offers an excellent source of information on various orthopedic conditions and procedures. There are also several subspecialty societies that have patient education information. For one of the most common procedures, total joint arthroplasty, the Association of American Hip and Knee Surgeons has a patient education portal. Physicians and health care professionals can direct patients to this peer-reviewed content.

Quality of information on social media

Quality of health-related information on the Internet is a key point. It is especially true for SM, so much so that Agarwal and Yiliyasi described the information quality in SM, where low barriers to publication and easy-to-use interactive interfaces contribute to various problems, as a challenge [26]. Some

characteristics of the SM themselves threaten the quality of information: public availability, possibility to be altered anytime, global audience, immediacy of the information, and easy usability. Then, the challenges for the quality of the information on SM are represented by the attack of spammers, the contextual and almost personal relevance of the information (information that is relevant to someone may be irrelevant to other), colloquial usage, intentional misspelling, information overload, and freshness of information [26]. More than 15 years ago, facing the already known concerns brought by the new rising media, Sildberg et al. [27] on *Journal of the American Medical Association (JAMA)* defined basic standards to be applied to the information on the web relying on the accountability of people behind the web publishing. They proposed four standards to make the information useful and suitable for reader decision-making: authorship, attribution, disclosure, and currency. Otherwise, the risk is that the SM can resemble more a "cocktail conversation" rather than an effective and useful means of communication. As for authorship, authors and contributors, their affiliations, and relevant credentials should be provided in the web site. Attribution means that references and sources for all contents ought to be listed clearly, along with copyright information. Disclosure implies that web site ownership, any sponsorship, advertising, underwriting, commercial funding arrangements or support, or potential conflicts of interest should be disclosed. Currency demands that each content and any update should be dated. It is possible to rate the quality awarding one point to each criterion and obtaining a score ranging from 0 to 4.

The need for further quality measures has been claimed in the past years. By now, several instruments are available to evaluate the quality of online information. In addition to the JAMA benchmark previously described, the most popular are the DISCERN criteria [28] and the Health On the Net code (HONcode) seal [29]. The DISCERN contains a total of 16 questions (clarity, balance, content, reader's impression), each one was graded from one to five and ranges from 16 to 80 points. Sites that have satisfied the HONcode criteria (authoritative, complementarity, privacy, attribution, justifiability, transparency, financial disclosure, advertising policy) can display the relative seal.

Recently, Cassidy and Baker performed a review on orthopedic patient information on the World Wide Web [30•], showing that despite different study designs, the results of papers analyzing the quality of the information in the last 5 years were similar. The quality of the information was generally poor, and only a maximum of one to two of every three web sites visited were of suitable quality.

Over the past years, the video contents of SM have been a subject of studies. Brooks et al. [31•] assess the quality of videos available for viewing on the subject of lumbar discectomy. Of 81 videos analyzed, only 16 were rated as good, whereas 40 were poor or inadequate. The most common information lacking in the video were complications following surgery and nonsurgical or conservative management. For the authors, this could reflect the

market for which some of these videos were intended and that the people/organizations posting these videos wanted to offer the patients a quick resolution of their symptoms. The authors concluded asserting that they would have not advised patients to use YouTube™ as a source for information relating to lumbar discectomy. The findings of another study by Elhassan et al. [32•], describing the information about discectomy on the Internet both on SM and websites, were similar. Just one third of the sites were of good quality, with a slight trend toward improvement compared to 10 years ago. On the contrary, it has been shown that well-designed and verified videos can be beneficial for patients. Lately, the Orthopedic Surgery Department at Mayo Clinic in Florida tested and ascertained the educational value of 16 YouTube videos creating a virtual hospital experience for primary total hip and knee replacement patients to reduce anxiety on the day of the surgery. In summary, for the dynamic and changing nature of SM themselves, the quality of information appears really difficult to control and be guaranteed.

Conclusion

Social media platforms offer the possibility for patients to communicate among them and with physicians. These platforms can help patients to be better informed about their condition and more involved in their treatment. In this way, patients are not passive consumers of health information but can play an active role in the delivery of health services through an online environment. However, it is difficult to control or regulate the sources and their quality, and bad or misleading information can be detrimental for patients as well as influence their confidence on physicians and their mutual relationship.

Compliance with ethical standards

Conflict of interest All authors declare that they have no conflict of interest.

Human and animal rights and informed consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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