



## 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).

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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 faking 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

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