



# Empowering patients through social media: The benefits and challenges

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## Abstract

This article explores the range of social media platforms used by patients and examines the benefits and challenges of using these tools from a patient perspective. A literature review was performed to investigate the use of social media technology by patients. The MEDLINE database was searched using the terms “social media” and “patient.” The search was conducted in September 2012 and yielded 765 abstracts. Initially, 63 abstracts were selected. All articles dating from 2004 through 2012 were included. Only 12 articles were found to be relevant for the purposes of the review. The results of this research found that there appears to be an increase in the use of social media by patients across the healthcare spectrum. The research indicates a promising future for the use of social media by patients; however, evidence related to the efficacy and effectiveness of social media is currently limited. Various challenges have also been identified relating to privacy and security concerns, usability, the manipulation of identity, and misinformation. The use of social media technology is an emerging trend for patients who are seeking health information. Conclusions are that such technology holds promise for improving patient engagement and empowerment and community building. Social media has a future in healthcare, especially with regard to patient engagement and empowerment; however, there are several challenges to overcome before the technology can achieve its potential.

## Keywords

E-health, healthcare, patient empowerment, patient engagement, social media challenges, social media benefits, technology

## Introduction

The use of social media for personal and health use is on the rise. This is part of a growing realization that social media can provide a platform for patients to gather information, explore options, and

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share their experiences.<sup>1</sup> Social media provide online platforms for interactions to occur around various health topics relating to patient education, health promotion, public relations, and crisis communication.<sup>2</sup> Social media include various technological approaches such as blogs, microblogging (e.g. Twitter), social networking (e.g. Facebook and Patients Like Me), video- and file-sharing sites (e.g. YouTube), e-games, and wikis. The benefits of social media in improving patient care have not yet been well documented, and with over 80 percent of Americans seeking health information online,<sup>2</sup> the impacts of social media on health cannot be ignored.

Patient groups have mostly benefited from the use of social media for health purposes. It is estimated that in the United States, 67% of all Internet users utilize social media,<sup>3</sup> and searching for online health information has become one of the most popular online activities.<sup>2</sup> Patients can use social media for a variety of reasons that include education, information, networking, research, support, goal setting, and tracking personal progress. Patients have the ability to express themselves, share their stories, learn from others, and spread health knowledge.<sup>4</sup> Social media create a forum for patient participation that extends beyond the reach of the hospital or the local clinic. Such resources can help empower and uplift patients when they read the experiences of other patients.<sup>4</sup> Some physicians believe that social media can be beneficial for patients with chronic disease, cancer, rare diseases, maternal and infant care, depression, wellness, prevention, and weight management.<sup>4</sup> Studies have found that different age groups, income groups, and genders use social media in different and similar ways. For example, Korda et al.<sup>5</sup> note that women are more likely than men to look for information relating to symptoms, treatments, diseases and conditions, and medication, whereas men are more likely to search for information about vitamins and supplements, health insurance providers, and physicians. Patients benefit from using social networking for health reasons because the applications are patient focused, allow for meaningful patient participation, and empower the patient, attributes that are central to patient-centered e-health (PCEH).

Little work has been conducted on PCEH, especially as it relates to social media. Much of the current literature focuses on how healthcare organizations use social media or how clinicians use this technology for networking and information sharing. Studies that have addressed the impacts of social media from a patient's perspective are more limited. The purpose of this article is to review the literature on social media and their use by patients. As part of the review, the study will address the following question: what are the benefits and challenges of the use of social media by patients? Previous literature has not specifically addressed this important topic, and little is known about the general benefits and challenges of using social media from a patient-centered perspective.

## Background

Healthcare providers are struggling to find new ways of communicating with patients as existing patterns of communication (e.g. pamphlets, newsletters) are becoming obsolete.<sup>6</sup> It is estimated that 1229 US hospitals use social media to engage with their patients. These institutions mostly use Facebook, Foursquare, Twitter, YouTube, LinkedIn, and blogs.<sup>1</sup> For example, in 2010, the Mayo Clinic established the Social Media Network with a stated vision of being "the authentic voice for patients and healthcare professionals, building relationships through the revolutionary power of social media." There are currently over 100 members affiliated with the Mayo Clinic initiative, and their broad initiatives to engage various community stakeholders include blogs, Twitter posts, conferences, and webinars. In fact, in a recent study on health consumer expectations regarding the use of social media and their impact on health services selection, 57 percent of consumers reported that the use of social media by hospitals to engage patients increases the likelihood of whether a patient would

use hospital services. It was also reported that one in four consumers expected to connect with a hospital through social media. The survey further found that 81 percent of consumers felt that the image of a hospital as cutting edge was enhanced when the institution was using social media.<sup>1</sup>

Although there are high expectations that the use of social media will provide more patient-centered care, there is currently little evidence within the academic literature showing the health benefits of the use of social media by patients. Much of the academic work on how consumers use social media in healthcare has been limited, and more studies should be conducted in this research area.<sup>6</sup> A recent review of the literature on the use of social media in healthcare showed that only 71 studies surveyed and interviewed patients, whereas the remaining studies were mostly descriptive.<sup>6,7</sup> The challenge for academics is to begin exploring the impacts of social media on health outcomes and the benefits and challenges relating to the use of social media in healthcare as patients and hospitals are increasing their use of social media.

## Methodology

The current evaluation was conducted by reviewing the literature surrounding the use of social media by patients. Articles included in the present review included some evaluations of social media interventions by patients. Other articles were purely reviews, surveys, observational articles, or conceptual articles. Articles were included if they addressed the use of social media by patients or health consumers. Articles were excluded if they focused on hospital or clinical use of social media. Commentaries, editorials, and non-peer-reviewed articles were also excluded from the study.

## Search strategy

A comprehensive search of the MEDLINE database was conducted in September 2012 for this review. To focus on the topic of social media use and patient-centered care, two main concepts were included in our search strategy: social media and patients. The initial search was conducted by typing the words “social media” and “patient” separately in the MEDLINE database. The results of both searches were then combined, yielding 765 articles. All of the resulting abstracts were reviewed, and a total of 63 articles met the inclusion criteria. Each of the articles was then retrieved for further analysis, and upon further examination, it was found that 12 of the 63 articles met the study inclusion criteria. Only studies from between 2004 and 2012 were included in the study.

## Results

Of the 12 selected articles, four studied programs or interventions that use various social media. Three of the studies focused on reviewing the literature, another three were observational studies, one was a survey, and one was conceptual in nature. Of the four intervention studies, one focused on a qualitative study of teenage patients and their attitudes toward privacy when using social media.<sup>7</sup> Another study was related to HIV education and counseling,<sup>8</sup> and the third examined the participation of cancer survivors in social media and identity construction.<sup>9</sup> The fourth interventional study was a pilot study on the use of social media to support chronic disease self-management.<sup>10</sup> There were three observational studies: one provided an analysis of YouTube videos,<sup>11</sup> another focused on the qualitative evaluation of Facebook data for diabetes patients,<sup>12</sup> and one cross-sectional study focused on the use of social networking by patients with fertility problems. The survey article focused on assessing patients’ interest in the use of social media in healthcare.<sup>13</sup> The three literature reviews focused on patient engagement,<sup>1</sup> the use of social media to support people with

rheumatologic conditions,<sup>14</sup> and consumer empowerment.<sup>6</sup> The one conceptual article focused on the roles of social media for patients and consumer health.<sup>15</sup>

### *Patient-centered benefits of using social media*

**Video sharing.** Two of the selected studies focused on the benefits to patients of using digital social media (e.g. YouTube). In their systematic analysis of YouTube videos on cancer tumors, Clerici et al.<sup>11</sup> found several benefits to using that type of digital social media. The authors noted that online videos are a more effective way of sharing health information than written text. They also reported that it was easier for patients to describe their experiences and firsthand impressions relating to their disease using YouTube. Patients could describe and share their emotional perspectives and provide necessary coping skills, support, and resources for other patients.

In their review of self-management interventions in the digital age for patients with rheumatologic conditions, Li et al.<sup>14</sup> discussed the advantages of the use of digital media. The authors discussed benefits such as the use of digital media to deliver targeted videos to population groups that can use the information and resources (which cannot be done with written text). Drama, music, and dance can also be used to enhance patients' interactions with shared health information. As the authors noted, the more that viewers are emotionally involved through a video narrative, the more likely they are to make behavioral changes in response to the story that they visually see through the digital media. The authors also noted that for those with poor literacy skills, video provides a more user-friendly approach to sharing and understanding health information. Additionally, video can help reach ethnic population groups, especially when it is done through animation.

**Text sharing social media.** Most of the studies focused on text-based social media such as Facebook. The advantages to using Facebook for health consumers are numerous. Greene et al., in their study on social networking by patients with diabetes, noted several benefits of using Facebook for diabetes management. The authors identified the 15 largest Facebook groups focused on diabetes management and analyzed 690 comments from wall posts and discussion topics. The authors noted that there were several advantages to using Facebook related to information sharing, patient-centered management, community building, and data collection functions. The users accessed forms of specialized knowledge on diabetes management from peers, created realistic self-images of diabetics, and used Facebook as a community mobilization tool to write letters to prominent politicians with regard to insurance coverage.

Fisher and Clayton<sup>13</sup> conducted a survey completed at an outpatient family practice clinic in the United States. The study found that there were various benefits to the use of social media by patients. The survey reported that patients found more benefits to using social media when providers were more engaged in their care in areas such as providing appointment reservations and reminders, reporting diagnostic results, sending prescription notifications, providing health information, and answering general questions. The authors also discussed the benefits of social media for the elderly; as the number of elderly patients using social media increases, more effort is needed to engage the elderly population. The authors discussed other benefits of social media such as the rapid dissemination of support and information and the engagement of patients as active participants in their health, leading to a more educated consumer base. Because social media technologies are accessible, inexpensive, and easy to use, they can appeal to the vast majority of health consumers, which can improve patient engagement and empowerment. Finally, from the perspective of personal determinants of health, the authors remarked that social media can improve participation, autonomy, motivation, perceived self-efficacy, and trust for patients. Greene et al. also noted that

Facebook can be used for building identity, emotional support, logistical support, and easy-to-access disease management information.

In their literature review, Lober and Flowers focused on consumer empowerment in healthcare in the context of the Internet and social media. The authors conducted a literature review, including technical reports, white papers, books, journal articles, and websites.<sup>6</sup> They reported that there are several benefits to the use of social media by patients, such as the ability to share their experiences, seek information and opinions, and engage with peers and providers. The authors also discussed the high accessibility and interactiveness of social media as reasons behind its rapid penetration into healthcare. Additionally, they examined the advent of the social media website Patients Like Me, which enables patients to exchange information on treatment options and symptoms. The authors noted that social media websites such as Patients Like Me will lead to improved disease self-management.

Roblin<sup>10</sup> studied the potential use of mobile social networking healthcare<sup>17–19</sup> to aid in the support of chronic disease self-management. The author conducted a pilot study in which social media programs enhanced by mobile devices were used to mediate communication between adults with type 2 diabetes and to motivate them to self-monitor their blood glucose levels. Because of its relatively good design, the participants found it easy to use. Some of the diabetic patients put more care into their self-monitoring and also observed improved emotional health as a result of the peer support enabled by the social network.

Only one other article specifically discussed the benefits of using social media for patient engagement. In this conceptual review article, Thielst<sup>1</sup> discussed the role of social media and their impact on patient engagement. The author reported that social media can help patients find information when they are diagnosed with a condition that requires ongoing treatment and management. The author also noted that social media technologies can be used to reduce the utilization of health services and improve patient responsibility and acceptance. The author discusses other benefits of social media relating to sunscreen use, health behaviors, eating behavior, addictions, and patient empowerment.

### *Patient challenges in using social media*

**Video sharing.** Clerici et al.<sup>11</sup> and Li et al.<sup>14</sup> discussed the benefits of video-sharing social media sites also discussed some of the challenges associated with them. Clerici et al.<sup>11</sup> found several challenges to using digital social media such as YouTube. The authors reported that there was a risk of misinformation being circulated that would result in misleading patients and potentially harming patient safety. Thielst,<sup>1</sup> Greene et al., and Omurtag et al. noted similar challenges with regard to misinformation in both video- and text-based health information shared on Facebook. Li et al.<sup>14</sup> noted that another challenge to the use of videos in social media will be budgeting for ongoing maintenance and information technology (IT) support and the challenges of collaboration between the health and digital media sectors in the development and evaluation of health video content.

Song et al.<sup>9</sup> studied survivor identity in a video social media intervention. The study focused on how cancer survivors construct their identities using social media and the impacts of the use of social media on psychological health, specifically depression. Fourteen adult cancer survivors participated in the 6-month study and were asked to share their stories through video messages. The results of the study showed that cancer survivors who had negative stereotypes about cancer survivors were more prone to depression, whereas those with more positive associations did not. The authors reported other findings, including that some of the patients did not like to discuss cancer stereotypes and were more reluctant to discuss their experiences via social media sites.

*Text sharing social media.* Van der Velden and El Emam<sup>7</sup> conducted a qualitative study of teenage patients, privacy, and social media. The purpose of the study was to understand how chronically ill teenage patients are able to manage their privacy settings when using social media. The authors found that even though most teenage patients in the study use social media, rarely were such formats used to discuss personal health information. The authors noted that when teenagers used social media, it was not as a forum to discuss their treatment or diagnosis but as a place to act “normal”; they did not want to be reminded of their sickness or pain. The study reported that discussing their condition presents a risk for teenage patients, as it may impact their ability to establish relationships or obtain jobs or insurance. Song et al.<sup>9</sup> found similar results where cancer patients preferred not to represent themselves as patients online. With regard to privacy, Lober and Flowers<sup>6</sup> also noted that patients of various ages find privacy to be a primary concern when using social media for health-related information.

Van der Velden and El Emam also reported other challenges relating to the usability of social media. The authors noted that there is a mismatch between what users expect from their privacy settings and what is actually there, which has led some teenagers to ignore a social media site’s privacy settings.<sup>7</sup> Lau et al.<sup>15</sup> also discussed the importance of usability in the development of social media programs. The authors noted that it will be a challenge to develop social media sites that can benefit patient engagement and information delivery. They argued that more time should be devoted to including all stakeholders in the development of such sites and in testing the software programs for errors. When testing a social media system for usability, Roblin<sup>10</sup> found that there were rarely such issues arising with its use; however, issues related to concerns about sharing private health information were reported.

Rossotti et al.<sup>8</sup> conducted a multicenter Italian study involving physicians providing counseling and education to HIV patients through the use of Facebook. The authors identified various challenges in using social media to engage patients. The authors found that patients using Facebook would manipulate their virtual image and be untruthful by exaggerating their life experiences to seem more amicable and more appealing. Omurtag et al.<sup>13</sup> found that open communication regarding sensitive health information regarding fertility and sterility was also difficult. Another challenge reported by Rossotti et al.<sup>8</sup> is that Facebook messages are short and fast, which makes it difficult to conduct more intellectual and detailed educational sessions on complicated issues. Furthermore, Rossotti et al.<sup>8</sup> noted that it was difficult to indicate the type of patient engagement that was taking place between physicians and patients. Finally, the authors noted that the use of Facebook for HIV counseling and education only reached a limited audience.

Various studies included in this review addressed the issue of misinformation. Greene et al. qualitatively evaluated the content of diabetes communication in Facebook. The authors identified the largest Facebook groups on diabetes management. The authors found very little evidence of dangerous or misleading information on the diabetes Facebook pages. However, the authors noted that it was difficult to identify the authors of postings, especially when they were trying to promote non-Food and Drug Administration (FDA)-approved medications. The authors noted that this posed a significant problem with the credibility of the information posted on Facebook. Additionally, it was difficult to evaluate the truthfulness of individuals who discussed cures and treatments that have helped improve their management of diabetes. Clerici et al.,<sup>11</sup> Thielst,<sup>1</sup> Greene et al., and Omurtag et al.<sup>21</sup> found similar challenges with regard to misinformation in both video- and text-based health information being shared on Facebook.



## Discussion

The current state of the literature documenting patient use of social media for health shows that there are various benefits and challenges for patients when using social media for health. Overall, this review shows that there appears to be a promising future for the use of social media in health-care because it can be used as a tool to engage and empower the patient. The review found that using video through social media can have more of an impact on patient engagement than text-based interventions. The study also found that there is a promising future for social media in community engagement, information sharing, data collection functions, appointment setting, prescription notifications, providing health information, engagement of the elderly, improved participation, autonomy, motivation, trust, and perceived self-efficacy. We perceive these benefits as promising; however, more research is required to determine whether these benefits are realized in patient care.

Most of the studies included in this review were noninterventional, and those that were interventional did not focus on the health outcomes associated with social media use. Moving forward, future research should study the impacts of social media on health outcomes directly rather than using patient engagement, empowerment, or education as proxy measures for healthy living. We therefore advocate further research in this area to study the impacts of social media on health outcomes.

Finally, the articles that were identified in this review suggest that various challenges are developing at the same time that more patients are being engaged with social media. The primary challenges are related to privacy, security, the usability of social media programs, the manipulation of identity, and misinformation. These factors can pose serious threats to patient safety if not addressed appropriately by those who wish to engage patients through social media. These challenges should be incorporated into the research as objectives, as more information is needed to understand the future challenges of social media use in terms of patient safety, community engagement, and patient empowerment.

## Implications for patients

A number of issues emerge from the consideration of the research on social media in healthcare that have implications for patients. The use of a variety of different modes of interaction and media types has been described, such as text and video sharing, social media sites such as Patients Like Me and new and emerging applications. The extent to which these developments lead to improved patient empowerment in a way that improves health outcomes remains to be understood, but it is expected that these developments will lead to a greater involvement of patients in their own care. However, it is unclear how the types of participation supported through social media might lead to improved outcomes.

At present, very little is known about the type of information that is posted on social media platforms (i.e. in terms of information quality and evidence to support the use of that information). The implications of the type of information that patients obtain from social media platforms will need to be studied. Social media offer patients the opportunity to provide information as well as obtain and respond to content and information provided by others (i.e. information is exchanged between individuals or groups), and this information may be provided by those who have a similar health issue. Little is known about the quality of that information or how much of it is evidence-based. Additionally, little is known about patient review of such information and the decisions of social media users to either use or not use the information that is provided by other users. Here, we

need to understand the use of the available information as well as how patients react to and decide to use/not use information that they perceive as being incorrect. For example, do patients ask further questions of the individuals who generate the information, and do they ask for more information about context (i.e. is the creator of that information credible? Does the creator have the same disease or similar symptoms?).

Further studies of both the “usability” (in terms of ease of use) and “usefulness” of social media for effecting positive change and positive impacts to healthcare are needed. Along these lines, more outcome-based and process-focused studies would be useful. This could involve usability testing or remote live recording and analysis of users. Studies are needed to determine how the use of social media (1) affects understanding of health and illness, (2) promotes healthy behaviors, (3) affects personal health decision making, (4) affects how patients perceive their privacy and access to their information by others, and (5) impacts the relationships of patients with their healthcare providers. Evidence to date from the above review indicates that patients have a positive perception of social media use, but there is a need to better understand the deeper issues surrounding concerns about privacy, the potential for misinformation and the potential for integration into the healthcare system, including the desire indicated by patients for engagement with healthcare providers through social media.<sup>13</sup>

## Limitations

As noted, our current understanding of the impact of social media on patient empowerment and engagement is limited by the lack of studies that have involved interventions with trials and/or an analysis of health outcomes. Further work is needed to understand the problems users have when using each of the technologies, how the interactions involved in social media can be used, and what the privacy implications are, especially in terms of sharing sensitive health information through social media.<sup>16–19</sup> Ultimately, we need to better understand how social media can support patient empowerment in a useful way that will improve healthcare outcomes.

## Conclusion

Although there appears to be a growing number of research articles on the use of social media within healthcare, scarce primary research is available regarding the impacts of social media on patient engagement, empowerment, safety, or education. The few articles included in this review do show promise in the use of social media for patients on various levels. Although there are several challenges to be aware of for the patient, the review describes many more benefits for patients than harm to patients. However, a number of issues and challenges remain to be addressed to understand how social media can best lead to patient empowerment and, ultimately, improved healthcare. Out of the various challenges mentioned earlier, the primary challenge, from a patient’s perspective, is determining the impacts of social media on improved healthcare outcomes.

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