What will happen in this session?
Discussion in small groups based on background reading and cases

Objectives:
- To identify positive learning, networking and advocacy opportunities through appropriate social media engagement as a health professional
- To recognize potential professionalism issues within social media engagement, and discuss strategies to mitigate these

CanMEDS roles:
- Professional
- Health Advocate

Preparation:
Read through the sample 2 cases ‘Friending patients on social media’ (including referenced links) and the attached references.

Questions for small group discussion:
1) Identify issues related to professionalism with social media engagement
2) Discussion the following cases within your small groups:
   a. In the past, a family practitioner in a small town would be both a doctor and a friend, and may answer medical questions in social settings. How is this different than being a ‘friend’ with patients in social media?
   b. What do you think about providing medical advice to your social circles on Facebook?
   c. If you notice a post on Facebook about an urgent serious medical condition that you might be able to help by posting a response, would you? Would it be different if it was a friend of a friend, or a close friend?
3) Imagine yourself mentoring a medical student or resident. What advice would you give him or her based on these cases and your discussion?
Using social media effectively

Olaf Kraus de Camargo (@DevPeds)

Social Media and Work:

"Social media has become a primary method of communication for the majority of Canadians. This includes our patients, families, partners, and our workforce. Social media offers us the opportunity to connect with our communities in new, meaningful ways and to share important information in a timely manner. As stewards of Hamilton Health Sciences’ online presence, the Public Relations & Communications team at HHS is here to support our staff, physicians and volunteers in using social media safely and effectively.

To engage our workforce on social media, we have developed two new channels for staff: a Twitter account (@HHS_staff), and a private LinkedIn group (“Hamilton Health Sciences Staff”). These two new communication tools are a place for you to get updates, learn about events and interact with fellow employees.

We have also created a hashtag, #myHHS, that we encourage you to include in your social media posts on Twitter and Instagram to showcase your workplace pride. Each month, you can enter a contest by using the #myHHS hashtag in a post about our monthly theme. For example, in March, we encouraged you to share a photo of your healthy lunch for Nutrition Month, using #myHHS.

Social media can be a great way to learn about new topics and to stay connected to your organization and colleagues. Before posting on social media, please take a moment to familiarize yourself with HHS’ social media policy. You can read the policy and find additional resources by visiting http://corpweb/socialmedia on the HHS Intranet." (by Elise Copps, Public Relations & Communications, RJCHC Internal Newsletter April 2017)
Background Reading:


This paper gives an overview of the challenges and knowledge gaps found among pediatric residents in the US concerning social media use.

After reading the paper, discuss with your group, if the results would be similar among the colleagues you know. Identify strategies to use to ensure professionalism when online. You can also refer to the existing Canadian guidelines (refs. 2 and 3) and discuss how they apply to practice.


CPSO statement and guidelines about Social media use by physicians


CMA statement and guidelines about Social media use by physicians


This paper is to exemplify how a social media presence can be used professionally and in research to engage with caregivers in a constructive way.
Discuss what constitutes an online community and what it means to engage with such a community as a professional.

Case Discussions - Friending Patients on Social Media

1 - After doctors initially misdiagnosed her son with strep throat, a mother posted several pictures of her son’s worsening rash and facial edema on Facebook. Although she received many responses that were incorrect, a non-physician neighbor suspected the boy had Kawasaki’s disease based on previous experience with the illness in her own son. The mother took the son to the hospital for immediate work up, and it turned out to be the correct diagnosis. As a result of social media, her son avoided additional complications and recovered from Kawasaki associated liver dysfunction.

Source:
http://www.slate.com/articles/double_x/doublex/2011/07/how_facebook_saved_my_sons_life.2.html

2 - A dermatology resident begins a clinic visit with a patient, an adolescent girl, who is accompanied by her mother. After completing the history and physical examination, the mother asks the daughter to leave the room and tells the resident that she would prefer seeing another physician to be her daughter’s doctor. The mother says that she saw some of the resident’s pictures on Facebook depicting the resident partying during medical school on a spring break. The resident’s profile was set to be viewable only to friends, and it turned out that one of the resident’s relatives was a close friend of the patient’s, and had shown the photos to her. The dermatology resident was shocked and had forgotten those pictures were on Facebook since there were from so long ago.

http://www.springerlink.com/content/j64m6213w5115873/fulltext.html
Appendix

HHS on Social Media:

Hamilton Health Sciences Social Media Policy – Fact Sheet

The intent of the Social Media Policy is to provide guidelines for behavior and use of social media as it relates to
Hamilton Health Sciences. Both this fact sheet and the policy are available as downloads in the menu on this page.

When does the policy affect you?

You are using a Hamilton Health Sciences social media platform.

You are connected to Hamilton Health Sciences as an employee, physician, volunteer, contractor, consultant or
temporary employee

What is social media?

Electronic communication through which users create online communities to share information, such as text,
audio, video, messages, blogs, podcasts, images and other multimedia communications. Facebook and Twitter are
examples, but there are many forums and names.

Basic principles of the policy:

Individual conduct in/on social media forums/platforms is the responsibility of that individual.

Social media is a public space and should be treated as such. Please represent yourself and our organization on
social media the same way you would in the halls of our hospitals.

The comments you make on any social media site have a permanent nature.

When making public comments regarding Hamilton Health Sciences (HHS), its agents, staff, policies,
patients/families, or any work-related information, employees are responsible to:

• Adhere to the spirit of HHS’ mission, vision and values in all comments and interactions.
• Post a simple, visible disclaimer to confirm that any views expressed are those of the individual and not
  those of HHS.
• Adhere to the terms of hospital policies that address privacy and confidentiality as they relate to patients,
families, staff and all aspects of the business of HHS.
• Not divulge any personal health information.
• Post only comments that meet the criteria defined in the HHS Values-Based Code of Conduct, and any
  applicable college guidelines or code of ethics.
• Consult with HHS administration before publicly supporting groups, petitions, or causes that may be in
  conflict with Hamilton Health Sciences’ mission, vision and/or values or Hamilton Health Sciences
  Corporation or any of its hospitals, programs or services. Any alignment with third parties should be done
  so in accordance with HHS policies.
• Not endorse, advertise, and/or solicit for any particular provider, treatment, service, device or
  medication.
• Not use HHS’ logos or anything that would suggest their social media site and/or communication is an
  “official” site or representation of the organization.

HHS’ Social Media Policy can be found in the Policy and Document Library on the HHS Intranet, or by clicking HERE.

For further information, contact Public Relations at PublicRelations@hhsc.ca or ext. 75387.

Our Department on Social Media:

Facebook:
McMaster Pediatric Residency Program Facebook Page:
https://www.facebook.com/macpeds/
Developmental Pediatrics Education Facebook Page for Learners:
https://www.facebook.com/DevPeds
Developmental Pediatrics Facebook Page for Parents and Patients:
https://www.facebook.com/DPRpage/
**Other Interesting Professionals and Organizations to Follow:**

**McMaster IT Security @McMaster_ITSec**
Providing resources to help protect the McMaster community from threats to private information. Find us on facebook at https://www.facebook.com/mcmaster.itsec

**St. Joe’s Hamilton Verified account @STJOESHAMILTON**
A premier academic & research health care organization affiliated with McMaster University, Mohawk College & led by the St. Joseph’s Health System.

**City of Hamilton Verified account @cityofhamilton**
Official City of Hamilton communications account. For service requests, contact 905-546-CITY or askcity@hamilton.ca. Account monitored Mon-Fri, 8:30a-4:30p.

**David Gilbert @DavidGilbert43**
Patient Director @SussexMSK | Writer in Residence @Bethlem_Gallery | Patients as partners | mental health | poetry | #lufc | own views

**Dept. of Pediatrics @McGillPeds**
Michael Shevell-Chair of Pediatrics (McGill University); Pediatrician-in-Chief (Montreal Children's Hospital); Pediatric Neurologist; FCAHS; Hower Award (2014)

**PONDA @pondanetwork**
Physicians in Ontario Neurodevelopmental Advocacy: Working towards a better Ontario for persons with special needs.

**Vinay Prasad @VinayPrasad82**
#researchparasite interested in policy, heme-onc, EBM & medical reversal; Specialize in lymphoma; Author of: http://www.amazon.com/Ending-Medical-Reversal-Improving-Outcomes/dp/1421417723 ... Funded by @LJA_Foundation

**CanChild @canchild_ca**
A research and educational centre that provides evidence-based information to improve the lives of children and youth with disabilities and their families.

**Trisha Greenhalgh @trishgreenhalgh**
Doctor, academic, Europhile. Featured lecture: https://www.youtube.com/watch?v=qYvdhA697jl&list=PLPdZt8Yj1_fCdMQiFysZUAglFz2g2t-T&index=5 ...

**OACRS @OACRS**
Ontario Association of Children's Rehabilitation Services: the voice of Children's Treatment Centres in Ontario serving children & youth with special needs

**Adam Cifu @adamcifu**
Professor of Medicine, University of Chicago. General Internal Medicine, Medical Education, Evidence Based Medicine. COI: https://tinyurl.com/hjfavut

**CAPHC @CAPHCTweets**
The Canadian Association of Paediatric Health Centres is a recognized leader & advocate for advancing improvement of healthcare for Canada’s children & youth

**Jenn Sprung @mindthecompany**
Wife, poker-faced mother of three, closet chef, medical sleuth, circus clown, astronaut, vulcanologist. Live long and prosper.
Anthony Ford-Jones @afordjones
Husband, Father, Grandfather, Paediatrician. Rotarian. Advocate for Children, Youth and Social Justice issues. Proud to be a Briton and an adoptive Canadian.

SickKids_TheHospital Verified account @SickKidsNews

Crystal Chin @_Crystal_Chin
Youth /Patient Advisor @HBKidsHospital | @OntarioBrain | @CivicActionGTHA | @PatientsCanada -Board | @ChildBrightNet | @OneYoungWorld Tweets are my own
The term ‘social media’ refers to web and mobile technologies and practices that people use to share content, opinions, insights, experiences, and perspectives online. There are many prominent examples of social media platforms, including Facebook, Twitter, YouTube, LinkedIn, and blogging sites, among many others.

Social media can be used for both personal and professional purposes. Many physicians are now using social media in their practices to interact with colleagues and patients, to seek out medical information online, and to share content with a broad audience.

Whether engaging in social media for personal or professional use, the nature of these platforms, which are highly accessible, informal, and public, raise important questions about the steps physicians should take to uphold their important professional obligations while online.

Purpose

This document provides guidance to physicians about how to engage in social media while continuing to meet relevant legal and professional obligations.

This document is not a policy, nor does it establish any new expectations for physicians that are unique to social media. Rather, this document clarifies how existing professional expectations can be met in the social media sphere.

College position on social media

The College’s position is that physicians are expected to comply with all of their existing professional expectations, including those set out in relevant legislation, codes of ethics, and College policies, when engaging in the use of social media platforms and technologies. If physicians do so, the College recognizes that social media platforms may present important opportunities to enhance patient care, medical education, professional competence, and collegiality, among other potential benefits.
In order to satisfy the above professional expectations while engaging in social media, it is recommended that physicians:

They are as follows:

- Comply with all legal and professional obligations to maintain patient privacy and confidentiality.¹
- Maintain appropriate professional boundaries with patients and those close to them.²
- Maintain professional and respectful relationships with patients, colleagues, and other members of the health-care team.³
- Comply with relevant legislation with respect to physician advertising.⁴
- Comply with the law related to defamation, copyright, and plagiarism when posting content online.⁵
- Avoid conflicts of interest.⁶

Guidelines

In order to satisfy the above professional expectations while engaging in social media, it is recommended that physicians:

1. Assume that all content on the Internet is public and accessible to all.

2. Exercise caution when posting information online that relates to an actual patient, in order to ensure compliance with legal and professional obligations to maintain privacy and confidentiality. Bear in mind that an unnamed patient may still be identified through a range of other information, such as a description of their clinical condition, or area of residence.⁷

3. Refrain from providing clinical advice to specific patients through social media.⁸ It is acceptable, however, to use social media to disseminate generic medical or health information for educational or information sharing purposes.

4. Protect their own reputation, the reputation of the profession, and the public trust by not posting content that could be viewed as unprofessional.
5. Be mindful of their Internet presence, and be proactive in removing content posted by themselves or others which may be viewed as unprofessional.\(^9\)

6. Refrain from establishing personal connections with patients or persons closely associated with them online, as this may not allow physicians to maintain appropriate professional boundaries and may compromise physicians’ objectivity.\(^10\) It is acceptable to create an online connection with patients for professional purposes only.

7. Refrain from seeking out patient information that may be available online without prior consent.\(^11\)

8. Read, understand, and apply the strictest privacy settings necessary to maintain control over access to their personal information, and social media presence undertaken for personal purposes only.

9. Remember that social media platforms are constantly evolving, and be proactive in considering how professional expectations apply in any given set of circumstances.

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Endnotes


2. For more information please see the CPSO’s Maintaining Appropriate Boundaries and Preventing Sexual Abuse and Treating Self and Family Members policies.

3. The duty of physicians to maintain professional and respectful relationships is set out in the CPSO's Physician Behaviour in the Professional Environment policy, and the Practice Guide.


5. For example, *Copyright Act*, R.S.C. 1985, c. C-42.

6. For more information on conflicts of interest, please see Part IV of the General, O. Reg., 114/94, and the CPSO’s Practice Guide.
7. A breach of confidentiality may be deemed to have occurred if the facts available are sufficient for the patient to be identified, even if only by themselves. This is consistent with the definition of “identifying information” in section (4)2 of PHIPA.

8. Clinical advice is defined as advice of a clinical nature that is directed toward a specific individual to address a medical concern. It is distinct from general health information that is not patient-specific, but disseminated to a general audience for education or information sharing purposes.

9. Be mindful that once information has been posted online, it may be difficult or impossible to remove. Reasonable steps should be taken to remove information that has been posted by one’s self or others.

10. Some physicians may find it preferable to maintain a separate online presence for their personal and professional networks. For more information on maintaining appropriate professional boundaries, please see the CPSO’s Maintaining Professional Boundaries and Preventing Sexual Abuse policy, Treating Self and Family Members policy, and Dialogue article “Maintaining Boundaries.”

11. Patients are entitled to a reasonable expectation of privacy. While physicians are expected to adhere to all of their relevant legal obligations under PHIPA with respect to the collection of personal health information, they should also refrain from seeking out other types of non-protected information online without prior consent.

Related Links

Social Media FAQ

- available here
Original Paper

Pediatric Residents’ Perceptions of Potential Professionalism Violations on Social Media: A US National Survey

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³Department of Pediatrics, University of Alabama at Birmingham School of Medicine, Birmingham, AL, United States
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Abstract

Background: The ubiquitous use of social media by physicians poses professionalism challenges. Regulatory bodies have disseminated guidelines related to physicians’ use of social media.

Objective: This study had 2 objectives: (1) to understand what pediatric residents view as appropriate social media postings, and (2) to recognize the degree to which these residents are exposed to postings that violate social media professionalism guidelines.

Methods: We distributed an electronic survey to pediatric residents across the United States. The survey consisted of 5 postings from a hypothetical resident’s personal Facebook page. The vignettes highlighted common scenarios that challenge published social media professionalism guidelines. We asked 2 questions for each vignette regarding (1) the resident’s opinion of the posting’s appropriateness, and (2) their frequency of viewing similar posts. We also elicited demographic data (age, sex, postgraduate year level), frequency of Facebook use, awareness of their institutional policies, and prior social media training.

Results: Of 1628 respondents, 1498 (92.01%) of the pediatric residents acknowledged having a Facebook account, of whom 888/1628 (54.55%) reported daily use and 346/1628 (21.25%) reported using Facebook a few times a week. Residents frequently viewed posts that violated professionalism standards, including use of derogatory remarks about patients (1756/3256, 53.93%) and, much less frequently, about attending physicians (114/1628, 7.00%). The majority of the residents properly identified these postings as inappropriate. Residents had frequently viewed a post similar to one showing physicians drinking alcoholic beverages while in professional attire or scrubs and were neutral on this post’s appropriateness. Residents also reported a lack of knowledge about institutional policies on social media (651/1628, or 40.00%, were unaware of a policy, 204/1628, or 12.53%, said that no policy existed). A total of 372/1628 respondents (22.85%) stated that they had never received any structured training on social media professionalism.

Conclusions: Today’s residents, like others of their generation, use social media sites to converse with peers without considering the implications for the profession. The frequent use of social media by learners needs to change the emphasis educators and regulatory bodies place on social media guidelines and teaching professionalism in the digital age.

(JMIR Med Educ 2017;3(1):e2) doi:10.2196/mededu.5993

KEYWORDS
social media; professionalism; resident education; pediatrics; graduate medical education
Introduction

Physicians are using social networking sites with increasing frequency. Recent reviews of social media use by physicians indicate widespread use in medical education [1] and for personal and professional purposes [2-4]. A review of the characteristics of physicians using social media indicated a high use by those under 35 years old practicing internal medicine, pediatrics, obstetrics and gynecology, and family medicine [5].

Social media technology offers great educational benefits with its ability to reach a vast audience instantaneously. Patients and families are using social media to connect with health care providers and to seek medical advice.

At the same time, these advanced tools bring challenges to our profession in the form of ethical dilemmas regarding proper physician-patient relationships, privacy concerns, and the portrayal of physicians on the Internet.

Several reports [6] have highlighted these concerns by documenting breaches of professionalism by practicing physicians, prompting regulatory and professional organizations, such as the US Federation of State Medical Boards (FSMB), to develop and disseminate guidelines related to the use of social media by physicians [7-10].

Resident trainees are particularly at increased risk of the consequences of using social media. Some experts have reported concerns that the current generation of residents, who have been coined the “digital native generation” (born after 1980), will apply guidelines about online professionalism differently from the older digital “immigrant” generation [11].

In fact, a recent study reported that pediatric program directors find lapses in online professionalism by pediatric residents to be quite common, with over half of the program and associate program directors reporting inappropriate postings by residents in the past year [12]. Similar to the FSMB, medical schools have realized the need for social media educational guidance to trainees, noting online behaviors such as violations of patient privacy, use of profanity, depiction of intoxication, sexual suggestiveness, and communication about the medical profession or patients in a negative tone [13].

To date, most of the studies related to physicians’ use of social media have largely focused on its use, and guidelines for helping physicians navigate the blurred lines. Previous research has elicited the opinions and concerns of US medical school deans, state medical boards, and pediatric clerkship directors and residency program directors regarding social media use by learners [12-15]. One recent study compared perceptions of pediatric residents with those of program directors using descriptors of online activity [16]. However, to our knowledge, none have directly surveyed trainees by using actual Facebook posts.

By conducting a national survey in the United States of all pediatric residents we sought to determine (1) residents’ perspectives on appropriate social media postings, and (2) the degree to which residents are exposed to postings that violate regulatory and professional organization guidelines for social media use.

Methods

Recruitment

In March 2013, we distributed an electronic survey via SurveyMonkey (SurveyMonkey, San Mateo, CA, USA) to members of the American Academy of Pediatrics Section on Medical Students, Residents and Fellowship Trainees (AAP SOMSRTF) (now the Section on Pediatric Trainees). At the time of this study, approximately 98% of all pediatric residents were members of AAP SOMSRTF. For the purposes of this study, we used responses from the pediatric and medicine-pediatric residents only (N=9850). The survey site was open for 3 weeks from March 5 to March 25. No reminder emails were sent. The survey was voluntary, and we offered an incentive to complete the survey in the form of a chance to win a cash prize.

Survey Design

The survey consisted of 5 hypothetical postings from a resident’s personal Facebook page (Facebook, Inc, Menlo Park, CA, USA). We based these vignettes on our observations of actual postings by residents from their institutions and mirrored the main criteria used by state medical boards to discipline physicians for unprofessional behavior [7]. Among the vignettes, 3 depict physicians’ use of derogatory remarks about patients (vignettes 1 and 2) and about another physician (vignette 5); vignette 3 illustrates physicians wearing medical attire and consuming alcohol; vignette 4 addresses appropriate physician-patient boundaries (see Figure 1, Figure 2, Figure 3, Figure 4, and Figure 5). We tested the vignettes on a small focus group of early-career pediatric faculty at the primary author’s institution, Louisiana State University Health Science Center, which included both social media users and those without social media accounts. We refined the vignettes based on feedback from the focus group. The vignettes do not encompass all areas discussed in published social media guidelines but were chosen as those most commonly encountered by trainees.

Using a Likert format, we asked 2 questions for each vignette regarding (1) the resident’s opinion of the appropriateness of the posting, using a 5-point ordinal scale from “very inappropriate” to “very appropriate,” and (2) the frequency with which the resident had viewed similar posts, using a 4-point incremental scale from “frequently” or “often” to “never,” plus an additional “I have never used Facebook” option. We also elicited demographic data (age, sex, and postgraduate year), frequency of Facebook use, awareness of their institutional policies, and prior social media training.
Figure 1. Vignette 1, depicting physicians' use of derogatory remarks about patients. N/A: not applicable.

<table>
<thead>
<tr>
<th>How appropriate?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Inappropriate</td>
<td>433</td>
<td>26.6%</td>
</tr>
<tr>
<td>Inappropriate</td>
<td>844</td>
<td>51.8%</td>
</tr>
<tr>
<td>Neutral</td>
<td>276</td>
<td>17%</td>
</tr>
<tr>
<td>Appropriate</td>
<td>61</td>
<td>3.8%</td>
</tr>
<tr>
<td>Very Appropriate</td>
<td>14</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How frequently have you seen similar posts?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequently</td>
<td>264</td>
<td>16.2%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>708</td>
<td>43.5%</td>
</tr>
<tr>
<td>Rarely</td>
<td>378</td>
<td>23.2%</td>
</tr>
<tr>
<td>Never</td>
<td>195</td>
<td>12%</td>
</tr>
<tr>
<td>N/A I have never used Facebook</td>
<td>83</td>
<td>5.1%</td>
</tr>
</tbody>
</table>
Figure 2. Vignette 2, depicting a physician’s use of derogatory remarks about patients. ER: emergency room; N/A: not applicable.

<table>
<thead>
<tr>
<th>How appropriate?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Inappropriate</td>
<td>767</td>
<td>47.1%</td>
</tr>
<tr>
<td>Inappropriate</td>
<td>642</td>
<td>39.4%</td>
</tr>
<tr>
<td>Neutral</td>
<td>158</td>
<td>9.7%</td>
</tr>
<tr>
<td>Appropriate</td>
<td>46</td>
<td>2.8%</td>
</tr>
<tr>
<td>Very Appropriate</td>
<td>15</td>
<td>0.9%</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>How frequently have you seen similar posts?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequently</td>
<td>206</td>
<td>12.9%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>578</td>
<td>35.5%</td>
</tr>
<tr>
<td>Rarely</td>
<td>458</td>
<td>28.1%</td>
</tr>
<tr>
<td>Never</td>
<td>209</td>
<td>14.8%</td>
</tr>
<tr>
<td>N/A I have never used Facebook</td>
<td>87</td>
<td>5.3%</td>
</tr>
</tbody>
</table>

Figure 3. Vignette 3, depicting physicians wearing medical attire and consuming alcohol. N/A: not applicable.

<table>
<thead>
<tr>
<th>How appropriate?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Inappropriate</td>
<td>134</td>
<td>8.2%</td>
</tr>
<tr>
<td>Inappropriate</td>
<td>353</td>
<td>21.7%</td>
</tr>
<tr>
<td>Neutral</td>
<td>691</td>
<td>42.4%</td>
</tr>
<tr>
<td>Appropriate</td>
<td>385</td>
<td>23.7%</td>
</tr>
<tr>
<td>Very Appropriate</td>
<td>65</td>
<td>4%</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>How frequently have you seen similar posts?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequently</td>
<td>522</td>
<td>32.1%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>663</td>
<td>40.7%</td>
</tr>
<tr>
<td>Rarely</td>
<td>241</td>
<td>14.8%</td>
</tr>
<tr>
<td>Never</td>
<td>121</td>
<td>7.4%</td>
</tr>
<tr>
<td>N/A I have never used Facebook</td>
<td>81</td>
<td>5%</td>
</tr>
</tbody>
</table>
Analysis

We imported data from SurveyMonkey into Microsoft Excel 2007 (Microsoft Corporation, Redmond, WA, USA), in order to prepare the survey dataset for statistical and tabular analysis. The study dataset contained the responses of postgraduate years 1 through 4 training levels and chief residents. The data analysis was performed using Epi Info Version 7 (Centers for Disease Control and Prevention, Atlanta, GA, USA). We performed basic descriptive analyses of responses for each question and report the corresponding frequency for each question response. The institutional review boards of the Louisiana State University Health Sciences Center, the University of Alabama School of Medicine, and the University of Arkansas for Medical Sciences approved this study as exempt from requiring participants’ consent. Funding for this study was provided through a grant from the Louisiana State University Health Sciences Center New Orleans Academy for the Advancement of Educational Scholarship.

Results

Demographics

We received responses from 1628 pediatric residents (of 9850 surveyed; 16.53% participation rate). Of these, 92.01% (1498/1628) acknowledged having a Facebook account, of whom 888 (54.55%) reported daily use and 346 (21.25%) reported using Facebook a few times a week (Table 1).

<table>
<thead>
<tr>
<th>How appropriate?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Inappropriate</td>
<td>1217</td>
<td>74.8%</td>
</tr>
<tr>
<td>Inappropriate</td>
<td>365</td>
<td>22.5%</td>
</tr>
<tr>
<td>Neutral</td>
<td>35</td>
<td>2.2%</td>
</tr>
<tr>
<td>Appropriate</td>
<td>8</td>
<td>0.5%</td>
</tr>
<tr>
<td>Very Appropriate</td>
<td>2</td>
<td>0.1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How frequently have you seen similar posts?</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Often</td>
<td>14</td>
<td>0.9%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>100</td>
<td>6.1%</td>
</tr>
<tr>
<td>Rarely</td>
<td>403</td>
<td>24.8%</td>
</tr>
<tr>
<td>Never</td>
<td>1024</td>
<td>62.9%</td>
</tr>
<tr>
<td>N/A I have never used Facebook</td>
<td>87</td>
<td>5.3%</td>
</tr>
</tbody>
</table>

Figures

Figure 4. Vignette 4, addressing appropriate physician-patient boundaries. N/A: not applicable.

Figure 5. Vignette 5, depicting a physician's use of derogatory remarks about another physician. N/A: not applicable.
Table 1. Frequency of Facebook use among 1628 pediatric residents.

<table>
<thead>
<tr>
<th>Frequency</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily</td>
<td>888</td>
<td>54.55%</td>
</tr>
<tr>
<td>A few times a week</td>
<td>346</td>
<td>21.25%</td>
</tr>
<tr>
<td>A few times a month</td>
<td>130</td>
<td>7.99%</td>
</tr>
<tr>
<td>Rarely</td>
<td>145</td>
<td>8.91%</td>
</tr>
<tr>
<td>Never</td>
<td>119</td>
<td>7.31%</td>
</tr>
</tbody>
</table>

The total sample of 1628 residents included 1205 women (74.02%) and 423 men (25.98%). Mean age of the respondents using Facebook was 30 years (median 29 years; interquartile range 27-33 years). Mean age of the respondents who did not have a Facebook account was 31 years (median 30 years; interquartile range 25-37 years). Respondents were distributed throughout all postgraduate levels, with 554 (34.03%) in postgraduate year 1; 456 (28.01%) in year 2; 407 (25.00%) in year 3; and 211 (12.96%) in year 4 or chief residents.

Of note, there was no statistically significant difference in responses to the vignettes between Facebook users and non-Facebook users, nor was there a statistically significant difference between responses of various postgraduate year levels. Therefore, we report all responses in aggregate below.

Analysis

In vignettes 1 and 2 depicting physicians’ use of derogatory remarks about patients (Figure 1, Figure 2) and about attending physicians (Figure 5), the majority of the residents properly identified these posting as inappropriate. However, the residents reported often seeing something similar (972/1628, 59.71% for vignette 1 and 784/1628, 48.16% for vignette 2 responding often and sometimes), but not vignette 5 (1427/1628, 87.65% rarely and never).

The third vignette (Figure 3) shows physicians drinking alcoholic beverages while in professional attire (scrubs). On this very often viewed posting (1215/1628, 74.63%), most residents were neutral (691/1628, 42.44%), with an even distribution toward appropriate and inappropriate.

In the fourth vignette (Figure 4), the resident accepts a friend request from a mother of a patient. The majority of residents recognized this as inappropriate (1209/1628, 74.26%) and as rarely or never seen (1133/1628, 69.59%).

We asked residents about their knowledge of the presence of social media policies at their institutions, pediatrics departments, or residency programs. Almost half of respondents (765/1628, 46.99%) said that their institution did have a policy. However, almost as many (651/1628, 39.99%) were unsure whether their institution, department, or program had a social media policy in place. Residents were also asked about any formal training on appropriate use of social media, and 418 respondents stated that they had never received any structured training on social media professionalism.

The most common method for training was in-person discussions by program leaders (n=706 responses), followed by formal lectures and discussions by hospital administration (n=458) or risk management personnel (n=402 responses). Simulation was the training experienced by a small group of the respondents (n=53). Other methods of training mentioned in free-text answers included prior training in medical school but not during residency, Web-based modules, and emails from superiors of the program’s social media policy and about instances of inappropriate social media use. Another 2 comments indicated that training shouldn’t be needed, as online professionalism is the “common sense of being an adult.”

Discussion

Principal Findings

This study is, to our knowledge, the first to report a US national survey of pediatric residents’ perspectives using simulated physicians’ Facebook postings. Residents could identify some inappropriate content but reported being frequently exposed to unprofessional posts. Despite widely disseminated guidelines on the professional use of social media content, the data show that these professionalism standards are being violated as reported previously [12,16].

Residents did recognize the inappropriate scenarios as such in 4 of the 5 vignettes. The disconcerting exception is vignette 3, where 70% of residents were neutral about or comfortable with a post depicting physicians drinking alcohol while in medical attire. A recent study found that 40% of state medical boards would consider investigating a physician, with similar postings, for breaches of professional conduct [17]. While wearing scrubs when dining at a restaurant or bar is not necessarily a breach of professionalism, patients, colleagues, and the public may perceive the physician to be working while under the influence of alcohol. Residents, like many of the digital native generation, may not consider the future implications for career, professional standing, future job searches, etc, because Internet posts are “forever,” leaving a digital footprint behind [18].

Regulatory groups discourage entering into an electronic “friendship” with patients (vignette 4) [6], and our study respondents recognized it as inappropriate, but to a lesser degree (around 70%) than published data on program directors’ opinions (99% disapproval) [12]. Physicians should use the same guidelines in entering digital conversations as they would in real life and consider that shared personal information may cloud the typical boundary of the physician-patient relationship. Residents should continue to be educated on this issue, as patients may make these types of “friend” requests to an independent practitioner more frequently in an established, longer-term physician-patient relationship.
Residents’ being exposed to unprofessional social media posts, as we report, may increase their propensity to model this behavior. Making disparaging comments about patients and other health care providers has no place in the dialogue of our profession and will undermine the public’s respect. Physicians need to be cognizant that comments about patient experiences, as in vignettes 1 and 2, can be viewed as a breach of confidentiality, even if no personal identifiers are included, thus undermining the public’s trust.

Our data show that a remarkably high percentage (92%) of responding residents use Facebook, with over 50% using it daily and another 20% using it at least once a week. This mirrors data from the general population, where 59% of adult respondents to a Centers for Disease Control and Prevention survey [5] and 74% of respondents to a Pew survey [19] reported use of social networking sites, with the highest rate being among 18- to 29-year-olds, the age group encompassing most medical residents. The prevalence of use of interactive Web technology by these learners underscores the need for social media education by medical educators, professional organizations, and regulatory groups. Education should not be limited to adherence to guidelines but should include what actions residents should take when they observe guidelines being violated by others [16]. Providing an anonymous, safe process for reporting, investigating, and addressing unprofessional behaviors online could lead to corrective actions being taken before state medical boards would intervene. Most medical schools have policies, guidelines, and processes for addressing professionalism at work. Those processes could be modified to include unprofessional behavior online.

**Limitations and Benefits**

There are several limitations to our study. Although a large number of residents responded to this survey, the results represent only 16.53% of all pediatric residents who are members of the AAP SOMSRFT. We attribute this to our inability to send reminder emails to nonresponders. The study focused only on pediatric and medicine-pediatric residents. While the vignettes were not necessarily specific to pediatrics, the results may not be generalizable to all residents. The possibility that nonresponders were not Facebook users must be considered and could have skewed the results. In addition, physicians and health care professionals use other user-generated content sites, but we did not focus on these sites. Our questions were limited to 5 scenarios, which does not represent all potential violations that are enumerated by the FSMB social media guidelines. This self-reported study might also have been subject to recall bias.

This type of study has several benefits. As with case-based learning of medical diseases, the use of real posts would enhance the relevance to learners, stimulate greater discussion, and enhance the acceptability of teaching social media professionalism compared with simply providing a list of do’s and don’ts per published guidelines. Also, these results pinpointed generational and controversial areas, which can guide curriculum design. Due to the rapidly changing nature of the use of technology in medicine, follow-up studies would be useful to see whether lessons are learned and opinions evolve over time. Future studies may also compare learners of various levels versus attending physicians.

**Conclusion**

A high percentage of residents reported viewing and, in some instances, not recognizing unprofessional posts. This highlights the need for further education of residents about the potential hazards of online postings in order for the continued high standards of professional behaviors to be upheld by the next generation of physicians.

**Conflicts of Interest**

None declared.

**References**


Abbreviations

AAP SOMSRFT: American Academy of Pediatrics Section on Medical Students, Residents and Fellowship Trainees
FSMB: Federation of State Medical Boards

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Social media and Canadian physicians: Issues and rules of engagement

Important note:

For Canadian physicians, regulations and guidelines from provincial regulatory authorities or employers take precedence over any of the guidance provided here. Certain regulatory authorities such as the College of Physicians and Surgeons of British Columbia and the College of Physicians and Surgeons of New Brunswick have issued guidelines or statements with respect to social media.¹

Social media: What does it mean?

Social media are everywhere in Canadian society today. From Facebook to YouTube to Twitter, everyone seems to be engaged in electronic communications in some form or another with friends, family, colleagues and even complete strangers on websites and through mobile applications. Social media have changed the way people build relationships, communicate, interact and gather and disseminate information.

Social media and patients

There is currently widespread discussion among health care professionals, academics, social media observers and the public about how social media can and should be used in health care. The evidence base is currently lacking on whether the use of social media can improve patient outcomes.² But it is undeniable that the internet and social media
platforms have become an integral part of how patients and members of the public seek information about health and increase the sense of engagement patients have in their own care. Through a variety of websites and fuelled by the growing availability of electronic patient health records, patients are increasingly sharing information with other patients about their health conditions and their health care providers.

Social media and physicians: risks and benefits

For physicians, social media provide a unique set of opportunities and challenges. There is growing debate about whether the medical profession should play a role in using social media to communicate more effectively with individual patients and the patient community at large. The reality is that individual doctors and medical organizations have to consciously decide if, why and how to use the various social media platforms. While use of social media could potentially increase the exposure of physicians to disciplinary and medico-legal issues, those physicians who choose to use social media can help shape how these tools can improve health care in the future.

Social media pose a challenge for physicians (and other professionals) in terms of separating one’s personal and professional lives. While such a separation is a fundamental tenet of the medical profession, social media blur such boundaries in ways that can enrich communications, but can also put physicians at risk. It is an entirely new environment that medical professionalism has not yet satisfactorily addressed.

When communicating through social media, physicians must remember they remain governed by the same ethical and professional standards that have always applied and that are paramount.

As recent findings show, Canadian physicians believe social media present a variety of professional and legal risks, and they are uncertain of the potential benefits of these new forms of communication and interaction.

CMA’s role

This document is intended to provide guidance on how Canadian medical students, residents, fellows and practising physicians can approach social media, by acknowledging the potential benefits as well as the challenges and risks.

While these guidelines are based on the best available evidence, this is a constantly evolving field where technological innovations can change the playing field almost overnight. As such, the Canadian Medical Association (CMA) will review and update this document as required.

As an association, the CMA has a responsibility and obligation to its members to provide guidance about social media. In addition, the CMA monitors social media trends in health care and will attempt to speak for the profession as a whole to ensure social media are used in a way that provides maximum benefit to both patients and physicians.

The CMA acknowledges that, when social media become integrated into the health care delivery system, the individual provinces and territories will need to explore how to appropriately remunerate physicians for their time and activities.
Key issues

Patient confidentiality

- The privacy and security of individual patient information is paramount and should never be shared beyond the circle of care. This principle is also enshrined in CMA policy.\(^4\) In communicating with an individual patient in other than a face-to-face environment, a secure electronic communication platform must be used.\(^5\) Identifiable patient information, including images, should never be posted online or shared in electronic communications of a general nature.

- When using social media, physicians should endeavour to use the most stringent security and privacy settings available for the particular platform.

- Physicians with employees should make them aware of issues concerning patient confidentiality in their own use of social media. Consideration should be given to instituting a social media policy for the office or practice.

- Social networking sites cannot guarantee confidentiality. Anything written on a social networking site can theoretically be accessed and made public. For example, the Patriot Act in the United States makes it possible for the U.S. government under certain conditions to access any information posted on a social networking site or website hosted by a U.S. service provider, even if this information is located within the “private or direct message” area of the site.

Professionalism

- Having an online profile or identifiable presence on social media can have the same degree of positive or negative impact on a physician’s social reputation as being active in any other public venue. In fact, having access to a global audience can magnify this reputation.

- The most effective use of social media often involves communicating information that is both personal and professional. However, physicians must retain the appropriate boundaries of the patient-physician relationship when dealing with individual patients. The same standards of professionalism that would apply in face-to-face physician-patient interactions also apply in electronic interactions.

- If a physician is an employee of a health care institution or organization that has social media guidelines in place, he or she should review these and act accordingly.

Online communication issues

- Electronic communications are not anonymous and are always stored in some form. As such, it is possible to trace the author of a comment even if posted anonymously.

- Once their material is published online, authors of comments on social media sites no longer control how and where the information is disseminated, and these comments can sometimes lose context.
Postings to social media sites are subject to the same laws of copyright, libel and defamation as written or verbal communications.

Potential benefits

- More frequent communication with patients and the public improves the quality of medical care and satisfaction with physician care. Social media can enhance the role of traditional media in delivering important public health messages.
- Use of social media can provide patients and the public with quicker and easier access to medical expertise, often in a way that is more current, clear and concise than traditional media sources.
- Posting (with copyright permission) evidence-based medical information on social media sites can improve the quality of health information made available to patients and the public.

Rules of engagement

The following should be kept in mind when using social media:

- Understand the technology and your audience

  The many social media platforms work in different ways and often have different goals. Even broad types of social media such as social networking sites have different terms and conditions under which they operate. Some social networking sites, for example Facebook, are intended for use by everyone, but you set your own network of people you know. Others, like Twitter, are designed for interacting with people you might not know at all. And others still, such as Asklepios, are intended for peer-to-peer interaction between Canadian physicians only. In order to use social media effectively, it is necessary to have a good understanding of how they work and who your intended audience will be before using them.

- Be transparent

  Identify clearly who you are and any potential conflicts of interest you may have in association with information you are providing. Being transparent encourages more honest interaction with others and a more productive outcome. If you are discussing medical or health issues, it is probably beneficial to identify yourself as a physician. If you are employed by an institution or organization, you should state either that you are reflecting corporate policies or that the views expressed are yours alone and not those of your employer.

  When participating on a social networking site such as Facebook that may include patients in your practice, you should avoid communicating personal or private information. It is possible to establish a professional page, where you can post information about your practice and general health information and links.
Respect others

If you are posting information created by somebody else, proper permission should be obtained and acknowledgement given. Most social media sites have their own sets of rules, guidelines and etiquette, and these should be followed. If uncertain of how a specific site operates, spend more time listening and reading, prior to engaging in active dialogue. Always respect the principle of patient confidentiality.

Focus on areas of expertise

As a physician you can often bring most value to a forum or conversation by discussing issues on which you have a particular expertise. Sharing this information – as long as it does not contravene individual patient confidentiality – raises the level of discourse on social media sites and is likely to be viewed favourably by other participants.

You should anticipate that the information you provide on social media may be challenged by both other physicians and non-physicians. Remember to keep the tenor of the debate at a civilized level and do not be unnecessarily offended if your viewpoint is rejected, even if you do feel it is based on best available evidence.

If you choose to use your own website to communicate to a non-medical audience about medical or health issues, you should include a terms of use agreement to advise users that information is intended for Canadian residents and that individual health queries will not be addressed.

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1 College of Physicians and Surgeons of British Columbia Social Media and Online Networking Forums (https://www.cpsbc.ca/files/u6/Social-Media-and-Online-Networking-Forums.pdf);
2 College of Physicians and Surgeons of New Brunswick Facebook Guidelines (http://www.cpsnb.org/english/Guidelines/Facebook.htm);
3 However, numerous research studies are showing that social media tools and resources are being used to provide patients with health information and attempt to change health-related behaviours. See, for example, the abstracts of presentations from the four Med 2.0: Social Media and Web 2.0 in Health conferences (http://www.medicine20congress.com/ocs/index.php/med/med2011), or papers published in the Journal of Medical Internet Research (http://www.jmir.org/);
4 Social media use by physicians (http://www.cma.ca/advocacy/social-media-use-physicians);
5 CMA Health Information Privacy Code (http://www.cma.ca/index.php?ci_id=53584&la_id=1);
6 CMA Physician Guidelines for Online Communications with Patients (http://policybase.cma.ca/dbtw-wpd/PolicyPDF/PD05-03.pdf);
7 Health promotion: CMPA will assist (http://www.cmpa-acpmc.ca/cmpapd04/docs/member_assistance/more/com_is0890-e.cfm)
Original Paper

Knowledge Exchange and Discovery in the Age of Social Media: The Journey From Inception to Establishment of a Parent-Led Web-Based Research Advisory Community for Childhood Disability

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Abstract

Background: Efforts to involve parents and families in all aspects of research, from initiating the question through to dissemination and knowledge exchange, are increasing. While social media as a method for health communication has shown numerous benefits, including increasing accessibility, interactions with others, and access to health care information, little work has been published on the use of social media to enhance research partnerships.

Objective: Our objective was to describe the development and evaluation of a Web-based research advisory community, hosted on Facebook and connecting a diverse group of parents of special needs children with researchers at CanChild Centre for Childhood Disability Research. The goal of this community is to work together and exchange knowledge in order to improve research and the lives of children and their families.

Methods: The Web-based Parents Participating in Research (PPR) advisory community was a secret Facebook group launched in June 2014 and run by 2 parent moderators who worked in consultation with CanChild. We evaluated its success using Facebook statistics of engagement and activity (eg, number of posts, number of comments) between June 2014 and April 2015, and a Web-based survey of members.

Results: The PPR community had 96 participants (2 parent moderators, 13 researchers, and 81 family members) as of April 1, 2015. Over 9 months, 432 original posts were made: 155 (35.9%) by moderators, 197 (45.6%) by parents, and 80 (18.5%) by researchers. Posts had a median of 3 likes (range 0-24) and 4 comments (range 0-113). Members, rather than moderators, generated 64% (277/432) of posts. The survey had a 51% response rate (49/96 members), with 40 (82%) being parent members and 9 (18%) being researchers. The initial purpose of the group was to be an advisory to CanChild, and 76% (28/37) of parents and all the researchers (9/9) identified having an impact on childhood disability research as their reason for participating. A total of 58% (23/40) of parents and 56% (5/9) of researchers indicated they felt safe to share sensitive or personal information. While researchers shared evidence-based resources and consulted with families to get guidance on specific issues, there was an unexpected benefit of gaining an understanding of what issues were important to families in their daily lives. Parents felt a sense of belonging to this community where they could share their stories but also wanted more researcher participation and clarity on the purpose of the group.
Conclusions: The PPR community grew from inception to an established community with active engagement and knowledge exchange. Both parents and researchers described valuable experiences. Researchers should consider social media as a means of engaging families in all phases of research to ensure that research and its outcomes are meaningful to those who need it most.


KEYWORDS
knowledge exchange; research engagement; collaborative research; scientific collaboration; Web-based community; social media; Facebook; childhood disability; patient and public involvement (PPI)

Introduction
Families with children with disabilities and medical complexity constitute approximately 4.6% of Canada’s pediatric population under the age of 15 years [1]. The growth in this population over the past 20 years has driven an increase in childhood disability research. Historically, in childhood disability research, applied health researchers seeking to directly influence clinical practice have worked collaboratively with individuals responsible for making relevant clinical, health, and social policy decisions and allocating resources [2]. However, over the past 5 to 10 years, efforts to actively involve families and patients in research have been increasing. Rosenbaum, in a position piece on family-centered research, identified “how much richer our studies have become with the active input of families and parents and thoughtful critics during the development of projects” [3]. Involving families in research is believed to improve service delivery, patient experience, and patient outcomes [4]. Input from families generates research questions that are targeted at family needs, which are not always aligned with the priorities of researchers. Efforts to identify high-priority questions in cerebral palsy research found that, although there was considerable overlap between what clinicians and families considered key research topics, some topics that families identified as important were not considered important by clinicians. The researchers discovered that social issues and effective alternative therapies were not of interest to clinicians but were important to families as they related to daily function and activity [5].

In addition to the growing amount of support for the inclusion of families in the research process [2,3,6], the expectations of funding agencies that patients and families be included are also increasing [7-9]. Although the importance of and need for engagement have been acknowledged, little evidence exists about the best way to actively engage families to provide input that is valuable to clinicians and researchers [6,10,11]. Research conducted into engaging families in research has highlighted several barriers that limit the ability of families to participate in research and be fully engaged. From a researcher’s perspective, these barriers may include a desire to maintain control, unwillingness to consider parents as equals in terms of contributions and competence, and time and cost limitations. From a consumer’s perspective, these barriers may include time, difficulty accepting and transitioning into a new role, and lacking knowledge or the confidence to contribute [4].

Social media have received increased attention over the past 10 years as a means of connecting and improving health communication. Social media platforms such as Facebook and Twitter are free, and provide quick and accessible methods to access information and engage with other stakeholder groups. While 52% of online adults use multiple social media sites in the United States, 71% use Facebook, which remains the most popular site for those who use only one and overlaps significantly with other platforms [12]. In a systematic review, Moorhead et al identified the benefits of social media (including Wikipedia, YouTube, Facebook, and virtual game and social worlds) for health communication as (1) increased interactions with others, (2) more available, shared, and tailored information, (3) increased accessibility and widening access to health information, (4) peer, social, and emotional support, (5) public health surveillance, and 6) the potential to influence health policy [13]. Limitations were mainly related to concerns about reliability of information, confidentiality, and privacy. Of the 98 research studies included in the review by Moorhead et al, 13 were using Facebook as a means of increasing awareness and communicating about a range of topics (eg, concussion, diabetes, breast cancer, attention-deficit/hyperactivity disorder) [13]. Facebook has also been used as part of a social media campaign intended to raise awareness for Hirschsprung disease and to connect and engage families affected by this rare condition [14]. While reach and responsiveness are considered strengths of social media usage, other studies have reported benefits of creating smaller communities. In particular, a primary care maternity clinic in Finland provided its clients with a Web service containing social media tools similar to those of Facebook, in order to foster a support network for its members [15]. The participating mothers reported that one factor that increased their feelings of belongingness was the fact that membership was strictly limited to clients of the same maternity clinic. This closed network positively affected the mothers’ levels of trust and increased their willingness to discuss intimate issues.

While describing management strategies for online health communities, Young proposed a community life cycle that consists of 4 stages: inception, establishment, maturity, and mitosis [16]. Each stage is characterized by various milestones, and monitoring a community’s growth can facilitate progression through these stages. The inception stage is the first stage that starts as soon as an organization begins to engage potential members. The primary focus during this stage is to make connections and build a core group of active members. Engagement at this time is limited, with only 0% to 50% of activity initiated by community members. The establishment stage comes next and begins when community members generate more than 50% of the activity and ends when they generate most (90%) of the growth and activity. The primary focus of this stage is establishing a sense of community by
acknowledging the contributions of members and encouraging further participation and engagement. The maturity stage begins when more than 90% of community activity and growth is generated by its members. During this stage, the size of the community reaches its critical mass and the sense of community is well established. Although communities at this stage are considered self-sustaining, management is still needed. The final stage, known as the mitosis stage, begins when the community becomes largely self-sustaining and ends when activity and growth begin to negatively affect the sense of community. This is a critical stage, as successful communities run the risk of becoming too large and active, subsequently triggering member disengagement. Community monitoring is essential at this stage, as managers may witness the emergence of special interest groups and community subsets. These subgroups have the potential to split off to create splinter groups and begin the community life cycle once more.

We describe the development and evaluation of a Web-based research advisory committee hosted on Facebook and connecting a diverse group of parents of special needs children with researchers at CanChild at McMaster University in Hamilton, Ontario, Canada. The goal of establishing this parent-researcher community was to work together and exchange knowledge in order to improve research and the lives of children with special needs and their families. We describe the first year of our online community, during which we have moved from inception to an established community.

Methods

Building the Community

Based on CanChild’s knowledge translation strategic plan [17], CanChild planned on developing a research advisory group to facilitate active engagement from family members. The purpose of the group would be to exchange knowledge on project planning, research direction, the current state of special needs parenting, supports, and services, as well as how to translate research knowledge to best serve parents and youth living with disability. The original vision for our research advisory group was to bring together youth and young adults with disabilities, family members, and researchers for quarterly meetings (either in person or via teleconference) to facilitate the research direction. In early discussions (October 2012) related to the development of this group, a parent (JS) proposed the idea of a parent advisory community hosted on Facebook (Facebook, Inc, Menlo Park, CA, USA). It was thought that a virtual group would allow greater involvement from families and researchers (both geographically and categorically) and more instantaneous feedback, and would be more convenient. Since this parent (JS) had already developed a network of special needs families across Canada and the world, she partnered with another parent to see whether other parents were interested in supporting this idea. In less than 2 hours, more than 30 parents were interested in participating. While parents were keen to participate, it was also important to convince the researchers that this was a viable venture. Our parent made a presentation to the CanChild knowledge translation team, and this was taken to the entire CanChild team for approval. While not an overwhelming number of researchers were using Facebook, it was agreed to try it as a pilot project to be evaluated and revisited in 6 months.

Evaluation Method

To evaluate this Web-based community, we collected and analyzed posts, likes, and comments in the group over a period from June 2014 to March 2015. In addition, we gathered data through a survey sent to all members (active or not) of the group.

Facebook Evaluation

We informally evaluated the Facebook group at 6 months, when the CanChild director agreed to provide further support and resources for the group with the mandate to provide a more formal evaluation. The formal evaluation took place from June 2014 to April 2015. To determine whether the Parents Participating in Research (PPR) group was successful from both the researchers’ and families’ perspectives, we evaluated the group using quantitative Facebook statistics of engagement and activity (eg, number of posts, likes, comments, and engaged members). We further analyzed the posts by family members and researchers to determine what broad topics or discussions areas were most frequently discussed.

The PPR Web-Based Survey

We used a voluntary, closed, online survey of PPR Facebook members for further evaluation. The institutional review board committee deemed a separate approval for the survey not to be necessary, as the survey was part of a quality improvement measure. In developing the survey, we used a participatory approach and asked for parent volunteers within the Facebook group to help formulate the questions. There were 5 iterations of the questionnaire. The participation of the other members in designing the survey was mediated through the group moderator, who forwarded the suggestions and requests anonymized to DR and OK. The final version consisted of 13 questions covering the aspects “member’s description,” “research literacy,” “safety of the group,” “motivation,” “perceived change,” and “future directions,” along with an open-ended section for respondents to provide comments. The survey was distributed using SurveyMonkey (Palo Alto, CA, USA), and the link was shared with the group members through multiple channels as posts, email, and direct messages. Multimedia Appendix 1 shows a copy of the survey. According to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines, the link provided allowed for only one response per Internet protocol address, no personal information was collected, and participation was voluntary [18]. The intention was to also reach those parents and researchers who joined the Facebook group but did not use it on a regular basis. Over the period of 1 month (March 2015) the moderator launched 3 reminder actions. No incentive was offered for completing the survey.

We analyzed quantitative data using frequency statistics. For the open-ended question “what would you change about the group?” 2 of the authors reviewed and coded responses into categories based on agreement. Quotes selected to include in the paper were chosen by consensus of all authors that were thought to represent an interesting perspective on the Facebook group that wasn’t captured in the quantitative portion of the survey.
Results

Building the Community

In starting this Web-based community, several decisions had to be made based on principles established for community-based research [19]. The first was that the community would be set up and run by the 2 parent moderators. They worked in consultation with CanChild and considered everything from choosing the type of group, to finding members, to setting rules of engagement and deciding on areas of discussion. Tutoring was also a factor to help many members of the research team understand how to use Facebook.

Private Versus Public

It was decided that a private (or secret) Facebook group be set up for the purpose of this advisory community, and it was named “Parents Participating in Research” (PPR). The rationale for making the group private was that it allowed moderators to control who was part of the group (members would have to be invited to join by an administrator, and posts would be seen only by other members within the group) and that the group would not be searchable (allowing for increased confidentiality of information shared by parents and researchers).

Rules of Engagement

To moderate the space and ensure a clear purpose, rules of engagement were developed (see Multimedia Appendix 2). All members were asked to read and agree to follow the guidelines set out before commenting in the forum. We provided a community document for this purpose, with the idea that we would revisit these rules on a regular basis to ensure that we were providing a safe and comfortable space.

Community Space

The PPR Facebook group launched in June 2014 with its first members (primarily those who expressed an interest in the initial Facebook post) invited into the group on June 10 and 11, 2014. After signing on, the rules of engagement, they were invited to introduce themselves (or their children) in either the community photo album or in the group timeline. This was done to foster a sense of community and to help us remember that there is indeed a person behind every question and response. While not mandatory, introductions were encouraged to promote participation and engagement.

Icebreakers

Icebreakers were topics introduced by the moderator and used to help stimulate conversation and establish rapport. Multimedia Appendix 3 shows an example of an icebreaker.

Facebook Evaluation

As of April 1, 2015, the PPR Facebook page had a total of 96 members (2 parent moderators, 13 researchers/CanChild members, and 81 family members). The majority of the members were female, but there were 11 male members (7 of whom were researchers). We estimated that 4 members left the group during the pilot stage of this project. Members were primarily located in Canada (with representation from Alberta, Saskatchewan, Manitoba, Ontario, and Quebec; 1 from the United Kingdom, and 1 from Australia).

Engagement

During the time period June 2014 to March 2015, a total of 432 posts were made (this figure only includes original posts, not comments generated from the posts). Breaking this figure down further, 155 (35.9%) of these posts were made by a moderator (averaging 77.5 posts per member), and 197 (45.6%) posts were made by parents (averaging 2.4 posts per member). Researchers accounted for 80 (18.5%) of the 432 posts, averaging 6.2 posts per member. There was an initial surge of members in the inception phase (approximately June 2014) when a large proportion of members (n=31, 32%) were added to the group. This influx of members was accompanied by a high level of engagement, with a total of 64 primary posts being made in the month of June (mean posts per month: n=42.9, range 20-64 posts). Another period of increased engagement occurred in November of 2014 (64 primary posts made), as that month featured a Family Engagement Day hosted at McMaster University by CanChild, celebrating its 25th anniversary. As indicated above, moderators restricted access to the group to ensure that the group remained manageable and the group was not searchable from the public Facebook domain.

Based on the number of views, as displayed by Facebook, posts were generally seen by all members of the group (indicating that members checked in frequently). Posts had a median of 3 likes (range 0-24) and 4 comments (range 0-113).

Families

While the purpose of the Facebook group was to connect researchers and parents of special needs children, the Web-based community also provided a private environment in which parents could discuss personal issues and interact with other families with similar experiences. Many discussions covering various topics were initiated, and during the 9-month analysis period, 197 (45.6%) were made by parents alone (excluding moderators and researchers). Among these posts, the topics that were most frequently talked about were childcare (eg, topics surrounding behavioral issues, difficulties communicating with professionals), education and school (eg, topics surrounding participation and inclusion at school), and diagnosis-specific posts (eg, obtaining an accurate diagnosis, seeking research or therapy for a specific diagnosis). Furthermore, parents who connected with the group reported many benefits, including feelings of belonging, that this was truly a community they could be proud to call their own. They reported pride in making a difference in research, even if indirectly, and repeatedly said that they felt that their ideas, thoughts, and experiences were validated, that sharing their stories was not futile. As a result of parents recognizing the need for clinicians and researchers to hear their stories, several parent members initiated the development of a book of stories, which they will compile and whose proceeds will go back into furthering research. Additionally, parents indicated that they were able to ask questions and access information and resources that they would not have otherwise found, from people they could trust to give them the right information.
Researchers

This Web-based community provided researchers with an opportunity to consult families of special needs children to get guidance and hear issues that are important to them. Examples of the type of requests were a call for parents to read and provide input on a parent resource being developed, to provide input on the logistics and content of a Family Engagement Day, and to express their interest in contributing as a partner in a grant proposal to a national funding agency. An additional benefit was that researchers were able to guide parents to credible resources that were relevant to their needs, a limitation that was outlined in previous Web-based communities [13,14]. Of the 80 posts made by researchers, 44 (55%) were posts linking parents to a variety of credible resources, including websites, news stories, videos, info graphics, and articles.

One example of the direct impact and meaningfulness of the group for both parents and researchers was a post from one mother who expressed her disappointment that many family members do not understand the needs and abilities of her child. Family members tend to give well-meaned but hurtful advice that can lead to tension within the extended family. Other parents from our group suggested that writing up a short profile about her child may be helpful. The mother took that suggestion to heart, developed a beautiful profile of her child’s strengths, likes, and dislikes, and posted the profile for others in our group to review and comment on. Other members praised the idea and the approach of this mother, and it generated an important discussion, regardless of the underlying diagnoses of their children. It was noted that aspects such as attitudes, family supports, and the ability to participate are important aspects of the quality of life of children and their parents. This discussion overlapped with the interest of one of the researchers (OK) in using the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization [20], to better describe needs of patients with chronic health conditions and disabilities. The profile created by the mother was a good example to illustrate how the needs of the child could be classified in terms of the ICF. After obtaining consent from the mother who posted the profile, we used an anonymous version of it in a grant proposal to illustrate the needs of families in sharing meaningful information about their child using the ICF [21].

PPR Web-Based Survey Results

Members’ Description

With 49 of a possible 96 responders to the survey, the response rate was 51%. A total of 82% (n=40) of the responders indicated that they were participating in the Facebook group due to their personal experience with disability (parents) and 18% (n=9) due to their research experience (researchers). Approximately two-thirds of parents and researchers indicated that they read the posts on a daily basis.

Research Literacy

The parents were asked to rate their research knowledge on a scale from 1 (low) to 10 (high) for 2 time points: (1) a retrospective assessment of their knowledge when initially joining the group and (2) their current knowledge. The parents had a median value of 6 (responses ranging from 0 to 10) (n=40) at entry to the group, which had increased to 8 (with responses also ranging from 0 to 10) (n=40) at the time of filling out the survey.

Safety

To evaluate how safe the users felt participating in this group, we asked respondents to indicate to what extent they regulated what they posted. Among the parents, 23 (58%) indicated that they felt safe to post sensitive or personal information, 10 (25%) indicated that they regulated what they posted, and 4 (10%) indicated that they only read and did not post at all. A total of 3 parent respondents (7%) did not answer this question. Among the researchers, 5 of the 9 (56%) felt safe to post sensitive or personal information, 3 (33%) regulated what they posted, and only 1 (11%) read posts but did not post themselves.

Motivation

To understand our community’s motivation for participating in this group, we gave them 6 possible response options. Table 1 lists the responses from parents and Table 2 lists the responses from researchers, followed by quotes from the open-ended questions.

Parents’ Quotes

I never realized that as a parent I could make a difference. This group has given me the hope and proof that I can.

I have expanded my knowledge of childhood disability—which in turn has helped me make connections with other parents. Even if their disability diagnosis and experience is different than mine, I find it helpful to see things from their point of view. I think that may be key in learning how to advocate for change not just for my own child but for any child.

Researchers’ Quotes

I was not aware of the impact of the daily struggles that disabilities can have in the life of families. Many of the topics brought up in the group have not been brought up in the same way in clinical encounters.

I have also learned how eager and supportive families are of research and how willing they are to provide feedback on any issues.

Perceived Change

Members were asked if they had changed their behavior or attitude in any way as a result of participating in the group. Table 3 lists the parents’ responses and Table 4 lists the researchers’ responses.
Table 1. Parents’ motivation to join the Parents Participating in Research group (n=37).

<table>
<thead>
<tr>
<th>Motivation</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>To connect with like-minded people</td>
<td>35</td>
<td>95</td>
</tr>
<tr>
<td>To find information, eg, search for or ask a question</td>
<td>29</td>
<td>78</td>
</tr>
<tr>
<td>To have an impact on childhood disability research</td>
<td>28</td>
<td>76</td>
</tr>
<tr>
<td>To get or give emotional support</td>
<td>27</td>
<td>73</td>
</tr>
<tr>
<td>To share ideas and solicit feedback</td>
<td>22</td>
<td>59</td>
</tr>
<tr>
<td>To raise awareness about issues related to disability</td>
<td>19</td>
<td>51</td>
</tr>
</tbody>
</table>

Table 2. Researchers’ motivation to join the Parents Participating in Research group (n=9).

<table>
<thead>
<tr>
<th>Motivation</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>To have an impact on childhood disability research</td>
<td>9</td>
<td>100</td>
</tr>
<tr>
<td>To share ideas and solicit feedback</td>
<td>7</td>
<td>78</td>
</tr>
<tr>
<td>To connect with like-minded people</td>
<td>7</td>
<td>78</td>
</tr>
<tr>
<td>To raise awareness to issues related to childhood disability</td>
<td>6</td>
<td>67</td>
</tr>
<tr>
<td>To find information, eg, search for or ask a question</td>
<td>4</td>
<td>44</td>
</tr>
<tr>
<td>To get or give emotional support</td>
<td>4</td>
<td>44</td>
</tr>
</tbody>
</table>

Table 3. Parents’ perceived behavior and attitude changes after participating in the Parents Participating in Research advisory community (n=34).

<table>
<thead>
<tr>
<th>Changes</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No changes</td>
<td>19</td>
<td>56</td>
</tr>
<tr>
<td>Toward research</td>
<td>11</td>
<td>32</td>
</tr>
<tr>
<td>Toward their child/children</td>
<td>8</td>
<td>24</td>
</tr>
<tr>
<td>Toward their family</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Toward people with disabilities</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Toward their friends</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Toward their patients</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Other (eg, more aware of my child’s rights)</td>
<td>4</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 4. Researchers’ perceived behavior and attitude changes after participating in the Parents Participating in Research advisory community (n=9).

<table>
<thead>
<tr>
<th>Changes</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toward research</td>
<td>3</td>
<td>33</td>
</tr>
<tr>
<td>Toward their patients</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Toward people with disabilities</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Toward health care professionals</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Toward their child/children</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Toward their family</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Toward their friends</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>No change</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Other (eg, increased awareness of true engagement of parents in research)</td>
<td>2</td>
<td>22</td>
</tr>
</tbody>
</table>

What Would You Change About This Group?

Respondents were asked “if you could change one thing about this group, what would it be?” The answers were coded into themes by 2 authors (OK & DR). The 2 most frequently mentioned comments are summarized in the following 2 themes. First, more researcher input: 9 respondents mentioned that they would like to see more researchers actively involved in the group. They stated that they would like information on what research is being done, including what projects may require
partnering, and they wanted researchers to engage stakeholders in discussion on CanChild material already posted on the CanChild website. In addition, they wanted researchers to respond quicker when tagged and join the discussions not only as a professional but also with multifaceted dimensions of themselves as a whole person. They wished that the researchers wouldn’t shy away from empathetic responses and talking from personal experiences, as well as presenting data and evidence-based information. Second, 5 comments were made suggesting the need to better clarify the purpose of the group, as there was a lot of discussion about patient care and family topics in addition to research topics.

**Discussion**

Parent-led support groups have been found to serve a vital function in supporting families of children with disabilities [22,23] but are often specific to one health condition, rarely include other stakeholders such as clinicians or researchers, and are not framed to help move a research agenda forward. Likewise, research-initiated engagement activities are often limited in their scope; include limited number of individuals or voices, reflecting a potential biased view of the issue; focus only on a specific health condition; or only bring in families at strategic points in the research cycle (eg, at the end to disseminate the findings). Camden et al summarized strategies used in the past to recruit stakeholders in rehabilitation research (primarily people with disabilities and their families) as targeted (eg, by direct invitation to individuals) or open (eg, by asking partner organizations to solicit from their membership, or by using media) [10]. Most activities were done by committees and tended to be face-to-face meetings or teleconference meetings. Our approach, which was suggested by a parent, was to use Facebook as a useful, easily accessible way of actively engaging families in the research process.

CanChild’s overall mandate is to conduct clinically relevant research to improve the lives of children with disabilities and their families [24]. In order to fulfill this mandate, many of our research studies in the past have engaged youth with a disability or their family members as a collaborator and author (eg. The KIT “Keeping it Together,” Youth “KIT,” and Partnering for Change) [25-27]; however, we saw the opportunity to broaden our perspective by engaging a larger community of families to further address issues of importance to families, as well as create a community where there is an opportunity for ongoing meaningful dialogue.

The 4 stages of building an effective online health community as defined by Young are inception, establishment, maturity, and mitosis [16]. Using this framework, we describe the first year of our Web-based community, where we have moved through inception to having an established community

**Inception Phase**

Key components of the inception phase are to invite members, build relationships, establish the tone and style of interaction, and nurture an active core membership [16]. The PPR Facebook group was proposed, launched, and moderated by a parent of a child with special needs who was acting as a parent resource to CanChild. She immediately recruited another parent to help cofacilitate the group and began strategies to connect members and begin to build trust. The initial purpose of the group was to be an advisory to CanChild, and 76% of parents and all the researchers responding to the survey identified that the reason for participating in this group was to have an impact on childhood disability research. Parents were also keen to connect with like-minded people and find information, while researchers wanted to connect with like-minded people, share ideas, and elicit feedback.

**Establishment Phase**

When more than 50% of group content is generated by its members (as opposed to moderators), it is described as an established online community, while greater than 90% makes it a mature community [16]. The friendly icebreakers posted by the moderators were a safe and inviting way for people to begin sharing ideas, discuss common issues, and support each other. As time went on, the need for icebreakers was not as high, and members began to freely post discussion topics of their own. Members of the group (as opposed to moderators) generated 64% of initial posts, indicating that our group has transitioned into the established phase. With this shift it is important to recognize that the moderators still have an essential role to help ensure sustainability of the community [28]. The moderators readily respond to posts initiated by members or direct message, or tag others who may be able to add important perspectives to the discussion, ensuring that members feel heard and respected.

While a few researchers are active in this group, feedback from the survey highlighted the wish of parents for more researcher engagement, with ideas about what types of engagement would be welcomed.

An unexpected outcome was the shift in the emphasis of the group from acting primarily as an advisory to ongoing work at CanChild, to having a very active parent exchange where issues that are important to families readily came to the forefront. As one clinician researcher highlighted, the PPR Facebook group has provided a deeper understanding of what issues are important to families and the day-to-day issues they face, which don’t typically come up in clinic visits. This provides an opportunity to explore issues that may not have been thought of previously and to engage with participants to review the evidence and possibly develop the ideas into a research proposal. In a recently published study in the United Kingdom looking at research impact, Morton suggests it is not always possible to predict the impact that research partnerships will have at the outset, but that working closely with research users can help give a deep understanding of the users’ context, their actions to adapt research to their own needs, and the commitment to use research to make a difference [29].

Through the Facebook page, we had the opportunity to ask families for advice on a variety of issues (eg, topics and the format for CanChild’s Family Engagement Day; improving our website to be more parent friendly) and to ask for feedback and collaborators on papers, evidence briefs, grants and presentations. We have 3 parents from our group as authors on this paper, and 1 on a recent review of stakeholder engagement [10]. Our moderator has copresented with our researchers at
our provincial meeting of children’s rehabilitation organizations [30] and is providing a video to include in a panel discussion of family engagement at an upcoming international meeting. The moderator from our PPR group has participated in several CanChild research rounds, providing important family perspectives on a variety of issues.

**Maturity Phase: Strategies to Move Forward**

It has been suggested that, in order to be successful, communities need to have a clear purpose, have a management strategy, and foster a sense of community [16]. Feedback from the survey indicated that, even though there are terms of reference for the group, the purpose of the group still needs further clarification. This may be because this group was initially set up as an advisory to CanChild, but the number of researchers participating in the group is low relative to the number of parents, allowing parents to continue to use the page in a manner that best meets their needs. To do community-based research, it is important that the researchers establish trust and demonstrate commitment, spending time in the community on an ongoing basis [13]. The few research members who are actively engaging with families feel a strong sense of open exchange and community. CanChild is actively trying to engage more researchers into the Facebook group; however, this remains a challenge, as researchers who are not regular Facebook users are reluctant to take the time to learn and worry about the ongoing time commitment it would require. Some researchers also struggle with their professional boundaries and knowing when and how they are to interact on a more personal level with families—even though this is what parents are asking for.

Since the survey, we have instituted a number of strategies to try to increase researcher engagement. There is now a Community and Family Engagement Officer at CanChild who will actively monitor the site and identify researchers with expertise who might be able to respond to parent posts, even if they aren’t active Facebook users. We have recently presented the results of the PPR Facebook evaluation at CanChild research rounds, providing examples of many of the interesting topics discussed, the impact the group has had on research members’ research (e.g., the ICF example), and the request from parents for more researcher involvement. In addition, we have instituted a “meet the researcher” in our Facebook page to have a specific time that a researcher will be on the page to respond directly to parents’ questions. There is usually an introduction to the researchers’ area of research through a paper or news link prior to the meeting time. This has proved very successful in actively engaging members and introducing new researchers into the Facebook group. We also plan to act on ideas brought forward by families for more discussion on the content of our website.

We believe that several factors have contributed to the success of this group. The group’s growth from inception to an established community indicates the level of interest and engagement of its members. The importance of ongoing community conversations to maintain the interest and momentum of the group and engage members enough to feel safe to disclose personal information and provide advice cannot be underestimated. Since the moderators are parents of children with special needs who already had credibility with numerous parent groups was and still remains a real strength. Their knowing how to engage families and build a respectful, supportive environment while understanding the needs of the researchers and the overall purpose of the group were fundamental for the success of our group. The fact that the group welcomes families of children with a variety of diagnoses has allowed common issues to emerge, which are universal regardless of ability. The convenience that Facebook provides in terms of 24-hour accessibility was also seen as a positive for both busy parents and researchers as to when they can log in and participate.

**Limitations of the Study**

The response rate to our survey was only 51%, which leaves us with just under half our members’ views not incorporated in the results. In addition, the survey was developed with the input of parent and researcher members but was not tested for reliability prior to its use. A validated tool to evaluate the Facebook community would have been very useful.

Another limitation was that our Facebook site was set up as a “group” in order to have the ability to be closed or “secret” and, in retrospect, this made harnessing accurate Facebook metrics a challenge. We tried purchasing Facebook reporting software but it was limited in its ability to provide accurate data from posts prior to purchasing it and we therefore needed to collect our data manually.

**Conclusion**

The experience of being part of this Facebook group made participants aware of the need to invite youth with disabilities (in addition to parents) into the group or to organize a similar group to engage specifically with youth. The perspectives brought from the lived experience and the issues raised by youth would likely be quite different from the ones raised by their parents and are important for researchers to understand. This led to a focus group with 6 youth with special needs, and it became clear that they did not want to join the parent community but will move forward in developing their own community, which will provide opportunities to exchange ideas with CanChild researchers and each other. This is an example of what Young [16] might refer to as mitosis.

Young also suggested that the success of Web-based communities depends on having sustained organizational support in terms of financial and human resources [16]. Based on an initial positive review of the Facebook group at 6 months, CanChild has successfully applied for project funding to ensure sustainability of the group and allow financial support for the parent moderator with the goal to build a Web-based community in partnership with a national center of excellence for neurodevelopmental disabilities in Canada (NeuroDevNet, 2015-2018). We will use the results of this evaluation to help improve the Facebook page to meet the needs of CanChild, NeuroDevNet, and the PPR members as we work together to identify needs, important research questions, and actions to improve the lives of children and their families.

By acknowledging the benefits and being cognizant of the limitations of social media platforms, researchers can begin tapping into the potential for social media to be used as a means to...
of engaging parents and families in the research process. Families can connect with other families and researchers to share their experience and voice what is important to them, to ensure that research is meaningful and impactful for those who needed it most: the children and the families.

Acknowledgments
We would like to acknowledge all the members of our PPR Facebook community who so willingly share their personal experiences and eagerly work to help improve childhood disability research. This research is partially funded by NeuroDevNet, a national Network of Centres of Excellence. Funding of the Web-based community was also made possible by the generous contributions of McMaster Children’s Hospital Foundation and the Scotiabank Chair in Child Health Research held by Dr Jan Willem Gorter. Funders had no involvement in review or approval of the manuscript.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Parents Participating in Research online survey.

[PDF File (Adobe PDF File), 154KB - jmir_v18i11e293_app1.pdf]

Multimedia Appendix 2
Rules of Engagement for the Parents Participating in Research Facebook Community.

[PDF File (Adobe PDF File), 212KB - jmir_v18i11e293_app2.pdf]

Multimedia Appendix 3
Screenshot of a sample icebreaker from the Parents Participating in Research Facebook Community.

[PDF File (Adobe PDF File), 66KB - jmir_v18i11e293_app3.pdf]

References


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**Abbreviations**

CHERRIES: Checklist for Reporting Results of Internet E-Surveys  
ICF: International Classification of Functioning, Disability and Health  
PPR: Parents Participating in Research
How Facebook Saved My Son's Life

My social network helped diagnose a rare disease that our doctors initially missed.

By Deborah Kogan

Mother's Day morning, my 4-year-old woke up with a rash. It was my 16th Mother's Day. I was inclined to ignore rashes. But a note had just come home from day care reporting a case of strep in Leo's classroom, so I dutifully felt his forehead, noted it was hot, and made an appointment at a medical office with Sunday hours. While waiting for the results of the strep test, feeling bored and somewhat sorry for myself, I snapped a photo of my son on the exam table playfully covering his face with his blankie, which I then posted to Facebook with the following caption: "Nothing says Happy Mother's Day quite like a Sunday morning at the pediatrician's."

The rapid strep test came back negative, but none of my three kids' in-office strep tests have ever come back positive, even when they have strep. Plus Leo's fever was on the rise. "He looks really streppy," said the doctor on call. "I think we should treat him for strep, and if his throat culture comes back negative, you can reassess with your family doctor."

"Great," I said, happy to have the prescription for Amoxicillin in hand. I was on a tight deadline to hand in revisions on my new novel. The fewer days of daycare Leo missed, the better. I logged onto Facebook and saw that many of my friends and "friends" had...
already commented under the new photo, wanting to know what was wrong. Three years earlier, when I reluctantly joined Facebook in an effort to monitor the online bullying of my eldest, it was inconceivable to me that complete strangers would ever fret over my child's welfare, never mind that the act of posting itself has become as integral to my daily existence as talking, writing, thinking, dreaming.

"Strep," I tapped with my thumbs on my iPhone. "No biggie." No use going into the whole, Well, it could be strep, but we're not sure; like answering a tossed off "How are you?" with a litany of minor complaints. Besides, what else could it be? Nothing this veteran mother had ever seen. I filled the prescription at the nearest pharmacy and fed Leo his first dose. The sooner he took it, I knew, the sooner he'd be better.

Except the next morning he was worse. "Bring him in," said our family doctor. Scarlet fever—a fancy name for strep with a rash—was his tentative diagnosis as well, pending the results of the throat culture, due back the following morning. I snapped another photo of my now puffy, less playful child on the exam table and posted it to Facebook with the following less cheeky caption: "Baby getting sicker. Eyes swollen shut. Fever rising. Penicillin not working. Might be scarlet fever. Or roseola. Or...???? Sigh."

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Within three hours, 20 comments appeared underneath the photo, ranging from, “Allergic reaction?” to, “Scarlet fever isn't nearly as scary as it sounds,” to, “Deb, that doesn’t even look like Leo in the picture!! how's he doing now? so scary!”

Scary?, I thought. That's going a little over the top. Until the next morning, when my son's face was now swollen beyond recognition. "He looks like Eddie Murphy in The Nutty Professor," I said to my husband Paul, trying to keep it light—my normal modus operandi—though inside a definite heaviness was taking root.

"He's fine," said Paul, whose lack of alarmism can be both useful (say, in choppy waters, clinging to the Sunfish we'd capsized) and dangerous. When our 16-year-old, as a baby, produced a diaper full of blood, Paul, not yet processing the fact that his infant could be dead from intussusception within hours if left untreated, scolded me for calling the doctor at 10 p.m. on a week night. Afterward, he felt bad about it, but, still—when it comes to family emergencies, I've always been on my own.

While Paul, in his normal state of denial, dressed for work, I snapped a dozen iPhone photos of Leo from various angles to send to our family doctor via MMS, the least frightening of which I posted on Facebook so as not to alarm my (Facebook friend) mother. "Swelling worse," I typed, "especially eyes and chin. Fever still crazy high. Poor baby." Was I consciously trying to find an answer out there in the hive mind? No, but some subconscious part of me must have been wondering whether one of my hundreds of "friends" might be privy to some expertise on the befuddling Nutty Professor syndrome that had my child in its grips.

Ten minutes later, I received a call on my cell phone from Stephanie, a film actress and former neighbor. "I hope you'll excuse me for butting in," she said, "But you have to get to the hospital. Now." Her son Max had had the exact same symptoms, and was hospitalized for Kawasaki disease, a rare and sometimes fatal auto-immune disorder that attacks the coronary arteries surrounding the heart. "The longer you wait," she said, "the worse the damage."
I remembered Stephanie's son being rushed to the hospital a few years earlier, but I wondered whether she might be overreacting based on her own trauma. Then again, I thought, despite her profession, she's also not the type to overdramatize. I looked up Kawasaki disease online. Many of my son's symptoms seemed to match the descriptions therein, and yet they were also some of the same symptoms as the flu and scarlet fever. Did I really want to rush a kid with the flu to the hospital? The rational part of my brain said stay put, watch him for one more day at home, throw him in front of a video, sit down at your desk and do your work.

Then the Sunday pediatrician's office called. Leo's strep test was negative.

Now I was perplexed and slightly worried. If it wasn't scarlet fever, what was it?

Meanwhile, the most recent photo I'd posted to Facebook now had 36 comments underneath it, with various diagnoses and words of support, and my Facebook inbox was bulging with private messages, one of which was from Beth, a pediatrician, echoing Stephanie's fears.

My cousin Emily, a pediatric cardiologist who often has to deal with the fallout from untreated Kawasaki, also called after seeing the photo, urging me to go to the hospital. "The damage begins as early as five days after the onset of symptoms," she said. At this point, we were well into day three or perhaps even day four, depending on when the symptoms had begun. I wasn't sure. I'd spent all day Saturday working on my book, and my husband doesn't notice rashes and fevers.

I called my family doctor and told him I was heading to the hospital. "I just have a Spidey sense," I said, "that he's really sick." Not a lie, but not the whole truth, either, though what was I going to say? Three of my Facebook friends think my kid has an extremely rare childhood auto-immune disorder which I just read about on Wikipedia, and since they all contacted me after I posted a photo of him on my wall, I'm going? It seemed ... wrong! Reactionary. And yet as much as I wanted to be my usual mellow self, the immediacy of the Facebook feedback was enough to push me out the door.

From the hallway in triage, I finally called our family doctor. Admitted what I'd done—furtively filling in the reason-for-visit blank on the hospital form with "possible Kawasaki disease"—and why I'd done it. "You know what?" he said, "I was actually just Support Dahlia Lithwick's Supreme Court coverage. $35 intro rate. Join Slate Plus today.
thinking it could be Kawasaki disease. Makes total sense. Bravo, Facebook."

Over the next three weeks, as Leo was treated, released, retreated, and rereleased for, yes, first Kawasaki disease and then the Kawasaki-triggered liver disease from which he's still recovering, Facebook transformed from my son's inadvertent lifesaver to the most valuable tool in my arsenal: to keep family and friends abreast of his ever-mutating condition without having to steal time and emotional energy away from him; to pepper both Beth, the pediatrician, and Emily, the pediatric cardiologist, with an endless series of random questions with which I was too embarrassed to bother my own doctors; to feel connected—profoundly connected—to the human race while living, breathing, eating and sleeping in the isolating, fluorescent-lit bubble of a children's hospital ward, where any potential humans I might have "friended" on our floor were too distraught over the fates of their own children to make any room in their hearts for strangers.

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The day I posted a video of Leo blowing out the candles on his birthday cake, one woman commented, "We were all holding our breath for those candles," as if she, too, had come to know the virtual crowd that had gathered on my wall—the collective we—and was speaking on behalf of all of them. And when I finally posted that the revisions on my then overdue novel were done—my editor, a new Facebook friend, was understanding, given the chaotic state of said wall—the collective we went wild. "Woo hoo!" they wrote. "Way to go ..."

Leo's liver, two months later, is slowly recovering, and for now his enlarged heart is doing well, though he will have to endure echocardiograms every year for the rest of his life, and I will have to endure knowing, slightly more than most, that, in the middle of kindergarten, or on a soccer field, or as he's marching down an aisle to the accompaniment of "Pomp and Circumstance," or while holding the hand of his future spouse, my son could suddenly drop dead of a heart attack.

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Case 1

Venu Kirtane is a busy dermatologist in a large practice. Last month, Dr. Kirtane treated Mr. Blue, a 35 year old man, for mild psoriasis. This was Venu’s first time meeting Mr. Blue, and their brief encounter was a pleasant standard of care encounter to manage and treat Mr. Blue’s psoriasis. A month later, Mr. Blue asks Venu Kirtane to be his Facebook friend. Should Dr. Kirtane ‘friend’ one of his patients?

Facebook is a Web 2.0 application (see Table 14.1) that started in 2004 as a website for college students and by 2011 has more than 500 million users of all ages [1]. Web 2.0 applications are websites in which users generate the content. Facebook, YouTube, weblogs (blogs), LinkedIn, Twitter, and StudentDoctor.net are a few examples. On Facebook profiles, people share photographs, thoughts, interests, and day-to-day activities. In the health care system, there is no limit to who uses Facebook, as patients, families, physicians, medical students, and hospitals are all on Facebook. Some patients with rare diseases use Facebook to network with those who have been similarly diagnosed, such as the Epidermolysis Bullosa Facebook page [2]. Some physicians have ‘Fan Pages’ about themselves with information about the kind of medicine they practice, public health messages, and newly available treatments [3, 4]. A new job description at some large hospitals is Social Media Manager, a person whose role is to manage the hospital’s social media presence, use social media to communicate with patients, and teach physicians how to use social media [5]. In 2011, 719 hospitals used Facebook as part of their public marketing campaigns [6]. Thompson et al. found that Facebook use is prevalent among student doctors, as 44.5% of medical students and residents at the University of Florida have a Facebook profile [7].

Physicians who are new to Facebook often intend to use it to connect with family and friends. Likewise, many medical students and residents created their Facebook pages during high school or college as a way to connect with family and friends. When patients find their physician on Facebook, and when medical students and residents start seeing patients, is it professionally and ethically appropriate to ‘friend’ patients?

If Dr. Kirtane accepts Mr. Blue as a friend on Facebook, it does not mean they are really friends and there is no expectation to make plans together or start emailing. ‘ Friending’ Mr. Blue is like making a passing acquaintance. Dr. Kirtane may never directly interact with Mr. Blue online again, but they would be part of the same online network and be able to view each other’s Facebook profiles. If Dr. Kirtane is comfortable with patients viewing his Facebook profile and potentially interacting with his Facebook friends, he needs make sure his Facebook presence is the professional image he wishes to project. Professionalism is generally defined as behavior appropriate to the standard established by a given profession. Chief information officer of Children’s Hospital Boston has stated it is “probably not” appropriate for a patient to see “comments that my high school friends are talking about from 30 years ago” [8]. Content appropriate for friends and family may not be appropriate for patients.
An alternative to address this is to have a separate Facebook page for his practice which allows patients to access it, although patients may voluntarily surrender some privacy in doing so. If Dr. Kirtane wants to keep his Facebook profile private and separate from his professional life, we suggest he create a Facebook page and a Facebook profile. Crotty and Mostaghimi agree, and in their 2011 article published in Annals of Internal Medicine suggest this same approach. They call creating separate public and private online personas a “dual-citizenship” approach to being a part of online social networking [9].

The Facebook page would be Dr. Kirtane’s professional presence online to connect with patients, co-workers, and physicians in a professional setting. On his Facebook page, he can share information with fans about his practice, answer basic questions, or provide dermatologic information. His Facebook profile would be a platform for self-expression, where he can post photographs from vacations and perform social activities like connect online with members of the local camera club. We recommend that his private Facebook profile be professional so he does not inadvertently create a negative reputation and so he can safeguard private information.

What if Mr. Blue was Miss Blue, a single woman who flirts with Dr. Kirtane in the office? Then, perhaps, Venu might want to consider the implications this would have on the doctor-patient relationship. Accepting Miss Blue’s friendship might make Miss Blue think that Venu is interested in a romantic relationship. In this case, being a Facebook friend of Miss Blue might make the nature of the doctor-patient relationship ambiguous. What if Mr. Blue is 10 years old? Because he is a minor, his parents might think the interaction is inappropriate. Or, their friendship could be encouraged by parents who think Venu is a good role model for their son.

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<th>Table 14.1 Common Web 2.0 Jargon</th>
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<td><strong>Web 2.0 websites</strong></td>
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<td><strong>Facebook profile</strong></td>
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<td><strong>Facebook page</strong></td>
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<td><strong>Friend or friending</strong></td>
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<td><strong>Facebook Wall</strong></td>
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<td><strong>Tagging photos on Facebook</strong></td>
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Although Facebook friending of patients does not break any cardinal or unspoken rule of the doctor-patient relationship, some experts recommend against it [8]. The 2010 AMA Policy of Professionalism in the Use of Social Media states, “If physicians interact with patients on the Internet, physicians must maintain appropriate boundaries of the patient-physician relationship in accordance with professional ethical guidelines just, as they would in any other context” [10]. As long as Mr. Blue’s autonomy and privacy as a patient is maintained, it is ethically and legally acceptable for Dr. Kirtane to friend Mr. Blue.

If Venu chooses to interact with patients on the Internet, he needs to consider the potential for Health Insurance Portability and Accountability Act (HIPAA) violations. For example, if Venu wrote on Mr. Blue’s wall, “Great seeing you today at the office! Let me know if you have any additional questions about your psoriasis” this well intentioned comment would be a HIPAA violation, as Dr. Kirtane publicly stated that Mr. Blue is a patient and disclosed Venu’s protected health information (PHI) by saying he has psoriasis. In addition, if Mr. Blue were to privately message Dr. Kirtane in order to discuss some aspect of his protected health information (PHI), it probably would be in the doctor’s best interest to ask Mr. Blue to come into the for further discussion instead of replying through Facebook. However, this is a gray zone, and an example of the way social media and the internet are transforming the way physicians and patients communicate. Many physician offices refill prescriptions by requests received over the phone and by email, and so it is a logical extension to accept a request by Facebook. Likewise, physicians speak to their patients over the phone, some communicate with patients by e-mail, and there are likely some that already communicate with patients on Facebook. Experts recommend communicating with patients regarding their PHI by work email [8]. Although Facebook is not an ideal place to discuss PHI, its speed and convenience appeals to many patients. We recommend that if physicians would like to communicate with patients online, they should strive to use an appropriately secured work email, but as long as patients are aware their PHI has a higher risk of being inadvertently disclosed, physicians and patients may choose to communicate using Facebook.

Surgeons at the Henry Ford Hospital use Twitter to publically update interested parties about a patient’s progress in the operating room [11]. Such synergy of technology and rapid dissemination of information could be a promising tool for communicating with family and friends during a lengthy Mohs surgery. There are some ethical and legal hurdles, however, and HIPAA violations are a major concern. Full consent of the patient who will be tweeted about must be obtained. Twitter is public, and readers often know which hospital is tweeting. Therefore, the public could know the time, date, and location of the surgery. Depending on the content of the tweets, the public may also learn the gender and age of the patient, thus discovering the identity of the patient.

Additionally, communication barriers may develop between the surgeon and the patient’s family. The family members reading the tweets may not understand what the doctor is writing, or worse, may misinterpret a benign tweet as a turn for the worse during surgery. What if an adverse event occurred during the surgery? Would the family be satisfied learning about it immediately online, where the empathy of the physician cannot be fully conveyed and the family’s questions cannot be answered? HIPAA violations and patient preferences must be considered when attempting to use social networking sites so that non-maleficence is respected.

In most situations, friending a patient on Facebook is a benign action that depends on the comfort level of the physician and the patient. As long as physicians maintain a professional online demeanor and protect patient privacy, physicians can enjoy browsing their patients’ Facebook profiles and, if they choose, communicating with patients online.

Case 2

On a busy Wednesday afternoon at Imaginary University’s dermatology clinic, Julie Veniti, a PGY-2 dermatology resident, is assigned to see Angela White, an adolescent with cystic acne. Julie walks into the patient exam room to find Angela and her mother, Sarah White. Julie introduces herself, and then begins her history and physical examination of Angela. After Julie finishes the examination, Sarah asks Angela to leave the room for a moment.

As Angela shuts the door, Sarah turns to Julie and says, “I think it would be best for us if we could see another doctor here at the clinic.”
Julie clears her throat and says, “I’m sure I can find someone else to see your daughter. In the meantime, is there anything I can do to help solve the problem?”

“Well, it’s just that I don’t want you setting a bad example for my daughter...you know...with all that drinking and carrying on that you do...”

Embarrassed and wondering what Angela’s mother is referring to, Julie apologizes for any inconvenience and leaves the room. Wondering what Mrs. White was describing, Julie considers the possibility of some unrecalled online content. That night, Julie Veniti goes home and searches the Internet and her Facebook profile for any offending material. Julie searches for her name in Google and finds only professional information about her achievements during medical school. Julie’s Facebook profile is professional and most of the 586 photos of Julie Veniti are suitable for patients to view. Forgotten among some of the oldest photos of her on Facebook are 20 pictures from a spring break trip Julie took during her first year of medical school. That spring break, she and some of her medical school classmates went to Cabo San Lucas, Mexico, to enjoy the beach and local nightlife. This was so long ago that Julie had forgotten these photos were on Facebook. Julie’s friends ‘tagged’ Julie in some pictures at a bar, and in one of the photos, Julie is hugging a pole and pretending to lick it. When Julie sees these photos, she groans, knowing that this must be what Angela’s mother was referring to.

Julie Veniti checks her Facebook settings and confirms that access to her pictures and to her profile is set for the highest levels of privacy, which means that only those who she allows, her friends, can see her profile or photos of her. A host of questions flood Julie’s mind. How did Mrs. White, whom she does not know, and whom does not have access to her Facebook account, see these pictures? What if her friend does not agree take down the photos? What kind of disciplinary action could she face for these photos?

Back story: Julie Veniti is a Facebook friend of her younger cousin. Julie’s younger cousin is a close friend of Angela White. The two friends were on Julie’s cousin’s Facebook account looking at pictures of Julie, and they told Angela’s mother that they think it is “cool” that doctors drink and go to strip clubs because they saw Julie doing that.

It is a long-standing tradition for students, including medical students, to spend a night drinking as a way to celebrate key milestones in their education. On these nights, students may become uninhibited, use profanity, and “cut loose” with their friends in other professionally questionable ways. Just because this behavior occurs in a non-professional setting and context does not make the behavior professionally acceptable. And because no medical student would dream of handing over racy photographs to patients or faculty members, these private, unprofessional activities are rarely a public issue. However, with the advent of Facebook and other similar websites, when medical students celebrate the New Year, on New Year’s Day their friends are posting Facebook photos of them celebrating and tweeting about with whom they might have shared a New Year’s Eve kiss. Behavior that was once forgotten the next morning now has new life on the Internet.

In medical education, much attention has recently been given to teaching professionalism. According to the Accreditation Council for Graduate Medical Education (ACGME), professionalism is one of the six general competencies that residents must learn before graduating from residency [12]. Professionalism standards will also apply to Julie after she graduates from her residency program, as the American Medical Association (AMA) lists professionalism as one of the “standards of conduct that define the essentials of honorable behavior for the physician” [13]. Facebook blurs the lines between medical students’ professional lives and private lives, sometimes leading to an unintended extension of one’s private persona into the public sphere.

In 2008, Thompson et al. found that, “some [medical student and resident Facebook] accounts displayed potentially unprofessional material” [7]. In 2009, Chretien et al. found that “60% [of US medical schools] reported incidents of students posting unprofessional online content” [14]. Thirty-eight percent of medical schools believe their professionalism policies cover online content, yet “most of these (82%) reported that the policies do not explicitly mention Internet use” [14].

There are certainly degrees of unprofessionalism and there are many examples of unprofessional online content in the medical education literature that are far worse than Julie’s photograph. Some of the most egregious unprofessional conduct by medical students and residents includes: identifying patients in blogs, showing nudity, expressing blatant racism, and depicting medical students or residents using illicit drugs [7, 14]. By comparison, one questionable photo out of over 500
professional photos that shows a resident pretending to lick a pole is arguably not a major concern. Julie is not directly harming patients and her actions did not occur while she was engaged in medical education or in the treatment or care for patients. Relaxing on the beach, snorkeling, and drinking margaritas at bars are acceptable, age-appropriate behavior for a medical student in her early twenties who is enjoying a break from the rigors of medical school. However, Julie is a medical resident and not a college student and what was inappropriate about this situation is that the professional distance between Julie and her patient was not maintained. Privacy settings on Facebook can help maintain this distance, but are not absolute. Student doctors and physicians need to be aware that online content may negatively affect their reputation and can undermine the public trust of physicians.

A Harvard internist who wrote about the intersection of his Facebook profile and his patients noted that, “physicians, after all, are members of real-life communities and might be observed in public behaving in ways that are discordant with their professional personas. During medical training, the importance of maintaining professional distance—however much one desires to have a close, meaningful relationship with one’s patients—is taught by educators and reinforced by the use of beepers and paging services meant to shield physicians from their patients” [15].

In addition to teaching the principles of professionalism, the University of Florida College of Medicine counsels students to set their Facebook accounts to the highest security levels [16]. However, only 37.5% of University of Florida medical students and residents made their Facebook profile private [7]. While it is prudent to recommend strict privacy settings, Julie found that strict privacy settings did not prevent her patient from seeing unprofessional pictures of her. Even though Facebook maintains that their members’ Web sites are strictly private, in reality, the most private Facebook account is only as private as e-mail [17]. As with e-mail, an individual on another person’s private Facebook account can save a copy of the private material and send it to another individual or share their computer screen with others. Actions or photographs posted to the internet can stay there forever. This is the lesson we can learn from Julie’s experience. In the era of the Internet, it is both vitally important and increasingly challenging to maintain a professional persona online without revealing embarrassing or private information. Privacy settings on websites such as Facebook can help create this safeguard, but these settings are not complete. A good rule of thumb is: Only share things on the Internet that you would be willing to share with your fiancé(e)’s grandmother, no matter how ‘private’ you think the website is.

To medical students, residents, and other professionals who endeavor to maintain a professional persona, Facebook should be perceived as a public website, not a private forum. When Facebook is perceived as private, medical students and residents are more likely to compromise their professional personas [7, 14]. The consequences could be more than one upset patient, as deans, residency directors, and future employers can also access online content. Residency programs or employers may decide not to hire an applicant if they find unprofessional content online.

Julie Veniti wondered what sort of disciplinary action she might face. Chretien et al. found that the most common form of disciplinary action taken against a medical student for unprofessional online content was an informal warning [14]. Other reported actions were formal disciplinary meetings, no action, student dismissal, temporary suspension, and remedial projects [14]. In the business world, job applicants have been rejected because a prospective employer discovered their unprofessional online content [18]. The same could easily happen to medical students applying to residency programs or physicians applying for jobs.

In order to assist medical students and residents in managing their online activities, university centers need to encourage students to monitor their digital footprint for unprofessional content. We suggest the following:

1. Performing Google searches of one’s name is an easy way to quickly identify any potentially unprofessional content online, but one may be powerless to remove content or links from Google. One can pay websites such as http://www.reputation.com to help remove personal information from public databases.

2. Medical student and resident Facebook profiles should be professional. Posting unprofessional content, even if it is to a private web site, is strongly discouraged because it is likely to create a negative reputation for the individual, the institution, and erodes public trust of the medical profession. Assume that everything you post is public and stays online forever.
3. Rather than simply “untagging” unprofessional photos, ask Facebook to remove them. Others do not have the right to post pictures of you online without your expressed approval. Facebook’s policy states that, “You will not post content or take any action on Facebook that infringes or violates someone else’s rights” [19] and that “We can remove any content or information you post on Facebook if we believe that it violates this Statement” [19]. Therefore, if Julie’s friend refuses to take down the photo of her, Julie can contact Facebook and ask them to remove the photo directly.

The Internet has created the opportunity for rapid communication between physicians and millions of people. The professional distance traditionally kept between physicians and patients has grown smaller. The ease with which seemingly ‘private’ information can be spread to an unintended audience may create the appearance or reality of unprofessional images of medical students and residents. In order to ensure that inadvertent disclosure does not occur, medical schools and residency programs can educate students about what is considered professional and unprofessional online content and how to manage their online persona. Physicians and student doctors should anticipate the possibility of unintended consequences when creating an online persona and need to aggressively manage their online persona in order to ensure that a positive image is maintained.

References