Ethics Rounds: In the Eye of a Social Media Storm

Donna McKlindon, MSN, RN, PMHCNS-BC,[a] Jake A. Jacobson, MA,[b] Pamela Nathanson, MBE,[a] Jennifer K. Walter, MD, PhD, MS,[a] John D. Lantos, MD,[b] Chris Feudtner, MD, PhD, MPH[a]

abstract

Social media, no stranger to health care environments, is increasingly used by patients, families, clinicians, and institutions to interact and engage in new ways. The ethical challenges related to the use of social media in the clinical setting are familiar, yet come with a novel twist, including the possibility of having a conflict "go viral". Health care clinicians and institutions must understand and embrace these technologies, while at the same time promoting policies and practices that ensure the ethically appropriate use of social media and address strategies for preventing and responding to a social media crisis.

Social media is a novel aspect of health care in the 21st century. Now quite commonly, social media affects patient/parent–clinician communication, the ways in which both patients/parents and clinicians access medical information, and the ways that advocates for particular health policies can publicize their causes and garner public support. These developments can lead to unique ethical dilemmas. In this *Ethics Rounds*, we present a case (combining elements of several real cases) in which a family publicized health information about their son who was a patient at a children's hospital. We then ask clinicians from Children's Hospital of Philadelphia and a public relations (PR) expert from Children's Mercy Hospital in Kansas City to comment on how they would deal with the media attention that resulted.

THE CASE

The parents of a 10-year-old boy who was hospitalized with cancer started a blog. The blog included posts by both parents and the patient. The boy and his parents invited doctors, nurses, and other hospital staff to subscribe to his blog. Many did, joining an extensive community of supporters. By the time the boy was discharged months later, the blog had more than 1000 subscribers.

Not quite a year after going home, the boy was readmitted with a relapse of his cancer. He announced his relapse on his blog. On the fourth day of his hospitalization, several TV news station trucks arrive at the hospital to cover the developing story of how the boy's parents have launched an online petition to obtain access to a novel biologic agent that, in theory, could be used to treat his cancer. The novel biologic agent has not received US Food and Drug Administration approval. The pharmaceutical company developing the drug has not been willing to provide the drug outside of an institutional review board–approved research study. At the time of the parents' petition, no such IRB-approved studies are actively enrolling patients.

The online petition garnered 60,000 signatures in 48 hours. The hospital was unaware of the petition until the news trucks arrived. The oncologists are willing to treat the patient with

[a]*Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; and* [b]*Children's Mercy Hospital, Kansas City, Missouri*

All authors contributed to the design of this paper, the drafting of the manuscript, the review of the manuscript, and approved the final version.

DOI: 10.1542/peds.2016-1398

Accepted for publication Apr 28, 2016

Address correspondence to Chris Feudtner, MD PhD MPH, General Pediatrics, 3535 Market St, Room 1523, The Children's Hospital of Philadelphia, 34th St and Civic Center Blvd, Philadelphia, PA 19104. E-mail: feudtner@email.chop.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

To cite: McKlindon D, Jacobson JA, Nathanson P, et al. Ethics Rounds: In the Eye of a Social Media Storm. *Pediatrics.* 2016;138(3):e20161398

the drug on a compassionate use basis if the company will make the drug available. The hospital, hoping to avoid a media firestorm, seeks to resolve this situation quickly and amicably. The boy's parents are standing outside the hospital, with the hospital's name and logo in the background, speaking to the press. The hospital CEO calls the PR department and the ethics committee to huddle and decide how to respond.

Donna McKlindon and Colleagues Comment

Many patients, families, and health care professionals use social media, sharing their experiences and reflecting on the practice of medicine. Hospitals use social media as a way to engage patients and the public. Given the ubiquity of social media, questions about boundaries inevitably arise. Should doctors, nurses, and other hospital staff read or comment on patient blogs? Should professionals sign patients' online petitions? Can hospitals avoid media firestorms like the one in this case?

In many ways, the ethical challenges raised by social media are similar to those that health care professionals have always encountered. Clinicians have long worked to protect patient privacy, maintain appropriate therapeutic boundaries, help patients and families make difficult decisions, and treat all patients fairly. What has changed is the speed with which complex issues can be publicized and the fervor that can result. To develop an appropriate response, one must think of the general rules for social media and then apply those rules to crisis situations. Concerns arise about privacy, about therapeutic boundaries, and about fairness.

Social media underscores important asymmetries in the duty to maintain privacy. On the one hand, families are free to choose to share their child's illness and healthcare experience on social media. They forego their own privacy in exchange for the support and shared experience gained through public discussion of their illness and healthcare journey. On the other hand, clinicians and hospitals are duty bound to not disclose protected health information unless expressly granted permission by the family. Clinicians and institutions also have duties to protect the privacy of other patients. Families, by contrast, do not have explicit formal obligations to protect the privacy of these individuals. Hospitals need to inform all patients and families that they may not post information about or images of other patients, other patients' family members, or hospital staff without the express permission of these persons.

In pediatric cases, privacy has an additional complexity. Parents who choose to go public give up their child's privacy as well as their own. Even if a child participates, as in this case, the child may not understand the implications of social media posts. Information posted on social media will be part of an individual's virtual footprint forever.

The use of social media also raises questions related to professional boundaries.[1,2] The term "friend" implies reciprocal obligations. Professional organizations remind clinicians that, as much as we may like our patients, we are not their friends. Therapeutic boundaries are intended to protect both families and clinicians from either preferential treatment or from the obligation to take care of the professionals.[3] Another complex element of the boundary problems raised by the social media phenomenon is the way in which it brings strangers' voices into what were once private and confidential conversations. A parent may join a disease-specific support group where other parents provide advice about treatment options. Parents may see a posting about a "miracle cure" on another hospital's Web site and assume that their child should be receiving the same type of treatment. These additional voices may add misinformation and confusion and increase stress among the family and medical team. They may also give valuable information and empower patients.

Clinicians need to ask parents about information they have gathered online and take the time to review that information to address specific concerns in treatment conversations. But generally, clinical staff should not post or comment on disease-specific blogs unless their participation is a formal part of their role in the institution. Staff should generally not read online discussions about their patients without the patients' permission.

Fairness issues arise because not all families have equal access to social media or skill at using social media. Those with access and skill may be able to bring pressure on clinicians and institutions to provide preferential treatment. Health care institutions can promote fairness by treating patients equally regardless of their ability to bring pressure to bear via the use of social media. Institutions should reassure clinicians that as long as they are providing high quality care, the institution will support their actions even in the face of intense social media pressure, in the same way that institutions can provide similar support in the face of threats of legal action.

SOCIAL MEDIA CRISIS ETHICS

Challenges related to social media became more pronounced when a story goes viral and a social media crisis ensues. The same ethical concerns (related to privacy, therapeutic boundaries, and fairness) are still the main focus, but additional strains can tempt individuals or organizations away from the wisest course of action. Institutions need to plan proactively for how to respond to a social media crisis.

The duty to protect patient privacy is difficult to fulfill when the institution is thrust into the media spotlight by the patient and family. Stress is increased when people with little or no information about the facts of a case begin commenting on social media, or when a specific clinician or group of clinicians is being publicly criticized. Institutions may find themselves in a bind: they wish to provide clarity and respond to misinformation, but they must maintain patient privacy. The institution should maintain a calm presence and provide enough support for their clinicians to resist the understandable impulse to divulge confidential information or respond to criticism.

The increased pressure of a social media crisis may tempt clinicians to cross routine therapeutic boundaries. When a case is being discussed on the Web, in newspapers, and on TV, clinicians may feel an urge to reach out to the patient or family outside of usual clinical practice in an effort to explain matters or to express concern. In this case, a clinician who is sympathetic to the parents' plea for compassionate use may want to sign the online petition or make a statement of support on the patient's blog. That would be inappropriate. Clinicians should limit their communication with the patient and family to their usual clinical communication and resist the temptation to create a different level of relationship with this family. Otherwise, they may find themselves drawn into complex relationships that interfere with their ability to provide high quality care. In addition, when talking with parents about difficult decisions, clinicians should rely on information about parental preferences and goals of care received directly from the parents. They should avoid assuming that they fully understand the family's concerns or needs based on only what they have seen or heard through social or news media. Just as misinformation about hospitals may proliferate, clinicians should remember that a family's views may also be misrepresented.

Social media controversies in health care often involve an attempt to circumvent established means of accessing treatment. Heightened attention to the needs of 1 individual may unfairly disadvantage others equally in need. Before clinicians publicly advocate for a particular patient to receive a scarce resource (as they would be doing if they sign a patient's petition), they should consider whether other patients might perceive that their own case is not receiving the same level of attention or advocacy, and whether any "special" access or accommodation for the patient at the center of the social media storm would be fair to all.

If either patients, family members, or clinicians believe that the process of resolving the situation is not addressing their concerns and best interests fairly, those individuals should be enabled to seek an ethics consultation, or if deemed necessary, legal or external professional counsel.

PLANNING FOR SOCIAL MEDIA CRISES

Healthcare clinicians and institutions must both embrace social media as a force to promote their mission and engage with their patients and families while at the same time promoting care and caution when managing a social media crisis. Most organizations have policies in place regarding handling negative publicity in the traditional media. These policies can be adapted to the setting of social media.[4,5]

Institutions must develop an overall social media policy for staff at all levels of the organization. That policy should acknowledge the widespread use of social media by families and caregivers and also provide guidance to staff for proper use of social media to prevent staff from overstepping their roles in terms of information sharing when a social media crisis arises. Staff must be educated in how to appropriately engage with social media to prevent missteps that could potentially go viral.

Identifying and Managing a Crisis

Because social media crises can expand dramatically in a short period of time, a social media plan should identify the individuals who will monitor online "chatter" regarding the organization and decide when a potential crisis is unfolding. Hospitals also need to develop a social media crisis response team and plan, likely involving members of the clinical staff, family relations/family services, information services, internal communications, PR, and legal/risk management, with clear roles and responsibilities that each team member will play in the event of an actual crisis, including the designation of a single leader tasked with managing the crisis. Instructions will need to be provided to all staff regarding how to respond, or specifically not respond, to inquiries about the situation and where to turn for additional support. External statements will need to be provided that are factual without disclosing protected patient information and that reiterate the institution's mission and values. Finally, institutions must develop a coordinated social media effort of posting responses to complaints and comments and posting a series of ongoing proactive messages that are in line with the external statements being delivered to traditional media.

A media storm can drive people to lose sight of their better judgment. Hospitals and clinicians should strive to be both firm and flexible. They should make their own case without disclosing patient information, providing a response that is thoughtful and consistent with

core professional and organizational values.

Jake A. Jacobson Comments

This case illustrates the importance of emphasizing awareness and communication long before a situation like this arises. Rather than start with the hospital CEO's call to the PR team while the family and media wait outside, let's back up a bit to practices that should have already been in place.

Patients, like any category of consumer group, are turning to social media, online discussions, and physician review sites before and after (and sometimes during) their hospital visits to research their hospitals and specific doctors and to chronicle and critique their experience. These reviews can range from a simple check-in on Facebook or Twitter (which shows their friends and family where they seek services) to an in-depth Yelp review or personal blog post detailing the appointment and their satisfaction with it.

As the consumer conversation has gone digital, so must institutional listening and preparation. Three key components are online monitoring, community engagement, and internal communication.

Online monitoring can be as simple as your communications team setting up Google Alerts to notify them of every story or post about the hospital or checking their Twitter mentions (either the actual Twitter handle or different iterations of however the hospital may be referenced). Alerts can also be set up for specific physicians, experts or topics, or even patients' names. Free platforms, such as Hootsuite, also allow various methods of monitoring through separate feeds, all easy to check at a glance. Countless software vendors or PR agencies offer more robust monitoring solutions, but they all come down to the same concept: if people are talking about you online, you need to be aware.

Community engagement is a phrase that can apply to very different audiences and tactics (through social media [Twitter followers, Facebook fans, etc] or civic groups [chambers of commerce, auxiliary boards, etc]) but the objective remains the same: build an environment that transforms curious, casual consumers into loyal advocates and vocal champions. Many brands are satisfied when someone simply "likes" their page on Facebook. Community engagement is about turning that like into love by building a culture where your brand educates, celebrates, and brings together your fans, rather than just advertising to them. Whether online or in real life, a true "community of fans" will be there to rally and support the brand when the going gets tough, giving the brand the benefit of the doubt and gladly sharing their great experiences. But that doesn't work if organizations wait until things go sour before investing in their community. Simply put, you have to be there for your community before you need them to be there for you.

Finally, internal communication can help resolve many of these situations before they become "situations" at all. Hospitals must foster an environment where the clinical teams, patient advocacy teams, and communications teams work closely together, emphasizing that they're all on the same bigger team. If a physician, nurse, or social worker has an interaction that makes them wonder "what if" something were to happen, the PR and patient advocacy teams should be notified. If the PR team comes across a "red flag" on social media or through an alert, the patient advocacy team and respective department should be looped in. As situations escalate, other groups (legal, security, ethics, facilities, etc) are quickly brought into the discussion, but again the message is clear: if you see something, say something, and reduce the chances for surprises.

Let's return to our case and the potential "media firestorm," all of which could have been avoided if online monitoring would have brought the family's blog to the PR team's attention, not to mention the online petition being circulated and signed by 60 000 supporters. That online monitoring would have led to internal discussions focused on solving the patient's problem, rather than focusing on a potential PR problem. Had the PR, clinical, ethics and patient advocacy teams all been aware of the family's blog (and petition, had it even come to that), there would have been ample time for discussion with the parents and the drug company. There could have even been the opportunity for positive media coverage of the hospital and drug company working together to do everything they can to make an exception for this family in need. And with a strong community presence online and in-person, tens of thousands of fans would have been cheering on the hospital for going out of their way to explore an innovative cure for this child.

As with many scenarios, the best solution isn't found in discussing what to do when the crisis has reached its tipping point, but rather how to prevent it from happening at all.

John D. Lantos Comments

Revolutions in communication change the nature of society. The printing press was essential for democracy. Live radio and television bring the world closer together. The revolution in social media is still in its infancy. It is hard to know what the ultimate effects will be. But social media has already had profound effects on the way we think about privacy, confidentiality, intimacy, courtship, advocacy, and national security. Clinicians and hospitals

need to anticipate the type of crises that are likely to arise as a result of patients' and families' access to social media. These comments offer some sensible first steps.

ABBREVIATION

PR: public relations

REFERENCES

1. Shore R, Halsey J, Shah K, Crigger BJ, Douglas SP; AMA Council on Ethical and Judicial Affairs (CEJA). Report of the AMA Council on Ethical and Judicial Affairs: professionalism in the use of social media. *J Clin Ethics*. 2011;22(2):165–172
2. Farnan JM, Snyder Sulmasy L, Worster BK, Chaudhry HJ, Rhyne JA, Arora VM; American College of Physicians Ethics, Professionalism and Human Rights Committee; American College of Physicians Council of Associates; Federation of State Medical Boards Special Committee on Ethics and Professionalism*. Online medical professionalism: patient and public relationships: policy statement from the American College of Physicians and the Federation of State Medical Boards. *Ann Intern Med*. 2013;158(8):620–627
3. Committee on Bioethics. Policy statement--Pediatrician-family-patient relationships: managing the boundaries. *Pediatrics*. 2009;124(6):1685–1688
4. Social media. What your hospital should know. *Hosp Health Netw*. 2014;88(2):41–47
5. Rivkin S, Seitel FTaming a hospital crisis: 7 rules of the road. Becker's Hospital Review. January 17, 2012. Available at: http://www.beckershospitalreview.com/hospital-management-administration/taming-a-hospital-crisis-7-rules-of-the-road.html. Accessed February 3, 2016

Ethics Rounds: In the Eye of a Social Media Storm

Donna McKlindon, Jake A. Jacobson, Pamela Nathanson, Jennifer K. Walter, John D. Lantos and Chris Feudtner

Pediatrics 2016;138;
DOI: 10.1542/peds.2016-1398 originally published online August 5, 2016;

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Ethics Rounds: In the Eye of a Social Media Storm

Donna McKlindon, Jake A. Jacobson, Pamela Nathanson, Jennifer K. Walter, John D. Lantos and Chris Feudtner

Pediatrics 2016;138;
DOI: 10.1542/peds.2016-1398 originally published online August 5, 2016;