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The Social Media Effect: Examining Usage in Contentious Healthcare Cases

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Abstract

Background: In healthcare, social media is a powerful online communication tool used by patients, families and organisations to share perspectives and engage in dialogue. It has the ability to affect change and eliminate barriers in healthcare. However, it also has the ability to raise the profile of negative news and can compromise therapeutic relationships, public trust in organisations and call into question privacy issues.

Methods: A symposium was held to address ethical issues in contentious healthcare cases that involve social media. The symposium consisted of panelist presentations, full group discussion, and small audience breakout groups and a full group facilitated concluding discussion. Discussions were summarised and key themes abstracted.

Results: Three main discussion points arose: 1) what are the relevant distinctions in cases that become "viral"; 2) good practices for navigating contentious cases; and 3) considerations for managing cases in the social media domain. Improved literacy and clear definitions were recommended to help understand how different mediums influence the delivery and dissemination of messages. Support for staff and methods for dealing with the aftermath of cases involving social media were examined.

Conclusion: This forum promoted understanding of the evolving issues and role of social media in contentious cases. Improved engagement with patients must be realised to understand these cases and stymie their development when possible. Organizations need to consider which policies need to be updated or created to deal with new scenarios. More conversations on the topic would create improvements in the area of contentious cases in social media.

Keywords: Bioethics; Social media; Physician-patient relations; Professional-patient relations; Conflict

Introduction

Social Media is a powerful online communication tool used by patients, families and healthcare organizations to share perspectives and engage in dialogue [1-3]. With internet usage increasing in Canada, [3,4] there is more opportunity for social media to be used and spread in today's society [5]. Social media has the ability to affect change and eliminate barriers in healthcare, increase transparency and to advance patient and family-centred care [6]. However, it also has the ability to raise the profile of negative news and stories that can compromise therapeutic relationships, [2] and even public trust in organizations [3,6]. While many healthcare organizations have been developing their on-line presence and policies for engaging with various social media platforms, [1] an area for which we have little guidance is when highly contentious clinical cases "go viral" [1] (internet content which can be passed through electronic mail and social networking sites that spreads rapidly through a population by being frequently shared with a number of individuals) or when the perspective of only one of the parties in such a case is made public through social media.

In October of 2011, the Department of Bioethics at The Hospital for Sick Children, in collaboration with the University of Toronto, Joint Centre for Bioethics hosted a symposium entitled *Navigating Contentious Cases in the Public Eye: A Working Symposium* to address ethical issues in contentious healthcare cases. The objectives of the symposium were (1) To hear from experts with specialised experience in highly contentious clinical cases being profiled using social media, (2) To brainstorm with participants who have been or will likely be directly faced with such cases, and (3) To identify ethical issues and good practices for navigating contentious cases in the public eye. 82 individuals from across 13 healthcare organizations in Ontario, Canada participated. Participants included clinicians, communications experts, lawyers, bioethicists, quality and risk managers, senior managers, and family and patient council representatives.

The symposium consisted of panelist presentations, a full group discussion, small audience breakout groups, and a full group facilitated concluding discussion. This report presents the prevalent themes that were reflected in these discussion forums to facilitate a better understanding of the issues to be considered when parties to contentious healthcare cases engage in social media.

Panelist Summaries

The symposium was designed to provide an environment in which expert panelists and participants could discuss ethical issues and good practices for navigating contentious healthcare cases that are placed in the public eye via social media. Four panelists opened the discussion regarding social media usage and provided their perspectives on the subject.

The first panelist was Robert Sibbald, a bioethicist from the London Health Sciences Centre in Ontario. He discussed the different benefits that various parties (e.g. patient/family, hospital, public) could derive from publically discussing cases, but also warned that potential negative

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consequences might outweigh the benefits, in particular when it is a current case. Sibbald highlighted the need for assessing how a social media response should be formulated. The mediums the response are directed through should be considered, the nature of the organizational stance - defensive or proactive - and who has the authority to make such social media related decisions.

The second presenter was Daphne Jarvis, a civil litigator specializing in health law with experience providing counsel to healthcare professionals in publicized cases. Jarvis prefers not to involve herself personally in media coverage, but will support her clients' efforts, should they so choose, to both proactively and reactively engage with media to inject balance and accuracy. She is not convinced, however, that it works, in spite of very good efforts, and provided recent examples. She raised concerns that in can be an insurmountable challenge for healthcare organizations to combat inaccurate views portrayed in media. While the advent of social media certainly has many positive aspects and can provide instant access to information, it can also serve to foster narrow-mindedness and ignorance. She hoped that this symposium might provide insight into how to avoid that result.

The third panelist was Leslie Beard, a designer and manager at the University Health Network in Toronto, Ontario with an interest in using social media's ability to enhance healthcare communication and delivery. She acknowledged the drawbacks of using social media, but noted that it could be used by healthcare organizations to pro-actively address challenging patient care issues. Beard examined why social media becomes such an appealing option, and offered that one reason why social media is used - it fulfills needs that are not being met in traditional healthcare interactions.

The final panelist was Jennifer Johannesen, an author, blogger, and parent. She spoke about publishing her book, *No Ordinary Boy*, where she describes her dealings with healthcare during the life of her son. She spoke about him dying at the age of 12 from undiagnosed disabilities. Johannesen described having difficulties finding support groups through the hospital, and as a result developed a blog to document and share her experiences. She identified herself as being on the "parent's side" of social media issues. Johannesen spoke of the appeal social media held as an outlet. It offers an authentic representation of a person. Healthcare organizations have barriers to overcome to obtain this authenticity in social media. She recommended that healthcare organizations attempt to connect with families and gain their trust through social media as a way of trying to overcome a lack of relationship with the public.

Combined, these panelists provided diverse perspectives related to social media and contentious clinical cases. The subsequent full group and small group discussions reflected the following themes.

Thematic Discussion

Why do cases go viral?

The first issue focused on why some cases go "viral" and others do not, and whether or not there are qualitative differences between these cases. Determining differences may help to foresee future issues with contentious cases and may help organizations better prepare for such cases. Cases that end up being widely publicised in social media may require a different management and have different consequences than cases not popularised through social media. A main theme identified in determining which cases would become viral in the public sphere was the subject matter of the case. There are two elements to this: 1) is the subject contentious and 2) is the subject of interest to the masses or specific interest groups. An illustrative example is the case of Joseph Maraachli, a month old boy whose care at London Health Sciences Centre became the focus of intense social media attention in 2011. This infant was diagnosed with a severe, progressive neurodegenerative disease for which the healthcare team described no chance of recovery [7]. It was proposed that his breathing tube be removed, a DNR order be implemented, and that he receive palliative care [7]. The family disagreed with this and proposed that he receive a tracheostomy to attempt to prolong his life long enough for him to die at home. The healthcare team found this to be contrary to best interests of the child [8]. The case was taken to the Consent and Capacity Board of Ontario, a tribunal used to adjudicate consent, capacity and substitute-decision making [9]. Who agreed with the medical team [10]. During the case, Joseph's family used social media to garner attention for the infant via creating a Face book page [11]. The story reached various news outlets in both Canada and the United States and became widely followed. Due to this massive media attention and threats against medical staff caring for Joseph, the institution responded with media releases, publishing facts about the case. In an effort to respect patient confidentiality, they addressed only issues and information that was publically released through the family. There is no consensus on issues pertaining to end-of-life decision-making, a subject that is frequently associated with cases that become viral. These types of issues contain inherent conflict and as a result interest various parties to become involved in the social media conversation. Patients and families can be manipulated by third-parties whose goal is to advance their own political agenda. As a result, the focus can shift away from the best interests of the patient, and centre on outside parties' interests. The subject matter of the case appeared to be a necessary, but insufficient component in defining the differences between cases – there are many similar cases that touch upon the same contentious issues, but not all of them involve social media and receive mass attention.

Another theme in determining the qualitative difference between "viral" cases appeared to be the patient and family's perspective on their relationship with the case and organization. If they are seeking support through social media, they may feel they are not being sufficiently heard or included in the management of the clinical case. The relationship between patient and healthcare professional may be strained or not well-established. The family might feel that social media is their best option for rectifying their concerns. Lack of an available support system inside or outside the organization may also be a factor in choosing to use social media. A concern is that there is a lower threshold for privacy within social media, and posting information can be a "Pandora's Box"– once you reveal information to the public, it can never be retracted. The consequences are lasting and unfortunately often overlooked. There were diverging views about whether conflict or breakdown of communications over some aspect of case management was a hallmark of cases that go "viral". It was suggested that once a case reaches social media it is the responsibility of the healthcare organization to rectify the situation.

Clearly, ideas as to what separates a "viral" case from a regular case are themselves up for debate. One participant suggested that there are three central themes to dealing with contentious issues and social media involvement: the engagement in communication between the institution and the family, the roles of administration and physicians during this case, and the policies and procedures in place during the case. "Viral" cases appear to become out of control when communication with the family is not established, when the current policies are antiquated in the sense of dealing with new forms of social

media and information release, and the healthcare organization and professionals are unsure how they should respond.

Whether or not there is a qualitative difference in the case initially, the consensus was, there is a difference in the case after it becomes "viral". Publicity creates potential deterioration in the relationship between the patient and the healthcare professional and organization. By having third parties, involved, healthcare professionals may be hesitant in their actions due to increased public scrutiny. Future decisions might be influenced by concern that their next case could go "viral"; this concern can potentially compromise patient care, or the relationship between healthcare professionals and the patient. By having a case reach an audience through social media, interests other than just the care of the specific patient arise, and conversation becomes less intimate.

Good practices

Another issue discussed was identifying good practices for use within organizations for effective interactions with social media. Many agreed that healthcare organizations should continually engage with the patient and family to facilitate good communication and to be better equipped for dealing with strains in the healthcare professional-patient relationship. Suggestions for engaging with the patient and family included regular family meetings, providing consistent healthcare professionals, and having neutral third parties facilitate dialogue should conflict arise. The main objective is to engage with the patient and family on an ongoing basis. Family advisory committees can offer support to patients and families; suggestions were made to raise their profile to offer a more present, palpable support system within organizations. It was also noted that effective practices within a healthcare professional-patient relationship should not be changed due to influence by social media; doing so could protect the healthcare professional, but may not be in the best interest of the patient.

Concerns with using social media discussed thus far may dissuade some families from using it, but social media is an evolving field in healthcare and its use is growing [6]. Healthcare organizations should provide education for patients and the public teaching the benefits and risks of using social media. Providing alternative venues to seek support or voice opinions and establishing a line of communication with the family before the situation reaches social media could be helpful. As well, considerations should be proposed for the patient in releasing personal information about a healthcare professional into the social media forum.

When discussing when an organization should acknowledge or contact others via social media, it was agreed that social media contact should not substitute for face-to-face communication with the patient and family. Acknowledging the existence of social media discourse should be done to attempt to clarify communication and make a point of contact between the organization and the public, but in person, discussions should be encouraged with the patient and family. There are circumstances organizations should be cautious about when responding to and engaging with social media. Responding to comments on social media in a way that challenges the patient and/or family's views and information is disadvantageous. It can shape the conflict into a right versus wrong debate, which is not beneficial to all parties and may create an antagonistic atmosphere. Another key consideration in engaging with social media is the issue of disclosing personal health information without full consent.

Since social media will inevitably be used in the future, it was suggested that healthcare organizations consider engaging with social media on an ongoing basis, rather than wait for a contentious case. This could pre-emptively avert conflicts from becoming uncontrollable, while creating credibility, establishing trust with the public and protecting the reputation of the organization and staff by responding proactively. Attempting to create trust when the case has already progressed is difficult and may seem disingenuous. People want to be heard and feel that their interactions with the healthcare organization are significant. Other suggestions included organizations having their own online forum, allowing for ongoing dialogue with patients and families in real-time providing the organization the opportunity to respond to comments or concerns. This would involve employing social media experts to manage this forum and ensure prompt and appropriate responses. Using social media venues and Internet fora would help an organization converse with their patients and families, and provide the opportunity for healthcare professionals and the organization to learn about individual patient and family experiences. This could provide needed insight into why patients and families feel unheard, and feel the need to use social media.

The discussion moved to focus on the impact of viral cases on healthcare staff. Concerns about privacy when using social media are not limited to patients, but also pertains to staff. It was discussed that staff may feel negatively towards social media involvement in their case if it reveals personal information. They may not feel supported by the organization in the absence of a public response. For both healthcare staff and patients and families a common theme identified is that both parties feel powerless in their environment. Patients and families perceive a level of power within organizations that is unattainable.

Considerations in management of viral cases

The final issue examined was how an organization should manage a case when it has gone "viral". What are appropriate responses to social media from both the professionals and the organization as a whole, and what are the benefits to addressing the public? What are suitable reasons to respond to a family that goes public via social media? When cases go "viral" from social media, despite the influence of the case entering the public domain, there is still the notion that the organization and healthcare professionals should continue to stand by professional responsibilities and respect patient confidentiality. Public knowledge will inevitably change the case dynamics, reactions, conversations, and relations between staff and other involved parties. Healthcare organisations need to ensure that the best interests of the patient, their own duty to care, and confidentiality practices are a priority.

As previously mentioned, key players of the case should be brought together. Social media should be used as a means to establish contact with other parties (i.e. interest groups) and an open line of communication should continue to be provided to the patient and family. Responding to social media for the purpose of resolving a conflict and fostering engagement with the family would be a beneficial goal and could help to resolve the issue reactively if proactive measures to prevent escalation were unsuccessful.

There was agreement that there are limitations for which social media should be used. Clarifying issues by responding to social media might be seen as beneficial, but doing so with mentioning case details can cause privacy issues. The press uses restrictions placed against healthcare professionals from disclosing information to the public to forward their own story. A refusal to comment can be as incriminating as an unpopular statement with the public. Public perception often does not take into account that the organization is bound by confidentiality and privacy policy. As well, what might be beneficial to one party may not be to another. For instance, a particular response to social media might be beneficial in protecting hospital staff, the organization's reputation, or to ensure truth and accuracy, but if it is not in the

patient's best interest, then it becomes an ethical question as to how to balance competing interests.

As to other beneficial reasons for responding to social media, it might also be favourable to respond simply for engaging with the public. This creates an environment to help level the proverbial playing field between patients and families and the organization, and creates a less antagonistic perception between the two parties. Organizations should be aware that having social media involved in a case would make the authority of public opinion larger and more encompassing. Organizations would only be disadvantaged if they ignored this effect caused by social media.

Future Considerations

Many issues remain important when considering contentious cases that reach the public through social media. Improved literacy on the subject of social media would be effective in helping users understand how different fora influence messages given to the public, and how those messages are disseminated. Guidelines should be established to illustrate how to participate safely. There should be exploration of methods for educating patients about the consequences of using social media outlets and healthcare professionals so they can assist patients and families to assess whether or not to use social media. There should be exploration into how healthcare professionals can be supported so they feel protected from and less antagonised by social media use. Finally, healthcare organizations should explore methods of dealing with the aftermath of a case going "viral".

The Internet and social media involvement has only become an issue in recent years and is constantly evolving. Guidelines in policy and legislation require more clarification for this subject to keep up with issues in society today. Current policy appears vague or inadequate in application to current issues. Organizations need to consider what research is necessary and which policies need to be updated or created to deal with new social media scenarios. Discussions with all stakeholders (i.e. healthcare professionals, patients, staff, and the public) would help to inform the many issues related to use of social media in contentious healthcare cases.

Conclusion

The symposium promoted understanding of the evolving issues and role of social media in contentious healthcare cases. There are many issues that remain important when considering contentious cases that reach the public through social media. How to prevent cases from becoming viral, and how to respond to the aftermath of cases that have reached this level of social media involvement are concerns that have been expressed. Overall, discussions fulfilled the purposes of the symposium: to promote understanding of the issues in managing contentious "viral" healthcare cases, and to create a forum for open dialogue for these issues. Concrete solutions were not reached. The objective was to establish a forum for ongoing discussion and facilitate an environment for further developments in this field of bioethics. Improvements in healthcare organization practices and engagement with patients and families must be made to best respond to these cases and to stymie their development when possible.

References

1. St-Laurent-Gagnon T, Coughlin KW (2012) Canadian Paediatric Society, Bioethics Committee. Paediatricians, social media and blogs: Ethical considerations. Paediatr Child Health 17: 267-269.
2. Tunick R, Mednick L (2009) Commentary: electronic communication in the pediatric setting – dilemmas associated with patient blogs. J Pediatr Psychol 34: 585-587.
3. When private becomes public: the ethical challenges and opportunities of social media.
4. Leith J, Middleton CA (2007) Intensity of internet use in Canada: exploring Canadians' engagement with the internet.
5. Fordis M, Street RL, Volk RJ, Smith Q (2011) The prospects for Web 2.0 technologies for engagement, communication, and dissemination in the era of patient-centered outcomes research: selected articles developed from the Eisenberg conference series 2010 meeting. J Health Commun: International Perspectives16: sup1, 3-9.
6. Canadian Medical Association. Social media and Canadian physicians - issues and rules of engagement.
7. CCB ruling (2011) and in the matter of the health care consent act.
8. Consent and Capacity Board (2010) About Us.
9. JM Re (2011) CanLII 7955 [ON CCB], p.20.
10. "Save baby Joseph".
11. London Health Sciences Centre (2011) Just the Facts: Medical, Legal and Ethical Issues.