Ethical Issues of Social Media Usage in Healthcare

K. Denecke[1], P. Bamidis[2], C. Bond[3], E. Gabarron[4], M. Househ[5], A. Y. S. Lau[6], M. A. Mayer[7], M. Merolli[8], M. Hansen[9]

[1] University of Leipzig, Innovation Center Computer Assisted Surgery, Leipzig, Germany

[2] Aristotle University of Thessaloniki, Faculty of Health Sciences, Thessaloniki, Greece

[3] Bournemouth University, School of Health and Social Care, Bournemouth, United Kingdom

[4] The Arctic University of Norway, Faculty of Health Sciences, Tromsø, Norway

[5] College of Public Health and Health Informatics, King Saud Bin Abdulaziz University for Health Sciences, Ministry of National Guard - Health Affairs, Riyadh, Kingdom of Saudi Arabia

[6] Centre for Health Informatics, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

[7] Department of Experimental and Health Sciences, Universitat Pompeu Fabra - IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

[8] University of Melbourne, Health and Biomedical Informatics Centre, Melbourne, Australia

[9] University of San Francisco, School of Nursing and Health Professions, San Francisco, USA

Summary

Objective: Social media, web and mobile technologies are increasingly used in healthcare and directly support patient-centered care. Patients benefit from disease self-management tools, contact to others, and closer monitoring. Researchers study drug efficiency, or recruit patients for clinical studies via these technologies. However, low communication barriers in social-media, limited privacy and security issues lead to problems from an ethical perspective. This paper summarizes the ethical issues to be considered when social media is exploited in healthcare contexts.

Methods: Starting from our experiences in social-media research, we collected ethical issues for selected social-media use cases in the context of patient-centered care. Results were enriched by collecting and analyzing relevant literature and were discussed and interpreted by members of the IMIA Social Media Working Group.

Results: Most relevant issues in social-media applications are confidence and privacy that need to be carefully preserved. The patient-physician relationship can suffer from the new information gain on both sides since private information of both healthcare provider and consumer may be accessible through the Internet. Physicians need to ensure they keep the borders between private and professional intact. Beyond, preserving patient anonymity when citing Internet content is crucial for research studies.

Conclusion: Exploiting medical social-media in healthcare applications requires a careful reflection of roles and responsibilities. Availability of data and information can be useful in many settings, but the abuse of data needs to be prevented. Preserving privacy and confidentiality of online users is a main issue, as well as providing means for patients or Internet users to express concerns on data usage.

Keywords

Social media, health care ethics, information science, patient-centered care

1 Introduction

Due to improved possibilities and means to obtain information about diseases and treatments that go hand-in-hand with the development of social media and Internet technologies, patients are becoming more informed [1], and they increasingly want to be engaged in their care [2]. Social media are digital media and technologies that enable users to exchange information and to create media content individually or in community with others. This media is increasingly becoming a tool supporting healthcare processes, gathering and sharing information, bringing people together, and encouraging social networking and communication regarding health topics [3], and it supports in this way patient empowerment, i.e. it brings patients into the position to take control of their healthcare needs. The evolution of the Internet from a limited, technical resource, to today's dynamic "Web 2.0" where people are able to share information means increasing numbers of people living with a long-term condition are now putting personal health information into the public domain, including discussion boards, social network sites, blogs, videos and virtual environments [4].

1.1 Patient-centered Care and Medical Social Media

The phenomenon of social media and its increased importance in the private as well as in the public sector show there are many potentials even in healthcare settings enabling patient-centered care. In particular, individuals suffering from chronic diseases are using social media more and more to communicate with others, exchange information, and human experiences. **Peer-to Peer healthcare** is emerging as a source for patient information and support [5]. Patients, family members, and friends share personal medical information, receive emotional support, or request guidance and advice from healthcare professionals via social-media sites. **Social networking communities and data sharing platforms** support sharing experiences with conditions, symptoms, and treatment outcomes, but also enable to track personal health and be actively involved in one's own care coordination. For researchers, such data provide new opportunities to analyze observational data to confirm results from randomized trials [6]. Increasingly, social networks are being used to investigate adolescent and young adult behaviors and personality traits [7], as well as for data collection and education purposes. One application area in this context is **the recruitment of patients for clinical trials** based on social-media profiles or the exploitation of social-media data for epidemiological studies [8]. Beyond, physicians may use social networking to **crowdsource answers** to individual clinical questions. Researchers have found, based on the data posted on Twitter, they can **detect and monitor disease activity,** most notably disease outbreaks such as cholera

and influenza [9, 10], but more recently, data about issues like headache appearance was collected from tweets [11].

These examples show patient-centered healthcare, social media, and the Internet are beginning to come together. Patient behavior has notably changed already and will increasingly influence healthcare delivery and research. A couple of ethical questions arise when it comes to the use of social media in healthcare settings. If you have a Facebook or MySpace page with 600 "friends" is that your private page, or a public document? What do researchers need to consider when developing monitoring applications for healthcare using social media? What do health providers have to consider with respect to ethical questions of social-media usage?

1.2 Ethics in Healthcare

Ethics is defined as the discipline dealing with what is good and bad and with moral duty and obligation [12]. *Public health ethics* deal with the specific moral questions regarding public actions for disease prevention, life elongation, or psychological and physical well-being. This is in contrast to *medical ethics* which concentrates on the relationship between patients and doctors. The issue of how ethical principles may be applied to online health research is a current challenge for researchers, but also for health professionals and patients alike. In this paper, we start to explore these questions and topics.

2 Objective and Methods

The objective of this work is to examine the ethical implications of the aforementioned trends in the state of the art and to provide topics to be further addressed in the future. For this purpose, we selected use cases from our research work and analysis about the use of different social media platforms for health purposes. They include:

- the use of social media for the youth and the elderly,
- the impact on the patient-doctor

communication and relationship,
- crowdsourcing in healthcare,
- the integration of social media in clinical environments,
- the use of wearable technologies, and
- research regarding medical social-media including harnessing patient-reported data, conducting online surveys and participant recruitment.

We collected and summarized ethical issues related to these use cases from our experiences and conducted a review of the literature (both white and grey). Further, we performed an environmental scan of popular and current applications and services in this area. The results were then discussed and interpreted. We concentrated on identifying and discussing relevant ethical aspects without writing a systematic review to match with the IMIA Yearbook objectives and structures. The authors of this work, all members of the IMIA Social Media Working Group (http://www.imia-medinfo.org/new2/node/289), have skills and expertise to discuss around the results since we have a deep interest and a professional experience of using social media in healthcare. We have experienced ethical issues in our work.

3 Ethical Issues of Social Media Usage

3.1 Use of Social Media for Youth

There is a group of people who have grown up with the Internet: the youth, or the digital natives, regularly engage with new social-media [13], base their personal identities online [14], and social media is their natural environment. *Youth* is defined as a transition period from the dependence of childhood to adulthood's independence [15]. It is also the period when one's personal identity is formed, based on both individualities and the social environment [14]. For this digital native generation, the online social-media represents a space for connection, identity exploration, a space to express ideas, sexual identities, feelings, problems, and also a space where we receive feedback from others [16].

For a majority of youth, online social networking sites are their first point of call when they want to find information, including health-related matters [17, 18]. Thus, social media is a rich environment to recruit youth participants to participate in research. For example, recruiting participants from Facebook and Twitter is one of the most effective recruitment strategies in youth-related research studies [19, 20].

Although using social media to recruit participants for research is positively viewed by the youth [21], it presents a number of ethical issues that need to be addressed. Obtaining informed consent from adolescents via social media represents a number of concerns [19]. Recruited participants over 18 years may provide their consent online, or their written consent, if they are redirected to a study site. But, how may we obtain parental consent from those contacted or interested under 18 years of age via social media [19]? In fact, is it ethical for study advertising material to be circulated in social media, targeting at those who are under-aged, and may have not reached the cognitive maturity to decide whether to participate or not? An alternative (and arguably more ethical) way to recruit very young people would be to target parents rather than children [19]. However, one needs to remember that policy settings in social media frequently change. For example, although Facebook reviews all the advertisements targeting young people under 18 years, their privacy policies can change without prior notice, and there is no mechanism to confirm one's age declared online.

When trying to reach youth through social media, whether it is for public health education or for public health monitoring, the same confidentiality and privacy rules that are applicable offline should also apply [22]. Although social media is a platform that allows a researcher to easily reach their targeted audience, establishing a dialog with them may not be as easy as one perceives. A recent qualitative study examining teenage patients' privacy concerns related to health matters revealed most participants did not disclose their personal health information on social media [17]. In this study, Facebook was seen to be a place for these teenage patients to be 'regular' teenagers, to stay

up-to-date about their social life, and not seen as a place to discuss their diagnosis and treatment. In fact, the majority of them did not use social media to come into contact with others with similar conditions. Using social media as a health intervention needs to delicately consider participants' concerns for privacy. Some young users may prefer to interact with others anonymously, perhaps because they are struggling with sensitive issues, such as their sexual identities, or chronic diseases [17, 23]. Some would not want others to find out their true underlying health status and concerns, or they would not want updates about their health to be 'broadcasted' to their social network. On another scale, there are those who readily share very personal information that may be accessible by the broad general public [16]. In any case, young individuals' privacy and their level of comfort in discretion of health matters must be respected and preserved in the social media setting.

3.2   Social Media to Train the Elderly and their Care Givers

Like in the case of children and young people, elderly patients also have rights in the context of social media usage [24]. Despite recent discourse on whether the society should strive for technologic advancement of aging [25], or the related dispute between intrusiveness and isolation deepening with regards to elderly telecare/homecare [26, 27], this section touches issues related to the use of low-cost technology for elderly healthcare. Numerous efforts recently have been geared towards cognitive training or "brain training." The latter is usually marketed as a way for people to improve their memory and cognitive skills [28]. To this extent, the Internet and social media may be used as means of dementia (and other disease) prevention and health promotion [29] to train the elderly by cognitive exercises and novelty serious (web-based) games. For example, the training software Video GRade [30, 31] shows YouTube videos/documentaries to the elderly user (topics derived from nature, art and history etc.), and entails the user's attention control as it demands answers to simple questions at the end.

The aforementioned training piloting or deployment of the elderly through games and social-media content usually is confronted with the requirement of informed consent. This is highly associated with the certainty the affected party clearly understands what they are consenting to. Numerous studies have shown that whilst e.g. a checkbox may fulfill legal requirements to gather and record consent, it is not sufficient when the underlying ethical and environmental basis is that of elderly users, some of which may be mildly (cognitively) affected. Thus, future projects or systems could follow contemporary approaches to verify consent is both informed and relevant. This may be facilitated by suitable tutorial sessions and workshops on consent decisions and ensuring safe consent record keeping and processing. The consenting process could, in some cases, involve all interested stakeholders/parties: the patient, his/her care giver(s), and health professionals, in an effort to ascertain all parties understand what is being consented to.

Switching into a slightly different but still related theme, recent developments witness the use of the Internet and social-media content for training the elderly care giver(s) (formal or informal) [28]). For instance, the DISCOVER project aims at increasing carers' knowledge and independent digital skills development - as a way to enhancing their caring role - whilst at the same time providing a window to carers' needs for a range of service providers [32]. DISCOVER's ultimate aim is to improve the care giver's life quality, as well as the care and the life quality for those they care for. Usual ethical concerns in such projects, which often involve the conduction of relevant pilot trials, include those of confidentiality and privacy, consent, autonomy and choice, justice/fairness, inclusion, security, and dignity, with project guidelines not necessarily pointing to clear answers and possibly including conflicts between different ethical pointers. To accomplish care giver training, Internet content curation is one of the followed approaches enabled by means of appropriate curation tools like "Scoop.it!" and other project-based products. Within content curation, only carefully selected parts of content are considered and enriched with relevant commentary or insight, highlighting of

important parts, and always assigning credit to the content's originator [33]. In this direction, one of the relatively unexplored issues is content curation ethics, with only a few recent attempts at establishing best practice guidelines available [34].

A last issue in supporting web training of care givers with social-media content is concerned with the ethical dilemma between certification and accreditation [35]. Currently, the use of social media better resembles "lightweight" rewarding process schemes rather than formal accreditation tactics and policies governed by regulatory bodies. However, the latter may be more effective in job hunting prospects. Current best practices consider that certification without accreditation is the most viable option, as it is contended to play an important role in increasing care givers' motivation to complete pilot training activities, as they promote a sense of satisfaction and reward, while enabling them to exhibit skills progression and reflecting commitment to personal development. Using Internet certificates and Internet badges to demonstrate non-accredited training reflects a growing global trend which might be a suitable ethical resolution to this problem until care givers reach any formal assessment points having consumed enough social-media content.

3.3   Ethical Issues of Patient-doctor Communication through Social Media

We already considered ethical issues related to social-media usage and research involving the elderly and the youth. In this section, we will look at the implications of social-media usage in traditional care settings, which involves patient-physician communication. Patient-physician communication in the traditional sense comprises the direct contact and questioning of the patient by the physician, and the discussion of treatment options. Information on diseases, therapies, and medications is exchanged; sometimes, administrational issues are clarified, such as making appointments. This communication is strongly characterized by medical confidentiality, trust, and privacy. Data is expected to be

safely stored in the patient record, inaccessible to others, and even protected by law (e.g., in the Data Protection Directive 95/46/EC in Europe). With the development of Internet technologies, communication and monitoring in healthcare is starting to be outsourced to social media. Appointments can be made on-line, health information and even examination results can be distributed by e-mail. Social media can become an "icebreaker" that may improve the communication between patient and physician, resulting in better patient care [36]. However, this communication via the Internet is conflicted with a couple of ethical issues since technologies impact data privacy and security. Guidelines with respect to patient-doctor communications mainly address email communication [37, 38], and information exchange through websites, and concern confidentiality, unauthorized access to computers, informed consent, or privacy risks.

The patient-doctor relationship may suffer from two main situations. On the one hand, patients may have unrestricted access to their doctor's personal information as it is provided on the Internet. To address this issue, the American Medical Association (AMA) [39] recommends when using the Internet for social networking, physicians should use privacy settings to safeguard personal information and content or, even better, keep private and professional sectors separately. However, they should realize privacy settings are not absolute and once on the internet, content is likely to be there permanently. It is important for physicians and other healthcare professionals to famil-iarize themselves with the privacy provi-sions for different social-media applications and adjust the settings to ensure the content is clearly protected.

On the other hand, physicians have access to online patient information that may other-wise not be available in the healthcare setting (e.g. lifestyle information from patients posted in a personal blog). Such information about a patient received from online sources may be helpful in certain healthcare settings, but physicians need to be sensitive to the source and the way the information was displayed publicly. They should use their clinical judgment in determining whether and how to reveal such information during the treatment of patients. Digitally tracking

the personal behaviors of patients, such as determining whether they have indeed quit smoking or are maintaining a healthy diet, may threaten the trust needed for a strong patient-physician relationship and have an influence on their treatment of the patient [5].

In summary, physicians must carefully maintain professional relationships and confidentiality in online settings. Emails and other electronic means of communication may supplement, but not replace, face-to-face encounters. Establishing a patient-phy-sician-online relationship, for example to "friend" a patient or ask a patient to "friend" a physician is ethically questionable [5]. The problem results from the fact the profession-al boundaries of interactions are less clear. Physicians may share personal, but also professional content online. Maintaining professional trust in a patient-physician re-lationship requires physicians to consistently apply ethical principles for preserving the relationship, confidentiality, privacy, and respect for individuals in online settings and mutual communications [40]. Online interactions with patients may pose chal-lenges because of the ambiguity associated with written language without the context of body language or lack of awareness of the potential abuses of social-media data [5]. The AMA [39] also claims physicians should be aware of the standards of patient privacy and confidentiality that need to be maintained, and must refrain from posting identifiable patient information online.

3.4 Crowdsourcing in Healthcare

Another issue that influences the patient-doc-tor relationship is the opportunity for patients to seek answers to their healthcare questions through social media. Through crowdsourc-ing, patients can ask for a second or third opinion on a diagnosis or treatment of a med-ical condition. The "wisdom of the crowd" offers an opportunity to seek medical advice from other patients or clinicians from around the world through social networks such as Facebook, Twitter, HealthBoards, or Patients Like Me, and more recently, CrowdMed [41]. The term *Crowdhealth* referring to the use of social networks to solicit information from a large group of people on a treatment

and diagnosis, or for a general health advice is new to healthcare. For example, in 2012, TIME magazine published the story of a husband seeking treatment for his ill wife by posting her health information on Facebook. He posted her medical records, symptoms, confirmed suspicions through his Facebook page and posted "I am throwing down all my cards on this one." [42]

With the growth of *Crowdhealth*, there are a variety of ethical issues related to the privacy of health information that are worth exploring since our current understanding of privacy and confidentiality are being challenged. Today, people are sharing their general and sensitive health information online looking for feedback from virtual community members. To illustrate, in 2011, a study on the sharing of sensitive health in-formation through Facebook found Facebook users openly sought and shared information relating to behavioral, mental, and genetic health information [43]. The study explored publicly available Facebook groups and found users publicly identified themselves by divulging their name, photo, and location when seeking sensitive health information through online postings.

Furthermore, there is no contemporary healthcare privacy legislation in Europe or North America that may stop individuals from posting their health information online. The privacy laws in place today only protect an individual's healthcare information from institutions. *Crowdhealth* platforms, such as Crowdmed, clearly state on their Websites that "any medical information they provide will be published anonymously in the public domain, will be posted as-is, and it is the patient's own responsibility to remove any personally identifiable information from uploaded materials." [41].

Although the above statement is valid, the issue of healthcare privacy becomes murky when a parent shares their child's health information online along with pictures to a public audience, which was recently discovered on CrowdMed*. The posting has been removed, but the U.S. Children's Online

---

* The researcher conducted a search in July 2014, which found a Crowdmed patient posting their child's health information online along with a number of pictures of the child.

Privacy Protection Act (COPPA) states on its Website, that an operator must obtain verifiable consent from the child's parent before collecting, using, or disclosing personal information from a child [44]. In this case, the parent posted their child's health information online, but issues concerning consent and how the information was posted remain unclear.

The ethical issues related to sharing health information in *Crowdhealth* platforms are challenging our perceptions on healthcare privacy. There are many ethical issues relating to how information is shared, how consent is obtained, relating to the use of the information for research or for commercial use, the sharing of information of minors by parents, and the validation of the user and the information they post. *Crowdhealth,* a new arrival, will only exacerbate these ethical issues relating to healthcare privacy.