Developing a Research Agenda on Ethical Issues Related to Using Social Media in Healthcare

Lessons from the First Dutch Twitter Heart Operation

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Abstract: The consequences of using publicly available social media applications specifically for healthcare purposes are largely unaddressed in current research. Where they are addressed, the focus is primarily on issues of privacy and data protection. We therefore use a case study of the first live Twitter heart operation in the Netherlands, in combination with recent literature on social media from other academic fields, to identify a wide range of ethical issues related to using social media for health-related purposes. Although this case reflects an innovative approach to public education and patient centeredness, it also illustrates the need for institutions to weigh the various aspects of use and to develop a plan to deal with these on a per case basis. Given the continual development of technologies, researchers may not yet be able to oversee and anticipate all of the potential implications. Further development of a research agenda on this topic, the promotion of guidelines and policies, and the publication of case studies that reveal the granularity of individual situations will therefore help raise awareness and assist physicians and institutions in using social media to support existing care services.

Keywords: social media; Dutch heart operation; Twitter heart operation; social media; health-related; public education; innovation in healthcare

Introduction

Healthcare professionals and organizations increasingly view social media—web-based applications that facilitate collective knowledge production, social networking, and user-to-user information exchange—as important tools for facilitating patient engagement and improving the delivery of patient-centered care. But a move toward incorporating social media into established care processes brings institutions and professionals into quite different, relatively unfamiliar territory, for which "good practices" are not yet established. Social media are but one example of a changing pattern in healthcare: many applications first available to patients originate outside the healthcare sector and slowly diffuse in, often as a result of commercial push.[1] This alone suggests the importance of considering the ethical implications of appropriating such applications for health-related purposes, and their increased use in actual patient care delivery further magnifies this need.

Given the unique nature of social media and the fact that they are still developing, we must consider at a general level both the special characteristics of a specific application and how ongoing changes to the contracts and services of applications (e.g., consolidating user accounts, linking applications, and/or actively monitoring data exchange within and between applications) affect (health) information exchange. Social media use in healthcare also brings sector-specific ethical considerations that may not apply elsewhere—most specifically, characteristics that alter

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the boundaries of the patient-provider relationship by "opening" the traditionally protected space of the medical encounter.[2] In the Netherlands, this has led individual institutions and professional groups to develop policies[3,4,5,6] that address some of the practical issues related to social media use, such as educating both professionals and patients about the need to consider the publicness[7] and permanence of online activities *before* posting comments about one's own health, that of another, a clinical encounter, or the quality of a given treatment or care trajectory.

This combination of social media–specific characteristics and health sector–specific characteristics makes the increasing uptake of social media in healthcare a particularly fertile area for ethics research. Yet, the consequences of using publicly available social media applications or platforms specifically for healthcare or health-related purposes and the multiple trade-offs involved have been largely unaddressed until now. A recent review of literature on how microblogs (such as Twitter) are studied in the medical profession found no articles that explicitly address ethical issues.[8] Where the issue *is* raised—for example, with regard to public platforms where individuals may create, store, or share personal (and potentially sensitive) health-related data—the focus has been almost entirely on data protection and individual privacy.[9]

In this article, we therefore use a case study, in combination with relevant social science literature, to tease out a myriad of issues related to the use of social media in healthcare and to provide the groundwork for a much-needed research agenda on this topic. The purpose of this article is thus *not* to test adherence to a given policy or code, but to address—from a practice viewpoint—which issues arose during this experiment, how they were dealt with, and which issues warrant more attention in the future. The case is first live Twitter heart operation in the Netherlands, which—in terms used by scholars of media studies—became a national "media event." Although microblogs are a specific form of social media, with unique characteristics,[10] this case nonetheless provides a concrete example that can be extrapolated to other social media as well. Following a brief note on methods, we examine the ethical issues that arose in relation to the process of having health professionals and patients post on Twitter (i.e., "tweet") together about a specific health event, in relation to the specific operation, and in relation to other issues that remained more implicit in the case but were raised in internal discussions and may still be important in the future. The discussion outlines the implications of the aspects highlighted in this case for using social media in healthcare more generally.

Methods

Because of the novelty and uniqueness of this particular case, as well as the ongoing discussions related to social media use in daily life, we used an inductive approach to outline the issues that arose in practice. There was no preselected ethical framework applied to the data; rather, we followed, in a general sense, work on ethics and technology that views the relationship between the two as one of mutuality and accompaniment.[11] This work suggests that technology and ethical questions should be viewed not as two separate domains but as mutually shaping one another, whereby studying the use of the technology in practice enables researchers to identify points of moral reflection. Additionally, we draw on a number of recent discussions in media studies and science and technology studies about the unforeseen consequences of social media use.

Although the patient is not named, the high-profile, public nature of this case and reference to media attention and the hospital could indirectly lead to identification of the patient's identity. We therefore obtained express written permission from the patient and the Board of Directors of the hospital to use this case.

The Case

In 2012, the Catharina Hospital in Eindhoven, a nonacademic hospital, conducted the first Dutch Twitter heart operation. Plans for the operation were developed in conjunction with Philips Medical and were first announced as a teaser for a national conference on innovation in healthcare held in the region in 2011. The initiating physician hoped that both the operation and the conference would be a stimulus for policymakers to support more innovation in healthcare, especially the use of information and communications technology (ICT) for providing patient-centered care. The operation was also intended to introduce the face of the patient—the human factor aspect—into discussions among other stakeholders, such as policymakers, by allowing them to follow the day-to-day aspects of care.

Prior to the operation, the cardiologist identified several potential patients who might be interested in participating in this innovative project. The consenting patient was provided with an iPad and taught the basics of use, including how to tweet. Both the patient and the cardiologic team (physicians, nurses, and technicians) created Twitter accounts. In the weeks preceding the operation, the patient tweeted about the pending operation and preparations for the procedure, current health condition, etc. and responded to any questions posted on the Twitter feed by followers. Following the operation, the patient tweeted about the process of recovery. The surgeon answered followers' questions about the process. One of the hospital's surgical assistants tweeted about the progress of the procedure in situ. The cardiologist and the patient both had about 900 followers at the time of the operation, and 1.8 million people followed the live event.

A local newspaper picked up this human interest story, with a headline about how the Twitter community was providing the patient with moral support; a short spot was carried on regional television; and the story was then picked up by the national press. In response to the newspaper articles, the first author contacted the hospital about the possibility to analyze the case.

Ethical Issues

In this section, we discuss the ethical issues that the hospital encountered in developing this case. We begin with general issues related to the idea of and process around having health professionals and patients tweet together about a specific health event, followed by issues related to the operation itself. We finish with more general issues and a look toward the future.

The Process around the Procedure

The Twitter operation project began as a move toward more patient-centered care, but also as an innovative structure for garnering policymakers' attention regarding the importance of stimulating innovation in healthcare. One of the first aspects to examine, therefore, is the relationship between these two goals. Patient centeredness

is one of the central tenets of modern healthcare. But at the same time it is often used as a vehicle for meeting other (political or economic) goals, such as the implementation of new ICT systems in healthcare (often as a result of a strong market push)[12] and the implementation of consumer choice in public services prevalent in Western health systems over the last 20–30 years.[13] These particular goals are arguably intended to reduce costs while enabling high-quality care.

ICT is accompanied by a number of promises with regard to improving quality while cutting costs. Internet-based applications in particular are expected to fulfill such promises by allowing patients to take more responsibility for their health and have an active role in care-related processes, thereby lessening their reliance on health systems.[14,15] These applications are also expected to make communication within existing processes more efficient and effective.[16] ICT use in general, and this case in particular, raises the issue of whether the initial reason given (patient centeredness) is actually the end or whether it is primarily used as a means to another end (political attention, implementing new technologies, cost reduction, etc.).

Because ICT is also a symbol of innovation in care, the types of applications used can help healthcare providers better profile themselves (for example, as modern and patient centered), which becomes increasingly important in regulated-market settings, such as the Netherlands, where the aforementioned consumer choice agenda means that patients are actively encouraged to weigh all available options and choose the provider that best meets their needs. Institutions are increasingly using social media platforms such as Twitter for improving public relations;[17] however, they must also be careful that this does not (even unintentionally) oblige patients to use such technologies and in the process promote or validate specific types of *immaterial labor* (sometimes called "invisible work")[18] or allow commercial interests to capitalize on health promotion and individual users' data.[19]

This potential profiling goal on the part of the hospital was also evident in the coverage of this case in the popular press.[20] Although responses to the initiative were generally positive—displaying enthusiasm about this attempt to break through more traditional modes of communication and patient education or arguing its necessity for renewal in healthcare—from a distance there was some criticism. One concern was how this project might lead to more benefits for the hospital (for example, the Cardiology Department experienced an unexpected increase in the number of referrals in the three months following the operation) than for the patient, especially because patients currently do not request participation in these types of activities. In one of the responses to the human interest story in the local newspaper, a letter to the editor questioned, "What will the next hospital do to position itself as 'modern'?"[21]

This indicates that institutions need to be aware of the potential conflict between different goals and of the importance of not using patient centeredness in name only or as a means to another end. It also indicates the need to be open about motives for initiating such projects, as well as to be aware of the possibility that patients may feel a certain degree of social pressure to participate. Even when the patient is given the choice and such participation is not consciously or intentionally imposed by the physician or institution, the dependency of the patient within what is still a somewhat hierarchical relationship (despite the modern move toward viewing the doctor-patient relationship as a partnership involving shared decisionmaking) means that a request to participate could feel obligatory. In the

case discussed here, after the initial request, the patient was placed in the lead (as stated by the surgeon, the patient "carried" the project) to ensure that this was not the case. The hospital included a number of checks and balances, including extensive discussions with the patient about potential consequences, before proceeding with the media event.

During the Procedure

Probably the most obvious question that arises in regard to tweeting information about an operation in situ, with the identity of the patient being known to the public, is one of *patient privacy*, *confidentiality*, and the *limits to public disclosure* of information. Is it legally and morally acceptable, even with informed consent, to disclose, to the public, information from the protected space of the medical encounter? Moreover, how are the patient, the family members, and the public following the event to be protected in the event that something goes wrong?

This particular aspect of the operation reflects the trade-off between the highly celebrated nature of social media as a low-threshold avenue to population-based health education[22,23,24,25] and the protection of the individual patient in specific situations. The physician and hospital management were of course aware of the privacy issues that would come into play, as well as the risks associated with surgery, which they dealt with in turn. First of all, although there is always a certain degree of operative risk, patients approached to participate in the project were to undergo comparatively low-risk, routine surgery. Second, the hospital took the position that the public should not be proxy to any information that the family in the waiting room did not have, nor should they be able to deduce a problem through, for example, sudden radio silence. This was discussed ahead of time, and there was also a communication plan for the operation.

For the cardiologist it was important that the professionals remained in control of the information disclosed about the operation and that the patient and family members remained in control of any personal (health status) information that was publically disclosed. Therefore, the technician's tweets and the pictures that were relayed during the operation contained only standard details about the surgical process in order to educate the public, rather than specifics about the condition of the patient. For example, "Now making contrast images from the different chambers in order to post a 3D model of the left side" or "[cardiologist] is now carefully placing the catheter."

An additional potential concern about such an activity during the operative process is the *potential for distraction*. This is a professional concern that has arisen together with the increasing trend toward tweeting during operational procedures, even with educational intent. The potential distraction of surgeons due to special circumstances, when other things are going on, could deprive patients of highest-quality care. However, as Seeburger et al. point out, there is lack of scientific data to back up such concerns.[26] In the case presented here, the activities were compartmentalized to prevent the possibility of such distraction. Following similar practices elsewhere,[27,28] the surgical team was responsible for the surgery, whereas a colleague familiar with, but not involved in, the surgery (and who was physically located in the adjoining room) was responsible for the Twitter activities.

Other Issues and a Look to the Future

During discussions between the authors that were held several months after the operation, several concerns were raised with regard to future plans to stimulate more active use of social media in healthcare. Some of these questions are still related to the case, whereas others are more general.

First and foremost remain concerns regarding the role assigned to (and related protection of) the patient. Fortunately, in this case, the patient was open to the idea of sharing details about the operative process with a broad Dutch-speaking public and the response from that public was also primarily positive, indicating a specific therapeutic value as well. But, before institutions further stimulate similar projects, it is good to consider that such publicness and publicity may also potentially increase anxiety among some patients. Moreover, it is important for physicians and patients to consider how to respond to undesirable or hurtful texts and how to assess in each situation whether there is a necessity to screen interactions.

In the previous section it was evident that the hospital took an active approach to protecting patient privacy by compartmentalizing who posted what types of tweets. But there is another privacy point that was perhaps less evident to all parties involved. It is nonetheless an important aspect to consider. There is an additional privacy layer that goes beyond just disclosure of information to a following public. Social networking platforms attract large numbers of users who provide data that are interesting for (commercial) third parties. Platforms may store or collect, analyze, and/or sell these data to these other parties.[29] Besides the fact that most users rely on default privacy settings,[30] recent media coverage of social media privacy policies and user-tracking practices[31,32] has indicated that standard privacy settings guarantee protection of personal data only to a certain point. Moreover, policies for use continue to develop and shift, whereby data platforms become coupled in unpredictable ways. The importance of understanding and staying up to date on a given platform's policies for data exchange and use therefore remains an important point for healthcare providers, especially when using publicly (i.e., commercially) available software to engage with patients through social media. If institutions plan to or already encourage patients to use social media for health-related purposes, it is advisable to develop an in-house platform.

A second concern is the role and protection of the professional when engaging with patients through social media. Physicians realize that although many cases go well, mistakes can be made. Moreover, they currently wrestle with questions such as how they should respond if they see signs in social media posts that reflect a serious or acute problem—how far does the responsibility to act extend in the online context? Moreover, how should physicians respond if directly confronted via social media with a serious problem—to what degree does such contact establish a formal care relationship and to what degree are professionals held liable for the response they do or do not give? This is an issue that varies per country in terms of legal culture, professional agreements, and other factors. There is not one answer, but this indicates that professionals do have questions about what to expect and how to act. These are questions that need to be addressed in the local contexts where social media use in healthcare is stimulated.

Because this particular case was initiated to garner policymaker and insurer attention, a third concern is the relationship between social media and

financial reimbursement. This project had a small amount of material support from the medical supplier, in order to support the tweeting practices of the patient and the technician. This raises issues about not only the commodification of the patient experience[33] and various degrees of immaterial labor on the part of the patient (again related to the need of the hospital to profile)[34] but also larger issues about payment for health-related exchanges via social media in the future. How does the use of social media fit within existing payment/reimbursement structures, and what new ethical issues might subsequent changes to these structures raise?

Several points raised in this case are closely related to the overarching issue of *transparency*, whereby institutions disclose more information about internal processes. Transparency of performance has become an important concept in Western medicine in the last two decades. Many resources, online and off, have been devoted to helping patients determine the quality a care institution provides based on rankings, indicators, and so on. Increasingly, patients are expected to contribute to this transparency as well—for example, through rating and recommendation sites where they review various aspects of their care.[35] Because this is largely part of the choice agenda that is used to influence quality,[36] this move toward transparency relates to the issue of institutional profiling, as mentioned previously. The use of social media can help provide more insights into hospital and physician performance. Much like rating and recommendation sites, however, this raises the possibility that hospitals must deal with very public critiques, as was evidenced not only in the comments from letters to editors of newspapers, as mentioned previously, but also in a limited number of comments tweeted to the patient and physician. This also requires having a communication plan that allows the participants to respond to such open critiques but does not obscure transparency with predefined responses.

A final point is the role of the first author as social scientist in this story. There has been a recent reflexive turn in digital studies, with social scientists pointing to the need for researchers to consider the implications of our own roles, motives, and practices in using the data that we find online.[37,38,39,40] Both in healthcare and in other social sectors, researchers have pointed out that we, ourselves, should more thoroughly consider the consequences of our actions and be open about what we want to achieve in reviewing such data. What the conventional notions of private and public mean in online research venues is pertinent to the collection and analysis of data from social media.[41] The high-profile Harvard case[42,43] shows the seriousness of emerging ethical challenges faced by scholars in researching social networks and other online environments.

Especially in health research, which often deals with sensitive topics, this raises the question of how to establish ethical boundaries.[44,45] Just because information is posted online for the world to see does not always mean it is fair game for all uses. Although there is no consensus among social scientists, a general rule of thumb is to consider the issue of *intent* and *awareness* on the part of those posting information on the web. It is commonly accepted that persons posting do expect a certain degree of anonymity or privacy.[46] It is therefore important that researchers realize that there is no one answer to these concerns that applies across the board; rather the issues that arise depend on the specific context of use. This implies the need for thorough examination of the ethical aspects and considerations for each individual case. Despite the high-profile nature of this case, the first author

therefore still checked with the hospital and patient about any information that was potentially sensitive.

Discussion

The first Dutch Twitter heart operation is a fruitful case for teasing out the ethical issues that arise when social media are used to deliver patient-centered care and/or public health education. This case, although it is a first in the Netherlands, follows developments in other countries (primarily the United States),[47,48] where healthcare professionals tweet during surgery, sometimes with live-streaming video, for the purpose of educating the public. It further follows a longer media tradition of, for example, reality television broadcasts of operations, births, and so on, for the same educative purpose. The significant difference with this case, however, is the unique combination of widespread media attention, an active role for the patient, and the real-time nature of the event. Whereas the identity of the patient may be known in television shows, for example, these are usually edited prior to broadcast. In the case of U.S. Twitter operations that are broadcast in real time, the identity of the patient is generally protected. In this case, these two aspects are combined, with the patient being known by name and also becoming the "face" of the project prior to the actual operation. In this respect, the patient became a Dutch version of the well-known e-Patient Dave, who has opened up about the state of his health as part of his advocacy for innovative approaches to healthcare through technology.[49,50]

As was stated previously, use of social media is increasingly celebrated as better enabling the delivery of patient-centered care and population-based health education.[51,52,53] Twitter, especially, has been identified as a quasi-medical device that provides an increasingly valuable stream of medical data for the purposes of, for example, biosurveillance.[54,55] There are also longer-standing initiatives in which patients use websites for sharing data about their health,[56] and Google cofounder Larry Page recently argued that even more individuals should share their medical data.[57] But there is a need for caution here. The implications of such publicness in relation to healthcare (and, especially, of institutions or professionals actively encouraging patients to use public platforms for disclosing more information about their health, treatment, etc.) have not yet been thoroughly examined. Moreover, given the aforementioned continual development of social media technologies, we might not yet be able to oversee and anticipate all of the potential implications.

Insufficient protection of patient and professional rights could adversely impact the doctor-patient relationship.[58] Although there is some guidance at the local level from institutions and professional associations regarding social media use, further development and promotion of guidelines and policies is necessary. Moreover, there is a need for more research in this area. Case studies such as this that reveal the granularity of specific situations or offer points to consider[59] could raise more awareness about the interplay of various issues related to use and could assist physicians and institutions in using social media to support existing care services. Based on the insights developed during this project and commentary delivered in this article, we specifically recommend assessing on a per case basis how the points raised here apply to patients and their families, physicians and care institutions, the specific social media platform in question, and social scientists or other researchers interested in such data exchange.

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