Social Media for More Patient-Centered, Cost-Effective Healthcare Delivery

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Overview

• Issues in social media use for medicine
  • Privacy
  • Data security and theft
  • Unprofessional conduct
• Patient/citizen use of SM for health
• Provider/organization goals for SM
• Provider/organization challenges with SM
Issues Relevant to SM Use in Medicine

• Privacy and confidentiality
• Data security
• Playing nice together
  • Provider professionalism
  • Patient respect of boundaries
• Lack of legislative and regulatory clarity
• SM crosses borders, but laws vary by country
Privacy-Related Concerns for SM

• Organizations
  • Avoiding regulatory violations
  • Preventing unprofessional behavior by staff

• Providers
  • Inappropriate or problematic patient requests
  • Staying out of trouble
  • Managing professional, personal online lives

• Patients
  • Protecting self-generated info
  • Tech, application settings issues
Sources of SM Privacy Issues

• Data breaches
  • Flawed process or technology
  • Data theft
  • Unintended disclosure (ignorance)
  • Mischievous intent – “because I can”

• Questionable judgment
  • Physicians, students, business, others

• Inappropriate or malicious conduct
  • Patient/consumer against others
SM Privacy Issues Are Ongoing

- 60% of med schools reported unprofessional student conduct, 13% reported privacy violations by students (2009, Chretien)
- 31.8% anonymity, 57% negative language in pharmacist blogs (2010, Clauson)
- 3% tweets unprofessional, 0.7% potential patient privacy violations (2011, Chretien)
Data Theft

• Motivated by desire for financial information
  • Of 60 data breaches in healthcare, hackers mainly sought smaller low-risk targets to obtain payment info or implant malware to extract payment info quickly, to commit fraud (2012, Verizon)
  • Attacks against all businesses up 42% in 2012 (Ponemon Institute)

• Less frequently for business use
  • Sale of ER patient data to Florida attorneys
Mobile Data Breach Prevention

• Providers use multiple approaches to protect data accessed via mobile devices (KLAS, 2012)
  • Virtualization (52%)
  • Encryption (43%)
  • Mobile data management (MDM) (35%)
  • Limit devices (12%)
  • Internal cloud (11%)
  • Limit operating systems (6%)
  • External cloud (5%)
Scope of Unprofessional Conduct

• 92% of medical/osteopathic boards reported professionalism violations (Greyson, 2012)
  • Inappropriate patient communication online
  • Use of Web for inappropriate practice
  • Misrepresentation of credentials online

• 71% of boards took action
  • Formal hearings (50%)
  • Consent orders (40%)
  • Informal warnings (40%)
  • No action (25%)
Problematic Intersection of Medicine, SM

- Culture of mass sharing of personal info about self and others is not population-wide
- SM sites focus on privacy/access of user’s own media, not how SM use affects others
- Even when media is tagged, it’s difficult to monitor for negative/inappropriate content
- Some SM sites upload geolocation data, other metadata in content without users’ knowledge
  - Linking of pictures to others’ profiles
Patients Embrace SM for Health

- Data sharing with providers
  - Personal health records
  - Blue Button EHR download
  - Patient-reported outcomes
- Development of bodies of evidence
  - Multiple sclerosis: Venoplasty as a treatment for chronic cerebrospinal venous insufficiency (Mazanderani, 2013)
- Contributions to quality improvement efforts
  - Cloud of patient experience (Greaves, 2013)
Patients and SM [cont.]

- Community-building based on shared health interests and concerns
  - PatientsLikeMe
  - ACOR online cancer communities
- Individual health-related actions
  - Organ donor recruitment (Dyer, 2012)
- Promotion of healthy behavior within personal networks
Providers, Organizations Have Goals, Too

- Remote consultations
  - Teledermatology via Facebook (Garcia-Romero, 2011)
- Infectious disease tracking (Signorini, 2011)
- Organ donor recruitment (D’Alessandro, 2012)
- Shared Care Platform – clinical decision support for patients with multiple morbidities (Martinez-Garcia, 2013)
Provider/Organization SM Use [cont.]

- Hospital quality measurement (Timian, 2013)
  - Facebook “like” correlated w/30-day mortality
- Marketing and branding (Omurtag, 2013)
- Clinical trials recruitment
- Colleague consultations (e.g., Doximity)
- Continuing medical education (e.g., QuantiaMD)
- Patient education pre- and post-treatment
Providers Engage, But Have Challenges

• Looking up patient personal info online may trigger unexpected interactions (Jent, 2011)
  • Abuse or unlawful activity that must be reported to law enforcement

• Direct communication with patients, public can yield unintended consequences
  • Inaccurate statements about providers that cannot be addressed

• Patients uploading media that violate other patients’ HIPAA privacy rights (Jean, 2012)
Social media and the health encounter: a changing ethical code?

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Mijn naam is Ad. Ik ben 46 jaar, getrouwd en heb twee kinderen. Ik had ernstige hartritmestoornissen, waarvoor ik succesvol ben behandeld in het Catharina ZKH. Eindhoven. 
http://www.dialoog.skipr.nl/evolutieindezorg
November 2011-June 2012

Catharina Hospital (Eindhoven, the Netherlands) wanted more policy attention and support for patient-centered ICT innovation in healthcare

- Patient was asked to participate in an ICT-related event
- Philips Medical provided the patient with an iPad and training
  → An in-house journalist documented the story

- Plans jointly announced by both parties at a national conference held in Eindhoven
- Human-interest story featured on regional television
  → Received attention in the national press and on popular blogging sites

- Patient tweeted about pending operation and in recovery period
  → Family members tweeted on his behalf during the operation
- Members of operative team tweeted with pictures during the operation
  → Similar occurrences in US, sometimes with live-streaming video
- Cardiologist and patient had +/- 700 personal followers at the time of the operation and +/- 1 million people followed the operation
  → Many Twitter accounts made especially
- Referrals increased 60% (February - June 2012)
Research Project

- Started in Feb 2012 (just after the operation)
- Interviews with physician and management
- Analysis of the tweets (+/- 1000 over a 4-month period), news coverage and related social media sites
- Use of literature study to describe ethical considerations*
Process around the procedure

*Patient was asked to participate in an ICT-related event*

*Philips Medical provided the patient with an iPad and training*

*Plans jointly announced by both parties at a national conference held in Eindhoven*

*Referrals to the cardiology department increased 60% between February and June 2012*

*Social pressure to participate?*

*Patient centeredness used to meet other (politically-driven) goals*

*Increased demand for health providers to profile themselves*
During the procedure

*Patient and family members tweeted about all phases of the operation*
*Covered by in-house journalist of Philips, bloggers and regional/national press*

*Cardiologist and patient had +/- 700 followers at the time of the operation; +/- 1 million followed the operation live*

*Members of the operative team tweeted during the operation*

*Patient privacy, confidentiality and the limits to public disclosure*

*Legally and morally acceptable, even with informed consent?*

*Potential for distraction*
Other issues and a look to the future

Patients

Role assigned to patients; commodification of experience, immaterial labor

Professionals

Responsibility to act; liability

Media

Commercial interests and tracking; selling data

Social Scientists

More reflexivity about own motives and actions
A changing ethical code?

- Social media is said to change the ethical code
  - Literature and popular press largely focus on privacy/publicness
    - More/less? Generational? Sectoral?
    - In health, generally thought of in terms of consequences for patients

- This case shows ethical issues as more than just more/less patient privacy
  - Tensions between multiple ethical issues that affect various actors them
  - The professionals in this case were very aware of the most of the issues and tensions

- Delicate balance
  - Optimizing patient-centered care without endangering patient privacy and professional reputation or profiling the institution without unnecessarily imposing technologies and/or behaviors on patients
  - Importance of a well-thought out plan, but also more research attention and consciousness-raising
Regulations Affecting Social Media Use in Healthcare and Strategies for Engagement

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Organization Interests and Social Media Use

• Organizations’ interests
  – To protect the business/brand
  – To assess business needs
  – To communicate with stakeholders
  – To identify needs and opportunities to better meet them
  – To conduct clinical and community research
  – To engage with patients and citizens
Provider Interests and Social Media Use

- Providers’ interests
  - To engage with patients, citizens, and community
  - To identify patient needs and concerns, and ways to better address them
  - To develop and maintain relationships with other providers and share ideas (e.g., Clinical Wall)
  - To conduct research, e.g., clinical trials
  - To market health services and products
American Federal Regulatory Agencies

- Federal Trade Commission (FTC)
  - Regulation of unfair and/or deceptive trade practices
- Department of Justice (DoJ)
  - Sales of products and services
- Food and Drug Administration (FDA)
  - Drug, supplements marketed to consumers
State Medical Boards

• Have the authority to discipline providers for unprofessional behavior related to the inappropriate use of social media
  – Inappropriate communications with patients
  – Unprofessional behavior
  – Misrepresentation of credentials
  – Violations of patient confidentiality
  – Failure to disclose conflicts of interest
  – Derogatory remarks about a patient
  – On-line intoxication
  – Discriminatory language or practices
• Forbidden activities
  – Clinician should not publicly present PHI of individuals
  – Reporting of private academic information of another student or trainee

• Strongly encouraged activities
  – Clinicians should separate nonclinical presence from their professional presence
  – Present oneself in a mature, responsible, and professional manner
  – Use strictest privacy mechanisms available
AMA Guidelines for Social Media Use

- Refrain from posting identifiable patient info
- Routinely monitor Web presence to ascertain that content is accurate, appropriate
- Maintain appropriate boundaries in patient-physician relationship
- Separate personal, professional info
- Inform others of their inappropriate content
- Recognize that online actions, content may negatively affect reputation & the profession
Canadian Federal Regulatory Agencies

- Health Canada
  - Product safety assessment, health information development and dissemination
- Department of Justice (DoJ)
  - Office of the Privacy Commissioner
    - Personal Information Protection and Electronic Documents Act (PIPEDA)
- Competition Bureau
  - Trade regulation
Canadian Medical Associations

• Three cornerstones of confidentiality, privacy, and trust in doctor-patient relationship (CMA)
  – Those who access patient record must demonstrate care in protecting information

• Social media does not create new obligations (College of Physicians & Surgeons of Ontario)
  – No friending, connections w/patients
Use of social media can easily create a provider-patient relationship with all its attendant obligations and liabilities

- Provider may not know the patient
- Patient may not know the provider

Raises issues of
- Potential professional liability (malpractice)
- Patient abandonment
- Was the clinician supposed to do something?
Accessing Information from a Social Media Site

• Once a clinician has accessed patient information, a conundrum may exist
  – Balance the patient’s right to privacy with the provider’s need for information to treat
  – Accessing the site may mean all information with respect to a patient’s health status should be considered
  – A right to further inquire?

• Issues with accessing a site for clinical/medical-social research
Unlawful Practice of Medicine

• What is the site attempting to do?

• Could an individual reasonably believe he or she is seeking or obtaining medical advice?

• Or is it just overall medical information that is merely being made available to citizens?

• If there is a provider or pharmacist involved, is that individual licensed to practice medicine in accordance with applicable law?