Care taker blogs in caregiver fabricated illness in a child: A window on the caretaker’s thinking?

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ABSTRACT

Three recently diagnosed cases of caregiver-fabricated illness in a child at Seattle Children’s Hospital shed light on a new manifestation of their caretakers’ attention seeking. The patients’ mothers were actively blogging about their children’s reputed illnesses. Although it is not uncommon for parents of chronically ill children to blog about their child’s medical course, specific themes in these blogs of parents suspected of medically abusing their children were noted. In particular, gross distortions of the information parents had received from medical providers were presented online, describing an escalation of the severity of their children’s illnesses. The mothers reported contacting palliative care teams and Wish organizations, independently from their medical providers’ recommendations. They sought on-line donations for their children’s health needs. We believe these blogs provide additional direct evidence of the suspected caregivers’ fabrications. Although we have not performed formal content analysis, blogs might also provide insight into the caretakers’ motivations. Protective Services and/or police investigators could consider querying the internet for blogs related to children at risk for caregiver-fabricated illness in a child. These blogs, if viewed in parallel with the children’s medical records, could assist medical diagnosis and legal documentation of medical fabrication and assist in protective planning for the affected children.

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Introduction

Caregiver-fabricated illness in a child involves a caretaker fabricating or falsifying illness in his or her child (Flaherty, MacMillan, & the American Academy of Pediatrics Committee on Child Abuse and Neglect, 2013). The fabrications can take the form of completely fictional illness histories, exaggerated history about the severity of legitimate illnesses, falsification of medical signs and symptoms, or actual illness induction. In its initial description as Munchausen Syndrome by Proxy these fabrications were done in a manner to garner attention and nurture for the child’s caretaker through ongoing, futile efforts by the medical system to relieve their child’s illness (Meadow, 1977; Rosenberg, 1987). Chronic morbidity or death can occur from direct injury by the caretaker or from complications of medical therapy (Rosenberg, 1987; Sheridan, 2003).
Subsequently many alternative names have been proposed, including Pediatric Condition Falsification, Child Abuse in a Medical Setting, and Medical Child Abuse (Ayoub et al., 2002; Roesler & Jenny, 2009; Stirling & the American Academy of Pediatrics Committee on Child Abuse and Neglect, 2007). All these names were intended to focus the diagnosis on the abuse that the child suffers directly from their caretaker and indirectly through their medical providers’ excess efforts to obtain a medical diagnosis and effective treatment. Such names routinely have been controversial (Bursch et al., 2008; Roesler & Jenny, 2009). For this paper we choose to use the current American Academy of Pediatrics terminology (Flaherty et al., 2013).

It is the harm to the child which leads to legally mandated requirements that medical providers refer these children to protective services and/or the police. The names subsequent to Munchausen Syndrome by Proxy, including caregiver-fabricated illness in a child, do not attempt to define or diagnose the caretaker’s motivation. However, if the caretaker could be diagnosed with the DSM-4 diagnosis of factitious disorder by proxy (currently the DSM-5 diagnosis of factitious disorder imposed upon another), the combination of the child’s and caretaker’s diagnoses would be roughly equivalent to the older diagnosis of Munchausen Syndrome by Proxy (Ayoub et al., 2002). Although the caregiver’s diagnosis is not critical to defining the child’s abuse, it becomes important in treatment of the caretaker’s abusive behaviors (Ayoub et al., 2002; Bursch et al., 2008).

Utilization of the Internet to fabricate illness goes back to the creation of virtual support groups. Feldman, Bibby, and Crites discussed this topic and proposed the term Munchausen by Internet (1998). In their report, healthy individuals wove dramatic and often times fatalistic stories of illness to online support groups and chat rooms. They theorized the motivations to create a fictional story online. It appeared central to the disorder that the individuals tried to gain attention and popularity among followers by taking a sick role for themselves or establishing the sick role vicariously through a child (Feldman et al., 1998). Although they did not report the use of the Internet as a forum for lies, Bass and Jones (2011) reported that 61% of the perpetrators of fabricated or induced illness in children that they evaluated engaged in pathological lying in medical encounters and other aspects of their life. They noted that these lies were “often compulsive, habitual, and sometimes self-aggrandizing.” Likewise, 57% exhibited their own somatoform disorders.

As social networking has advanced, publically accessible blogs and social networking sites have become commonplace (Feldman, 2000). Such sites are often utilized by families who wish to communicate about their child’s legitimate illness, seek information and garner social, or even financial support. There is a range of patterns and utilization of caretaker blogs regarding sick children. The type of content discussed, amount of information shared, and privacy settings utilized by families who blog can vary.

Typically, sources of information which might reveal these fabrications have been limited to medical observations of the child and comparison between multiple medical records (Sanders & Bursch, 2002). We recently diagnosed three cases of caregiver-fabricated illness in a child involving children at Seattle Children’s Hospital. Their caretakers’ on-line blogs shed light on a previously unreported method of their attention seeking. In this report, we describe the attributes of the on-line blogs to alert clinicians, child abuse physicians, and other child abuse investigators to an additional potential source of information about caregiver-fabricated illness in a child and the caretakers’ possible motivations to fabricate. As social networking becomes more ubiquitous, the question arises whether this domain of parental behavior should be considered in routine investigations of caregiver-fabricated illness in a child. However, discovery of the blogs and the blogs’ potential impacts on child protection investigations raised challenging ethical issues, which are discussed in more detail in the “Ethical Considerations” section of this article.

Methods

These case reports are based on a non-consecutive convenience sample of children recently diagnosed with caregiver-fabricated illness in a child at Seattle Children’s Hospital.

The Seattle Children’s Hospital Institutional Review Board determined that this case report does not constitute human subjects research and is exempt from full board review. Because these cases all involved concerns for child abuse by their caretakers, we did not seek the caretakers’ permission; the patients were all too young to provide consent or assent. We have de-identified these reports and used merged case summaries where possible to protect patient and family identities.

Case reports

Seattle Children’s Hospital recently assessed three children who presented with chronic, complex medical conditions that were ultimately diagnosed to have resulted from caregiver-fabricated illness in a child. In all three cases, our staff confirmed and documented caregiver-fabricated illness in a child by traditional means (i.e., chart review and separation of the child from the parent resulting in subsequent significant clinical improvement and remarkable decrease in the victims’ symptoms; Table 1). The mothers were initially excluded from the hospital and the children were ultimately removed from their mothers’ care through protective services. In independent settings the children thrived and no longer exhibited most of their reputed illnesses.

In addition to the standard means of documenting caregiver fabricated illness, in each of these cases the parents in question maintained a blog documenting the child’s illnesses and hospitalizations. Providers were first alerted to the blogs when a parent involved in a caregiver-fabricated illness in a child evaluation invited the child’s physician to view his/her blog. Struck by the fundraising activity on the blog and aware of the hospital’s concerns for caregiver fabrication, that
### Table 1
Attributes of the 3 victims of caregiver-fabricated illness in a child.

<table>
<thead>
<tr>
<th>Age onset (mo)</th>
<th>Age Diagnosis (mo)</th>
<th>Problem</th>
<th>Diagnostic efforts</th>
<th>Treatment efforts</th>
<th>Symptoms after removal from parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case 1</td>
<td>Birth 13</td>
<td>Feeding aversion</td>
<td>Occupational therapy, video swallowing study</td>
<td>Nasogastric feeds, g-tube</td>
<td>Took eagerly orally</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Food allergies, food protein induced enterocolitis</td>
<td>Food IgEs, food elimination</td>
<td>Elemental formula, food elimination</td>
<td>Unlimited diet</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Constipation since birth</td>
<td>Barium enema</td>
<td>Laxatives, suppositories</td>
<td>Resolved, no treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Failure to thrive, including height, weight and OFC</td>
<td>Tube feeds, thyroid labs, pancreatic elastase, stool fats, stool culture, metabolic &amp; mitochondrial disease screening, GH IGF-1, IGF binding protein</td>
<td>Nasogastric/gastric tube feeds, high calorie formula</td>
<td>Resumed normal growth</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reflux</td>
<td>UGI, pH probe, NM gastric emptying, upper endoscope</td>
<td>H2 blockers, PPIs</td>
<td>None, no treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Apannea cyanosis Developmental delay Tongue tie, noisy respiration</td>
<td>Cardiac echo, monitoring Neurology exam ENT exam, nasopharyngoscopy</td>
<td>Reflux treatment PT/OT</td>
<td>None Normal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Developmental delay Fatigue, myalgia-motor regression (bedridden) Hypoventilation-sleep apnea</td>
<td>Developmental evaluation Brain &amp; spine MRI, see below</td>
<td>Speech, OT/PT Gabapentin, methadone, AFOs</td>
<td>Rapidly improved Normally ambulatory within 3 days</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Failure to thrive, gut dysmotility disorder, constipation</td>
<td>Sleep study</td>
<td>Oxygen nasal cannula &amp; biPAP</td>
<td>Weaned to room air</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Chronic bladder spasms/pain</td>
<td>Swallowing study, upper &amp; lower endoscopy, gut CMV testing</td>
<td>NG, laxatives, gastrostomy/Nissen, TPN (multiple 2° line infections)</td>
<td>Weaned to oral feeding, lines removed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Undefined neurologic/metabolic/mitochondrial disorder</td>
<td>Renal US, VCG</td>
<td>Onybutrin, narcotics</td>
<td>Resolved off medications Resolved off meds, except still thyroid dependent</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Seizures</td>
<td>EEG</td>
<td>Gabapentin</td>
<td>No seizures off meds Responding to iron</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anemia</td>
<td>Iron studies, epo level, coagulation and thrombophilia testing</td>
<td>Iron, vitamins</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hypoglycemia</td>
<td>Glucose, HbA1C, C-peptide, ACTH stimulation testing &lt; 3</td>
<td>Tube and parenteral feeding</td>
<td>Not present</td>
</tr>
<tr>
<td>Case 2</td>
<td>3 43</td>
<td>Feeding intolerance–gastric tube dependent, FTT, gastrointestinal reflux disease, constipation</td>
<td>OT/PT, swallowing studies, upper GI, 2 upper and 1 lower endoscopies and biopsies, pH probe, colon manometry, Renal US, MR abdomen, NM gastric emptying</td>
<td>g-tube, lansoprazole, ondansetron, seina, polyethylene glycol, Mother self referred for port-a-cath</td>
<td>Achieved full oral feeds, rapid weight gain, no constipation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alternating hemiplegia of childhood</td>
<td>Neurology, multiple gene probes &amp; mutation analysis, muscle and skin biopsies, EMG, LP, metabolic disease studies and consultation</td>
<td>Home health aids &amp; nurses through palliative care</td>
<td>No dystonia or hemiparesis events</td>
</tr>
<tr>
<td>Case 3</td>
<td>0 103</td>
<td>Feeding intolerance–gastric tube dependent, FTT, gastrointestinal reflux disease, constipation</td>
<td>OT/PT, swallowing studies, upper GI, 2 upper and 1 lower endoscopies and biopsies, pH probe, colon manometry, Renal US, MR abdomen, NM gastric emptying</td>
<td>g-tube, lansoprazole, ondansetron, seina, polyethylene glycol, Mother self referred for port-a-cath</td>
<td>Achieved full oral feeds, rapid weight gain, no constipation</td>
</tr>
</tbody>
</table>
Table 1 (Continued)

<table>
<thead>
<tr>
<th>Age onset (mo)</th>
<th>Age Diagnosis (mo)</th>
<th>Problem</th>
<th>Diagnostic efforts</th>
<th>Treatment efforts</th>
<th>Symptoms after removal from parent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Developmental delay-worsening motor abilities, truncal hypotonic, leg spasticity</td>
<td>See above, MR brain (mild peri-ventricular leukomalacia) &amp; spine, MR spect scan brain</td>
<td>Wheelchair, but can do transfers, autism program, mitochondrial disease cocktail, oral baclofen, botulinum toxin, home schooling kindergarten work</td>
<td>Walking with walker, on baclofen, mitochondrial medications stopped, spasticity persists, entered school</td>
</tr>
<tr>
<td>Seizure disorder</td>
<td>Multiple EEGs + 48 h EEG</td>
<td>Seizure disorder</td>
<td>Levetiracetam, valproic acid</td>
<td>No seizures, still on valproic acid 9 months later</td>
<td></td>
</tr>
<tr>
<td>Hyperventilation, central autonomic dysregulation</td>
<td>Pulmonary, psychiatry consultations, echocardiogram, blood testing</td>
<td>Hyperventilation, central autonomic dysregulation</td>
<td>Oxygen by cannula continuous</td>
<td>Severity resolving, rapidly off oxygen</td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>Pulmonary consultation, laryngoscopy, bronchoscopy, MR chest</td>
<td>Asthma</td>
<td>Albuterol, glycopyrrolate, fluticasone, montelucast</td>
<td>Off all but PRN albuterol, rare use</td>
<td></td>
</tr>
<tr>
<td>Obstructive sleep apnea, hypoxia</td>
<td>Sleep study</td>
<td>Obstructive sleep apnea, hypoxia</td>
<td>Oxygen</td>
<td>Resolved. Off oxygen</td>
<td></td>
</tr>
<tr>
<td>Medication allergies</td>
<td>Maternal history</td>
<td>Medication allergies</td>
<td>Avoidance</td>
<td>Number reduced by half, 2 others not challenged</td>
<td></td>
</tr>
<tr>
<td>Blue feet</td>
<td>Neurology, rheumatology, surgery, dermatology consultations, Leg angiography</td>
<td>Blue feet</td>
<td>Epidural medication</td>
<td>Improving off treatment</td>
<td></td>
</tr>
<tr>
<td>Recurrent pain</td>
<td>Pain consultation, epidural catheter for medications</td>
<td>Recurrent pain</td>
<td>Use of pacifier, clonidine, Prozac</td>
<td>Resolved, off medications Not present</td>
<td></td>
</tr>
<tr>
<td>Eye deviation</td>
<td>Ophthalmology consultation, visual evoked potentials</td>
<td>Eye deviation</td>
<td>None</td>
<td>No disease</td>
<td></td>
</tr>
<tr>
<td>Heart concerns</td>
<td>Cardiology consultation, EKG, Holter monitor</td>
<td>Heart concerns</td>
<td>None</td>
<td>No disease</td>
<td></td>
</tr>
<tr>
<td>Proteinaceous renal stone</td>
<td>Renal US, mildly high Ca/Cr ratio</td>
<td>Proteinaceous renal stone</td>
<td>None</td>
<td>No disease</td>
<td></td>
</tr>
</tbody>
</table>

The provider forwarded the blog content to the Children’s Protection Team. Two more cases of caregiver-fabricated illness in a child followed quickly thereafter. Because sharing the content discovered in the first blog had been extremely helpful to child protection services (CPS), members of our team decided to query the Internet for parental blogs related to the two subsequent cases. In those two cases, both mothers also had created blogs related to their children’s illness. These blogs were found on sites such as Caring Bridge (a website created for sharing information related to the course of illness with family members and friends). The caretakers also utilized independent blogs under the children’s names. The blogs were located by entering a search on the Internet with the child’s first and last name.

The mothers’ blogs were public and did not require special access, and they were they restricted by any privacy settings. In two of these cases the mothers had both public and private blogs in addition to Facebook pages set on a privacy setting. This online seeking of attention and secondary gain provided a new dimension to caregiver-fabricated illness in a child.

**Results**

**Common blog themes**

When these three blogs are viewed together, several common blog themes emerged.

**Distortion patterns.** When closely compared with the medical record, the blogging patterns in all three cases show clear examples of exaggeration and misrepresentation of the child’s symptoms, and in some cases, frank deception. These mothers related in their blogs many of the same symptoms and disease concerns which they had brought to medical providers. However, when normal test results were communicated to the mother by physicians and reflected in the medical chart they were selectively not posted on the mothers’ blogs. More often, medically excluded diseases were reported actually to be present. The mothers repeatedly blogged about their quest for answers for their children’s reported illnesses. However,
when they were clearly informed of test results or clinical observations by physicians that indicated their child was healthy and lacked suspected illnesses, they chose not to comment on these medical updates and reassurances in their blogs.

In addition to exaggeration of actual symptoms, the tone of the blogs appeared to be a dramatized account of the mothers’ worldview. One mother blogged about her struggle to have faith in the future when she recognized there would be none for her child.

**Escalation patterns.** In their blog journals, all three mothers represented their children as critically ill and nearing death, including references to “bucket lists,” referrals to palliative care specialists, consideration of organ donation, and concerns for potentially bereaved siblings. Ruminations about the impact of the child’s death on the family and siblings were discussed. Although some of these behaviors are common for a stressed parent with a seriously ill child, the content was quite concerning in the context of parents who were clearly told by medical providers that their children were not dying.

**Attention patterns.** The blog entries we reviewed often generated concerned responses from online readers. In two cases, the blogs developed “followers” who tracked the children’s downward spiraling health and medical course. Through this type of interaction, it appears the mothers had a virtual audience to which they repeatedly reported inaccurate medical information, yet they were directly rewarded with concern and support. The overarching tone in the blogs was about the mothers’ own experiences as the caretakers of sick children and interaction with their online audience. The children’s welfare was depicted as secondary to the parents’ struggles.

**Exposure of the children to public viewing.** All of the blogs we reviewed contained visual images of the children. In two of the cases the family posted graphic images of the child’s medical interventions, including images of incision sites, the child’s intravenous lines and medical equipment. As infants and young children cannot consent or assent to such on-line exposure, the graphic and identifying nature of the photos was concerning. This would be true for any posting of explicit images of a child, but taken together with the above pattern of parental behavior there may be added concerns about exploitation of the children, particularly in the case which involved requests for money.

**Attitudes toward medical providers.** The tone of the blogs was often critical of the children’s medical providers. Although there is nothing wrong with parents challenging the medical system or individual providers, in this context, the “us-versus-them” theme was part of a storyline. All three children were identified by their mothers as having rare, undiagnosed, “one of kind” medical disorders. The mothers represented themselves as medical experts, frustrated by incompetent doctors who could not figure out what was wrong with their children. In turn, the mothers’ blogged about their refusal to agree to requests from doctors to limit diagnostic efforts or interventions. All three mothers refused doctor’s recommendations to wean their children from high doses of pain medications and physician’s recommendations to increase their children’s physical activity. The mothers described their efforts as protective, while they were actually refusing to allow their children to attain a higher state of functioning. Such reports were pervasive throughout all three blogs. This narrative was repeatedly reinforced among blog followers’ comments with positive accolades for being such good advocates for their children.

**Fundraising and charity.** Two of the blogs discussed how the caretakers sought support from “Wish” organizations for their chronically ill children. In our conversations with staff from our hospital’s cancer units, we have been consistently told that families of children who legitimately qualified for “wishes” usually postpone contact with these organizations because of the emotional difficulty acknowledging their child’s declining medical course. In the three cases we reviewed, the mothers had initiated the referrals to the Wish organizations early and without physician recommendations and they pursued the referrals vigorously.

One family established several separate sites to receive monetary donations. Another one included a PayPal icon where individuals could donate money for the family’s needs and hardships caring for a disabled child. In this particular case, it was later revealed the child was neither terminally ill nor infirm. Similarly, they sought Social Security disability benefits under false claims of illness. Through one website we learned that the family used the donated money to buy expensive durable goods which would directly benefit the parents. Multiple other blog followers linked the child’s illness blog to their own blogs in an attempt to reach an even greater network for fundraising. Many of the individuals following these mother’s blogs and fundraising for the child were not personal acquaintances, but strangers only connected through the Internet.

**Value of blogs to state investigating agencies.** In our suspected cases of caregiver-fabricated illness in a child, blogs and other social media sites extended the scope of information available to CPS case workers. Their investigators reported to our team that review of the blogs was extremely helpful during their investigations. Protective services investigators reported that they submitted the blog content as evidence during the dependency process. While subsequently managing the cases, CPS workers continued to monitor the parents’ on-line blogging activity. In two of the cases, the parents continued blogging about their children’s reported illnesses after court ordered intervention. This behavior was viewed as an indicator that the initial protective intervention had not been successful and the child remained at risk. This information became crucial for investigators, as the parents otherwise appeared compliant with court ordered evaluations and supervision plans and
Table 2
On-line blog clues to caregiver-fabricated illness in a child.

| The blog’s author seeks sympathy for her/his own tribulations caring for a chronically ill child. |
| Blogs focus on the caretaker’s difficulties, instead of the child’s needs. |
| Blogs dramatize the child’s illness and caretaker’s efforts. |
| Blogs include graphic images of the child’s medical therapies. |
| Blogs share the child’s medical information publically with a wide audience, instead of with close family acquaintances. |
| Blog content contradicts physician statements and the child’s actual medical findings. |
| Blogs describe a downhill illness course, which contrasts with the child’s actual medical status. |
| Blogs suggest an adversarial relationship between the medically knowledgeable caretaker and the physicians who are unable to or lack the skill to diagnose the child’s problems. |
| Blogs indicate that “Wish” foundations have been approached directly by the caretaker. |
| Blogs solicit funds from strangers to help the family care for a sick child. |

appeared to have responded to the protective interventions. Investigators reported that the parent’s continued on-line blogging content was considered strong evidence that the child remained unsafe to return home.

Discussion

Blogs as a manifestation of caregiver-fabricated illness in a child

The blogs created by these parents with behaviors diagnosed as caregiver-fabricated illness in a child were unlike those of families of legitimately ill children. Rather than seeking social support from friends and family with blog entries designed to inform and update, these blogs resembled Munchausen by Internet behavior in their content patterns (i.e., using dramatic language and complex stories to exaggerate their children’s illnesses or completely fabrication illnesses). These blogs described graphic procedures and symptoms, often followed by strong fears of impending child death, fears which were not supported by medical observations. The self-aggrandizing nature of the caretaker’s blogs is similar to the behaviors seen by (Jones, 2011) in their forensic evaluations of perpetrators of fabricated or induced illness in children. Some characteristics of these blogs are listed in Table 2.

Researchers have suggested that a parent’s motivation to create the perception of illness in their child is to obtain attention (Sanders & Bursch, 2002; Sheridan, 2003; Schreier, 2002). The Internet provides a boundless audience for such attention. The sicker you represent your child on the Internet, the greater the potential for an outpouring of affection and support. Pulman and Taylor (2012) discuss the vast community of Internet followers that online health-related blogs can generate.

Referrals to protective authorities for caregiver-fabricated illness in a child are cumbersome and problematic. Often the child’s various medical providers are not unanimous in suspecting fabrication; some retain belief in the child’s illnesses and continue to search for unique medical conditions. These cases are complex and contentious medically; they usually involve some unintentional complicity by medical providers (Roesler & Jenny, 2009; Schreier, 2002). Review of these blogs opened some uncertain physicians’ eyes to their own victimization by the caretakers’ deceptions. They saw how their opinions and actions were misrepresented.

Investigators and the court system often have trouble believing that a parent could do such a thing to their child and therefore struggle to understand the caretaker’s motivation. Why would a rational person, without serious psychiatric illness, fabric a child’s illness? Perhaps the parent misheard or misunderstood the doctor? Perhaps the doctor misheard the parent? So often we hear, “She is probably just an overly concerned parent, who cares too much.” Often the parent claims she was only following medical recommendations, without acknowledging that those recommendations were driven by her incessant fabrications. Contrary to this claim, the blogs we saw suggested caretaker intentionality. Although blogs should not replace careful clinical assessments and comparison of medical records (Sanders & Bursch, 2002), they may provide one additional written account of what the parent believes or at least how they present their child’s illness to others. Blogs may also preserve a chronology of the escalation of the caregiver’s reports of their child’s illness.

The fact that many parents of complexly ill children are deeply concerned, vigilant, challenging, and are also good and caring parents (Krener & Adelman, 1988) makes identifying medically abusive parents all the more difficult (Sanders & Bursch, 2002). Where do parents cross the line? For cases of caregiver-fabricated illness in a child, the bright line for intervention has to be confirmation of harm to the child by unneeded, invasive evaluations and interventions and the negative emotional impact on the child of an inappropriate and stressful medical odyssey.

These children suffer not only physical harm, but emotional injury leading to adverse behaviors and assumption of a sick role and self-image (Byrk and Siegal, 1997; Liebow, 1995; McGuire & Feldman, 1989). Evidence of such harm includes clinical and physical evaluations of the child, observations, and conversations with parents and other family members and observation of changes in the child’s symptoms when at home versus when in environments outside their caretaker’s control.

The caretakers’ online fund raising activities and search for Social Security benefits have been identified by local prosecutors as potentially fraudulent and criminal. In addition, they raise questions about possible darker motivations of secondary financial gain for maintaining a sick child. This fundraising raises additional concerns about the protective nature of the non-offending parent. These actions reflect possible shared motivations, as both parents actively participated in raising money and reaping the financial benefits.
In the adult Munchausen by Internet cases reported in the literature (Feldman, 2000), fabrications were generally limited to the individuals’ narration of illnesses on the Internet, but the blogs’ authors were not actually seeking inappropriate medical care for themselves. They lacked an associated clinical record of falsified signs and symptoms. However, in our cases, the patients’ families not only sought attention and sympathy on the Internet, but also sought inappropriate medical care for their children, often resulting in risky treatments and invasive procedures.

After protective service becomes involved, observations of the child in another environment can belie a parent’s illness claims. Health care providers are obligated to be alert to and to report suspected cases of child abuse or neglect. Once a case is referred to and accepted by a child protection agency, case workers will often rely on the clinical team’s medical observations and evaluations as evidence to determine whether abuse and neglect has occurred. Medical recommendations may help identify the appropriate response to protect the child. In the cases we reviewed, investigators were able to compare daily or weekly online blog entries with actual doctors’ appointment records and chart notes. Parents were noted to exaggerate, distort, or completely fabricate results and medical opinions rendered during those appointments. They declared new diagnoses and dire prognoses online that had not been communicated to them during appointments. These blogs proved to be actual evidence of the parents’ deceptions. They also documented the failure of initial protective court interventions.

As we struggle to determine where on the continuum of risk to their child a perpetrating parent fits, the blogs may also reveal darker motivations. Blogs may reveal an escalation in the parent’s wish for a sicker or even deceased child. For example, if a parent blogs about her child’s imminent death while the child’s symptoms are worsening without medical explanation, we believe medical providers and protective services should have a high level of concern for the child’s immediate safety. In their paper, Munchausen by Internet, Feldman et al. (1998) suggested that this type of behavior is consistent with a more extreme form of factitious disorders.

These cases illustrate an emerging need to consider the medicalization of social networking by parents. Internet blogs may provide an additional, broader context for both clinicians and protective services to observe and assess behavior that may raise concerns of abuse or neglect.

As a practical issue, bringing concerns of a caretaker’s inappropriate illness exaggeration to her or him could dissuade that caretaker from appropriately seeking care for inevitable real intermittent illnesses. These cases tend to be so complex that caretaker confrontation must be delayed until there is sufficient evidence to exclude the parent from the hospital or obtain protective orders for the child. Thus, the issue of failure to seek care for real illness does not arise until after CPS has been contacted and a safety plan can be developed. Prior to this step, we will often place a warning in our hospital’s computer information system to notify our providers of the illness exaggeration concerns, request them to act upon objective signs and symptoms, and coordinate care with the child’s primary care physician and/or with a hospital physician who is aware of the concerns. Without this piece, the fragmented set of specialists in a large tertiary care hospital can be easily led astray by false history. We feel this approach allows us to be vigilant to fabrications, without ignoring real disease.

Ethical considerations

These cases illustrate the potential usefulness of expanding the domain of evidence in cases of suspected caregiver-fabricated illness in children to include parent blogs. However useful such evidence may be, justifying the scrutiny of family blogging activity as a matter of general practice raises several important ethical concerns worth careful consideration. Under what conditions would it be appropriate to look to parent blogging as potential evidence of suspected abuse of this type? And for whom is it appropriate: the clinicians involved in the care of the patient, members of an expert child abuse team, representatives from CPS, police, or others?

Process. Our hospital does not have a policy regarding the appropriate viewing of parent blogs, although many medical teams are familiar with the important role that social media can play for families with a sick child. In general practice, our clinicians follow reasonable caution and professionalism in respecting the boundaries of our families’ private lives, including not “friending” patients or families on social media sites or viewing family blogs without their invitation. This general caution is supported by statements on pediatric professionalism, although existing policies lack the specificity to address the types of cases presented here (Farnan et al., 2013; St-Laurent-Gagnon, Coughlin, & Canadian Paediatric Society, Bioethics Committee, 2012). These cases raised sufficient ethical concerns about professional boundaries that the medical team sought an ethics consultation concurrently during the investigation of suspected caregiver-fabricated illness in a child. An interdisciplinary team comprised of members of the hospital ethics committee, social work, child protection team, hospital legal counsel, and a supervisor from Washington State CPS met to discuss the ethical concerns surrounding accessing parent blogs and review of their content as part of the internal discussion and external CPS investigation. In the reported cases, the blogs were publically accessible and had been discovered after investigation of caregiver-fabricated illness already was being pursued. There was no disagreement about our primary obligation to investigate and report harm to patients when there is suspicion of potential harm of abuse or neglect based on clinical observations (Table 1). Likewise, everyone agreed that clinicians involved directly in the patient’s care have an obligation to document and report those concerns in order to assist in a child protection investigation. However, concerns were raised whether accessing the blogs inappropriately invaded family privacy and whether this created a precedent that could potentially undermine parent trust of providers, more generally, and potentially have a chilling effect on parents’ feeling free to challenge or question providers in advocating for their children.
Balancing child protection with respect for parental autonomy. In the context of pediatric medical care, the boundaries of ethical clinical practice have been defined by two dominant ethical frameworks, each worth considering in evaluating the issue at hand – how ought providers best balance obligations of child protection against the encroachment into family life inherent in child abuse and neglect investigations, including in these cases, the viewing of parent blogs? If we take the best interests standard and harm principle as guides, we would assume that the parents are generally in the best position to judge and protect the interests of their children. We would only challenge or override parental authority with state intervention when parents make choices that cause suffering, disability, or harm to the child (Diekema, 2004; Kopelman, 1997, 2013). On a slightly different analysis of constrained parental autonomy, the parents in these cases would be assumed to have a presumptive right of non-interference unless proven that they were failing to provide for their child’s basic needs – including physical and psychological safety, nutrition and health, and basic freedoms and opportunities (Buchanan & Brock, 1989; Ross, 1998).

Within those constraints, parents should be free to engage in a range of parenting activities, including seeking multiple medical opinions about suspected illness in a child and blogging about their child’s illness or hospitalization, unless and until the safety and the well being of the child are put at significant risk by such activities. Once that threshold is crossed and it is determined that the caretakers are no longer acting in their child’s interests or are failing to provide for the child’s basic needs of security and safety, the burden of child protection shifts – through legal processes – to protective authorities. Teachers and clinicians are the most common sentinels to alert outside authorities to child abuse and as such have a fiduciary obligation to document and report such concerns and to assist investigations conducted by CPS case workers.

In the cases under consideration, the blogs entered into the evaluation of parental behavior in two ways. In all three cases the blogs served as additional evidence of escalation of care seeking and fabrication or exaggeration of symptoms of illness when clinical evidence did not support that the children were ill. As such, the blogs provided a window into parenting behavior, much as a second hand report from a family member or a direct observation of parenting from a teacher or clinician would do. In addition to the question of whether blogs should be used as evidence in an abuse investigation, the activity of blogging about one’s child could be a harm, itself, constituting abuse or exploitation. For example, these parents posted graphic photographs of their sick children without the assent or consent of children capable of agreeing to such public exposure. Further, they sought donations that went beyond support of the children’s care needs. Such behaviors exploit the children for the parents’ financial gain, even if the children are not in fact ill. In our cases, the further harm lay in the eventually confirmed fact that the children were not actually sick, so illness was induced or fabricated to bring attention, sympathy and financial gain to the parents. This is an even clearer example of using a child as a mere means for parental gain. In this sense the blogs did offer more than additional documentation of patterns of fabrication of illness; the blogging activity itself exploited the children for financial gain and attention.

A difficult question, in practice, is to discern when parental behavior warrants suspicion, when suspicion warrants further investigation and when evidence supports the need for referral to child protective services. While the harm principle, best interests and constrained parental autonomy are useful for establishing a threshold for state intervention, these criteria do not provide detailed guidance for clinicians who may suspect abuse or neglect in less obvious cases, that is, cases falling outside more obvious instances of physical harm, such as healing fractures, bruising or other physical injuries. As mentioned, the phenomenon of caregiver-fabricated illness is a very challenging type of child abuse to diagnose and prove. Where overt physical abuse establishes the grounds for justified intervention in a clear way, establishing that a parent is harming a child through the falsification or exaggeration of illness may take more time to discern and greater care in gathering evidence. As with any case of suspected child abuse or neglect, the obligation to prevent harm to the child must be weighed against the harms of getting it wrong, of interfering in a family’s life and of disrupting the parent–child relationship without just cause.

Fidelity, trust and professional boundaries. The much more challenging issue raised by documenting cases of fabricated illness, is how strike a balance between trusting parents, giving them leeway to be challenging parents, and knowing when that the tide has shifted to one of potential medical abuse. Suspected abuse changes the nature of the relationship between clinicians and parents, by necessity. One’s obligation to care for the child in a family-centered way that respects and involves the parents necessarily shifts to an overriding concern for the child’s safety and well being. This may happen abruptly or slowly once such suspicions arise. As the clinicians’ trust in the parents is called into doubt, more invasive lines of questioning necessarily undermine parents’ trust in the medical team and hospital. Breakdown of trust can be partly mitigated by a procedural process that attempts to separate the roles of the child’s primary caretaking clinicians from the investigative role of hospital child protection teams and state services. This attempt at a division of labor can in part preserve the medical team’s ability to care for the child. It can include the parents in that care, unless and until there is sufficient evidence to determine abuse or neglect. In practice, however, that very process depends on clinicians “at the bedside” recognizing a possible problem and initiating a process which may or may not lead to an official investigation. The clinical triggers for evaluating abuse and neglect require clinicians to offer evidence of their suspicions. When there is overt evidence of child injury, such as photos of bruises or X-rays revealing healing fractures, we expect clinicians to collect that evidence and share it with protective services. In the cases above, the parent blogs were part of that evidence building process.

Although the team had concerns about a breach of family privacy, the encroachment of concern is not one of privacy in a strict sense; the online activity in all three of the cases occurred publically, on sites that were not password protected or limited to friends and family. Rather, the central question has to do with the maintenance of appropriate boundaries in the clinician-family relationship, which goes beyond concerns of privacy. In these cases, motivations matter. Is a resident looking at a parent’s public Facebook page or a family blog out of curiosity, to get a glimpse into the life of a patient or
family? This motivation would seem an inappropriate breach of the boundaries that help maintain trust between providers and patients. Contrast this motivation to a child abuse social worker who views a parent’s blog or online behavior because she has reason to suspect abuse or neglect based on other clinical evidence or even concerns. The latter motivation seems to fall squarely within the range of activities that follow from an obligation to investigate, document, and report suspected abuse or neglect. Looking for and reading a parent’s blog would be similar such activities as calling a school nurse to learn about the child’s illness behavior at school, talking to other family members about the conditions at home, or inquiring into the child’s behavior when the child is not with parents. Arguably, looking at a parent’s blog as potential evidence or information may be less invasive than other more traditional forms of evidence gathering, certainly less invasive than a home visit, for example.

In an active case of caregiver-fabricated illness in a child, a physician or nurse has cause to evaluate parental behavior in order to protect the child and to decide whether or not a case rises to the level of required reporting to protective services. Evaluation normally involves reviewing all accessible medical records and reasonably might include looking at an online illness support site. However, in respect of established professional boundaries in the clinician-family relationship, it would be inappropriate for providers to routinely review blogs without reason for abuse suspicion.

In the current age of social media, what constitutes family life is no longer contained within the more traditional domains of home, school and community settings – it now extends to online parenting behavior. Although our primary obligation is to the health and well being of our child patient, we must always work within the boundaries set by the values of parental autonomy and respect for the protected domain of family life, now understood in this broader Internet domain. Without reason to suspect harm or neglect of the child, respect for parental autonomy requires us to give parents the space to process a child’s illness, seek social support and even openly challenge or criticize providers without worrying about being scrutinized by those whose primary obligation is to provide medical care for their child. Once we recognize that blogging is now a ubiquitous extension of social and family life, it seems reasonable to consider parent blogs as an additional source of information in child abuse inquiries. Given the importance of maintaining parent trust in general, and recognizing that we are sometimes wrong in our suspicions of abuse or neglect, the most conservative approach may be for clinical teams to continue to rely on formal medical records and directly observed evidence of suspected medical abuse (Sanders & Bursch, 2002) while mentioning the possibility of medical blogs or sites to one’s hospital child protection team or outside child protection and police investigators. For police or state case workers, it seems clearer that any source of evidence of abuse or neglect of a child is important to pursue, including social networking sites. This should be no different than police seizure of personal computers in cases of suspected child pornography. Medical teams could play a role by educating investigators about the phenomenon of medical blogging in cases of suspected child abuse.

**Limitations**

As with any content on the Internet, it is certainly possible that someone could create a blog and falsely represent that they were the patient’s caregiver. We cannot be completely certain that these blogs were created by the parents for whom we had caregiver-fabricated illness in a child concerns. However, the included case details made it certain that the bloggers were intimately familiar with these children’s health issues. Likewise we cannot be certain that a parent blogging online has truly expressed how they really feel or what they desire. One could always argue that a parent did not mean what they wrote. However, we believe this information is still important during the course of a protective investigation and blogs should be considered as a legitimate additional information source.

**Conclusion**

Online blogging in relationship to children and home life is not only common practice, but it also can be extremely valuable to families struggling with a sick family member, who needs social support (Feldman, 2000). Many parents blog about their children’s illnesses. For example parents of a child with leukemia may blog about their child’s illness and treatment course to keep friends and relatives informed. However, as we illustrated here, blogging in suspected or confirmed cases of caregiver-fabricated illness in a child has a different and worrisome pattern, echoing other concerning patterns of falsification that are directly or indirectly harmful to the child. For this reason, online blogs might serve an important function for investigators. Blogs may provide documentation of the parent’s perception or presentation of their child’s illness. They may document the caretaker’s health care seeking activity and plans for future interventions that might be harmful. As opposed to Munchausen by Internet bloggers who only are the subject of their own virtual tall tales, our patients suffered real medical harm. This occurred due to their caretakers’ falsifications which led to a sick role and unwarranted, extensive medical diagnostic and treatment efforts. Such blogs could potentially assist protective investigation and intervention before caretakers actively induce illness.

**References**


