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MEDICAL CHILD ABUSE:
WHEN THE PRESENTING PATIENT IS NOT THE “REAL” PATIENT

Reading Materials

1. Biographical information on Ingrid Walker-Descartes, M.D., MPH, FAAP
2. Mommy Dead and Dearest documentary
3. Early Recognition and Management of Fabricated or Induced Illness in Children
4. Beyond Munchausen Syndrome by Proxy: Identification and Treatment of Child Abuse in a Medical Setting
5. My Mother Caused My Illness: The Story of a Survivor of Munchausen by Proxy Syndrome
6. Care Taker Blogs in Caregiver Fabricated Illness in a Child: A Window on the Caretaker’s Thinking?
7. Letter to the Editor: Beyond Munchausen Syndrome by Proxy
Ingrid Walker-Descartes MD, MPH, FAAP

Dr. Walker-Descartes attended the University Of Rochester School of Medicine & Dentistry where she obtained her Doctorate in Medicine. Upon graduating from medical school, she did a residency in Pediatrics at New York Methodist Hospital in Brooklyn, NY and subsequently pursued further training in a combined General Academic Pediatrics and Child Abuse Fellowship at Mount Sinai Hospital, New York. As a fellow, Dr. Walker-Descartes obtained her also Masters in Public Health at the Mount Sinai School of Medicine.

After fellowship, Dr. Walker-Descartes joined the pediatrics faculty at Maimonides Children’s Hospital of Brooklyn. She currently serves in two roles – one as a clinician and the other as an administrator. In her clinical role, she practices General Pediatrics and a Child Abuse Pediatrics. She does all the consults for pediatric traumas that are seen at the hospital and follows them in her outpatient clinic as needed. As an administrator, she serves in the role of the Program Director of the Pediatrics Residency training program and the Fellowship Director for the Child Abuse Fellowship Program (the first accredited Child Abuse Fellowship in New York State). She is also the Director of Child Maltreatment Services for the Children’s Hospital.

Dr. Walker-Descartes has published several articles in the International Journal of Child Abuse and Neglect as well as book chapters focused on the various forms of child maltreatment. Her involvement in child protection and advocacy also includes her involvement in several local and national professional organizations. She is a Fellow of the American Academy of Pediatrics (AAP), the Co-chair of the Chapter 2 Committee on the Prevention of Family Violence, a member of the AAP Special Interest Group on Child Abuse and Neglect, a member of Prevent Child Abuse New York, a member of the American Professional Society on the Abuse of Children (APSAC & NYPSAC), a member of the New York State Child Abuse Medical Provider Program (CHAMP) and a member of the Ray Helfer Society of Child Maltreatment Pediatricians.

Ingrid Walker-Descartes, MD, MPH
From Dr. Walker-Descartes:

I would recommend that your students watch the following documentary:

https://www.hbo.com/documentaries/mommy-dead-and-dearest

This documentary has also been featured on ABC News and a recent 20/20 episode


From Professor Denno: If you have a problem accessing the HBO documentary please let me know and I will make arrangements for you to watch it.
Factitious disorders 1

Early recognition and management of fabricated or induced illness in children

Christopher Bass, Danya Glaser

Fabricated or induced illness (previously known as Munchausen syndrome by proxy) takes place when a caregiver elicits health care on the child’s behalf in an unjustified way. Although the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders specifies deception as a perpetrator characteristic, a far wider range is encountered clinically and is included in this Review. We describe the features of fabricated or induced illness, its effect on the child, and the psychosocial characteristics of caregivers and their possible motives. Present evidence suggests that somatoform and factitious disorders are over-represented in caregivers, with possible intergenerational transmission of abnormal illness behaviour from the caregiver to the child. Paediatricians’ early recognition of perplexing presentations preceding fabricated or induced illness and their management might obviate the development of this disorder. In cases of fully developed fabricated or induced illness, as well as protection, the child will need help to return to healthy functioning and understand the fabricated or induced illness experience. Management of the perpetrator is largely dependent on their capacity to acknowledge the abusive behaviour and collaborate with helping agencies. If separation is necessary, reunification of mother and child is rare, but can be achieved in selected cases. More collaborative research is needed in this specialty, especially regarding close study of the characteristics of women with somatoform and factitious disorders who involve their children in abnormal illness behaviour. We recommend that general hospitals establish proactive networks including multidisciplinary cooperation between designated staff from both paediatric and adult mental health services.

Introduction

Many changes have taken place in nomenclature since Meadow first described Munchausen syndrome by proxy in 1977,1 including renaming to factitious disorder by proxy,2 paediatric condition falsification,3 fabricated or induced illness in the UK,4 and medical child abuse in the USA.5 In 2013, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5),6 introduced factitious disorder imposed on another (previously factitious disorder by proxy; panel 1).

Search strategy and selection criteria

We included the terms “Munchausen syndrome by proxy” OR “Factitious disorder” by proxy” OR “fabricated illness by carer” OR “Fabricated or induced illness by proxy” OR “Munchausen syndrome by proxy” OR “Munchausen by proxy” OR “P?diatric Condition Falsifi?cation” OR “Fabricated or Induced Illness” OR FII and entered them into PsychINFO and SCIE databases. We reviewed the reference lists of articles identified by the search strategy and included articles judged as relevant. We examined papers written in English and published since 2002, but also included widely referenced and highly regarded older publications and books published since 1998. We did not include the term malingering. We also did a PubMed search with the same terms, and a MeSH search. We did our search between Feb 19, 2013, and Aug 19, 2013. We cite findings from recent research and evidence from learned bodies (eg, Royal Colleges in the UK and American Academy of Pediatrics in the USA) and clinical experience.

Unlike other definitions, DSM-5 specifies identified deception by the perpetrator as an essential criterion. Although restriction of the definition in this way allows for clarity, the other definitions include a far wider range of motivations and behaviour that represent clinical reality. Justification for use of the wider definitions of abnormal illness behaviour by carers in relation to their children is that the harmful effects on the child are remarkably similar, irrespective of the mother’s actions and motivations. In this Review we use the term fabricated or induced illness and the terms perpetrator and caregiver are used when appropriate. We suggest techniques for earlier recognition, and possibly aversion of fabricated or induced illness, and discuss strategies for management of diagnosed fabricated or induced illness.

What constitutes fabricated or induced illness?

Fabricated or induced illness can involve reported concerns about both the physical and mental health of the child, such as difficulties in the autism spectrum.7 Fabricated or induced illness has been located on a continuum of parental health-care seeking for a child, which ranges from extreme neglect (failure to seek medical care for the child) to induced illness.8 This continuum includes both the more common erroneous verbal reports, which might or might not include an intention to deceive, and the far rarer use of hands by the caregiver to falsify the child’s medical records,9 interfere with specimens, or induce illness in the child, all of which are forms of deception (panel 2). This abnormal form of health-care-eliciting behaviour by the caregiver,
for the child, often co-exists with abnormal relationships
with health-care and social-work professionals that can
have an adverse effect on the child.

For fabricated or induced illness to arise, three parties
are actively, if inadvertently, involved: the child, the
caregiver, and a health professional (usually a doctor;
figure). Important to note is that the child might have past
or coexisting genuine health problems and sometimes,
the abnormal illness behaviour might involve adults.

Epidemiology
Fabricated or induced illness is not confined to English-
speaking industrialised countries. Feldman and Brown identified 59 articles from 24 countries describing at least 122 cases in nine different languages. Some disorders are more likely to be fabricated than others. Seizures are a presenting feature in 42% of cases of fabricated or induced illness, and are especially vulnerable to fabrication because they are common and intermittent. In a childhood asthma clinic, 1% of families had fabricated or induced illness, with abnormal parenting behaviour leading to combinations of treatment withholding and overtreatment. One series of child victims described high rates of asthma, allergy, and sinopulmonary infections that often led to unnecessary surgery.

Defining of incidence is dependent on the inclusion
criteria adopted by a specific study. With strict criteria,
McClure and colleagues reported a combined annual
criteria for factitious disorder imposed on another, code
F68) (International Classification of Diseases-10 code
300.19) is needed.

Key messages

- The definition of fabricated or induced illness in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders is clear, but narrow, and excludes the many cases of harm not caused by deception
- Early recognition by paediatricians of perplexing presentations with alerting signs, followed by direct observation of the child, might obviate the full development of fabricated or induced illness
- The fabricated or induced illness is established by paediatricians and child mental health professionals, not by adult psychiatrists
- Many children will have a past or coexisting genuine medical disorder
- The effects of fabricated or induced illness on children are serious, wide ranging, and similar, irrespective of perpetrator behaviour or motivation
- Interdisciplinary liaison is essential, with multidisciplinary planning for the child's protection
- Perpetrators of fabricated or induced illness are usually caregiving mothers who have reported high rates of early childhood privation, neglect, and abuse
- More than 50% of perpetrators have a somatoform or factitious disorder, and more than 75% have a coexisting personality disorder, particularly cluster B disorders (ie, sociopathic, borderline, or histrionic)
- Detection of factitious disorder in a mother of young children should provoke a search for fabricated or induced illness and other forms of maltreatment in her offspring
- The perpetrating caregiver needs comprehensive assessment of underlying psychopathological abnormalities and capacity to acknowledge responsibility before treatment can be considered
- The child and family will need therapeutic intervention to develop a narrative about their experiences and adjust to the child's more healthy functioning
- Reunification is feasible but only in very carefully selected cases for which some acknowledgment of fabricated or induced illness has been made; follow-up is needed
- When reunification is not possible, long-term treatment of the personality disturbance and any other coexisting mental disorder (often a somatoform disorder) is needed

Possible explanatory mechanisms and motivations
A possible overall explanation is that the caregiver has an underlying need to have the child recognised as being ill when they are not, or as more ill than they actually are.

Several reasons explain this need, which are not mutually
exclusive (panel 3).

Evidence has shown intergenerational transmission of
abnormal illness behaviour in these caregivers. Of the
medically unexplained symptoms reported by mothers
with somatoform disorders, a high proportion is pseudoneurological (fainting and pseudoseizures), gastroenterological (abdominal pain and nausea), and obstetric or gynaecological. Caregivers with pseudoneurological disorders might state that their offspring has similar distressing symptoms, such as syncope and seizures. In a report, a mother with adult factitious disorder induced illness, not only in herself but also in her three children, with exogenous insulin injection.

Characteristics of perpetrators
In view of the diverse motivations, caregivers have no one profile of behaviour, personality, or psychiatric disorder and no psychiatric diagnosis exists for Munchausen syndrome by proxy. People who fabricate illness in their children are almost always women and 14–30% have professional ties to the health-care profession. Sheridan reported that 76% of the perpetrators were the child’s biological mother and 7% were the father. In the few cases for which fathers are the main perpetrators, the father is likely to have either a factitious disorder or clinically significant somatoform disorder. Grandmothers sometimes support the mothers and someone in loco parentis can also fabricate illness in a child.

In general, the non-perpetrating fathers of child victims of fabricated or induced illness tend to be distant, uninvolved, and emotionally and physically detached from the family system. Some fathers are truly unaware, some might believe the mother’s contentions, and some might be suspicious and attempt to challenge the mother unsuccessfully.

Findings from studies of female perpetrators have shown high rates of reported privation, childhood abuse, and significant loss and bereavement. In this study of 41 children (15 with failure to thrive through active withdrawal of food or alleged allergies) and 26 victims of fabricated or induced illness, six mothers had a factitious disorder, one had hypochondriasis, and 16 had a history of depression.

Somatoform and factitious disorders
Somatoform and factitious disorders are over-represented among perpetrators: in a study of 47 mothers, 30 of whom were active inducers, Bools and colleagues noted that the most probable diagnosis for 34 (72%) participants was a somatoform disorder (of whom 25 [74%] had a factitious disorder with physical symptoms). Similar findings were reported in a more recent study of 28 mothers (all with evidence of fabrication or induction of illness in children), in which somatoform disorders were reported in 57% of participants and factitious disorders in 64%, with co-occurrence of these disorders in 39% of participants. A third of these patients were in receipt of disability benefits. Detailed examination of both primary care and extensive medical and social-work records might uncover episodes of illness deception and pathological lying, often coexisting with somatoform presentations.

The distinction between a somatoform and factitious disorder is mainly based on volitional choice and the known consequences that might follow its exercise in specific situations. With a somatoform disorder the adult does not consciously or deliberately fabricate symptoms, whereas with factitious disorders the caregiver consciously
chooses this behaviour, or is at least consciously aware of the deception and possible gains involved.

These findings are important for two reasons: (1) mothers with somatoform disorders have children with more health problems and higher rates of medical consultations than those of well mothers or organically ill mothers;14–16 (2) that some of these mothers include their children in abnormal illness behaviour suggests their capacity to care for them appropriately is impaired. As a consequence the children of mothers with rigidly held or abnormal health beliefs can become medicalised and in turn the victims of abnormal illness behaviour by proxy. At present it is not known what characteristics of mothers with somatoform or factitious disorders might determine that they will involve their children in abnormal care-eliciting behaviours. Only by assessment of cohorts of childbearing women with somatoform disorders will this question be answered.36

Personality disorder

Very few studies have been done of personality in female perpetrators. In a systematic study of personality in 19 mothers with fabricated or induced illness (two-thirds with evidence of deception), high rates of personality disorder were identified in 17 (89%) mothers, with antisocial, histrionic, borderline, avoidant, and narcissistic categories being most frequently identified.29 Some mothers had more than one personality disorder. In a German study, three of four mothers had a personality disorder, with paranoid personality diagnosed in two mothers.30 Borderline personality disorder in particular is associated with marked difficulties in mother–infant interaction.31

The role of attachment

Fabricated or induced illness has been suggested to represent an abnormality in the attachment system between mother and child.32 Because attachment theory provides an account of both care eliciting and caregiving as developmental systems operating between parents and children,33 this theory might be useful for understanding dynamics within fabricated or induced illness. Attachment insecurity is over-represented in maltreating parents compared with non-clinical samples, including in those with fabricated or induced illness.34 An attachment perspective might also be relevant because of the association between attachment security and both illness behaviour and medically unexplained symptoms in adults. Patients with fearful and insecure attachment report substantially more physical symptoms than do secure patients,35 and patients with chronic widespread pain are more likely to have insecure attachment than are those who are free from pain.36 The early attachment experiences of these mothers are likely to affect both parenting capacity and personality development.37 These findings suggest an important association between abnormal forms of attachment, childhood adversity, adult somatisation, and, in some women, transmission of abnormal illness behaviour to their offspring.38

Effect on the child

At the rare, severe end with illness induction, several accounts have been reported by victims of this abuse,39 and a bestselling book by Gregory40 describes the physical, behavioural, and emotional consequences. In a review of 451 cases of fabricated or induced illness from 154 articles from medical and psychological journals,36 time elapsed from onset to diagnosis averaged 21·8 months. Most of the 6% of children who died had illness induced, and 7% were judged to have suffered long-term or permanent injury. 25% of victims' known siblings were dead, and 61% of siblings had illnesses similar to those of the victim or which raised suspicions of fabricated or induced illness.

Aside from mortality, which is associated with illness induction, the child has the same forms of harm, irrespective of the nature of the mother's behaviour. The harm to the child can be grouped within three domains (panel 4).49

Many children also have comorbid emotional and behavioural problems not directly related to the illness fabrication or induction, but probably related to parent–child interactions.10

Effects in adolescence

In adolescence the complexity of the situation increases. Some children who independently falsify illness might have had a previous experience of victimisation or encouragement of illness falsification by a caregiver,11 and so-called symptom coaching has been described.12
Cases have been reported of victims of fabricated or induced illness corroborating and participating in the perpetrator’s deception, or continuing to be the victims of fabricated illness by their parents decades after the initial abuse. In a remarkable case an adolescent male victim, after separation from the perpetrator, continued to endorse symptoms of chronic medical illnesses for which there were no causes. Of particular interest is that adolescents with factitious disorders have strikingly similar clinical and demographic characteristics to the adult perpetrators of fabricated or induced illness. In a recent retrospective study of adolescents with factitious disorder (mean age 16 years), three-quarters were female, half had witnessed severe somatic illness within their immediate family, a third had personally had severe or chronic illness, half had been adopted or fostered, 42% had histories of self-harm, and 42% history of physical or sexual abuse.

**Presentation and recognition**

Many children who are subjected to fabricated or induced illness also have, or have had, a genuine medical (physical or psychological) disorder or disability. Fabricated or induced illness should be recognised and identified early in the process by several alerting features in the child’s presentation, usually to doctors (panel 5). Other professionals including, in particular, teachers, might notice some of these features. For example, fabricated educational difficulties were described in nine children from five families whose mothers were insistent that they had attention deficit hyperactivity disorder. Notably, two of the five mothers in this series had a factitious disorder, and four (44%) of the children had a coexisting fabricated medical disorder. The mother’s actions might be inferred, false reporting sometimes witnessed, physical actions rarely observed, and her actions (verbal and physical) occasionally admitted to by the mother. Guidelines for school and other personnel confronted with repeated requests for unwarranted special educational services have been published.

Fabricated or induced illness can present in obstetric settings, and mothers who are responsible for fabricated or induced illness in their children have been described with factitious disorder in pregnancy. Characteristic fabricated presentations include antepartum haemorrhage, feigned premature labour, and induced post-partum bleeding leading to anaemia. Self-induced labour has been described leading to death of a child. These findings suggest that a finding of fabricated or induced illness in a previous child should suggest to the obstetrician an increased risk of obstetric factitious disorder in a pregnant woman. Furthermore, the presence of factitious symptoms during pregnancy should alert the paediatrician to the possibility of fabricated or induced illness. Increased rates of pseudocyesis (false pregnancy) have been reported in female perpetrators.

**Medical contribution**

Unlike the usual medical response to ill health or a sick child, for fabricated or induced illness there seems to be an over-reliance on parental reports even when they do not accord with others’ direct observations of the child. This over-reliance often leads to over investigation and inappropriate treatment of the child’s reported symptoms and incidental abnormal findings from investigations, neglecting the harm to the child’s present functioning. Moreover, doctors might also support or not question the child’s low or non-attendance at school, confirm the use of aids that the child might not actually need, and support seeking of financial and welfare payments for the care of the child. Several possible explanations exist for this medical response, which become obstacles to a more adaptive or appropriate approach (panel 6).

Conversely and rarely, paediatricians might conclude a decision of possible fabricated or induced illness too early, and not pursue sufficient investigations. The balance between overinvestigation and underinvestigation is potentially difficult to make.

**Earlier recognition and management of potential fabricated or induced illness**

With the exception of some cases of illness induction, a substantial delay almost invariably takes place before an explicit mention of fabricated or induced illness by a doctor. During this period, alerting features of fabricated
or induced illness are repeatedly encountered, meaning doctors face perplexing presentations.\textsuperscript{66} However, not all perplexing presentations are, or need to be treated as, fabricated or induced illness.

To shorten the process, reduce harm to the child, and possibly avoid the development of fabricated or induced illness, the doctor should establish as quickly as possible what is or not wrong with the child as soon as they feel perplexed, after undertaking the usually expected examination and investigations. To achieve early identification, several steps are needed.\textsuperscript{44} At this early stage, the responsibility lies with paediatric services, although information might also be needed from other agencies. The appendix provides a full account of this alternative approach.

**Child protection process**

Child protection procedures to manage probable cases of fabricated or induced illness have been well described\textsuperscript{66} and entail joint responsibility of children’s social care services and the police. Any possible evidence of physical actions by the mother requires preservation for the police of all relevant specimens and materials that might have been tampered with. An aspect of concern during investigations of fabricated or induced illness is the theoretical possibility that if the mother becomes aware of suspicions before the child is removed from her care, she might cause serious harm to the child by illness induction to prove her contention that the child is unwell.

Recognition of fabricated or induced illness in a child usually results in care proceedings to establish whether the abusing parent should continue to care for the child. Other siblings are also at risk.\textsuperscript{13,26,30} Therefore, in most cases children will, in the first instance, be placed in the care of the non-abusing parent (if separated), grandparents (only if they accept the presence of fabricated or induced illness), or the local authority. Criminal prosecution of the parent can be pursued by the police if deemed to be in the public interest, but is not a main or necessary part of child protection.

**Assessment of the caregiver and the role of the psychiatrist**

After the paediatric assessment and investigation has established the existence of fabricated or induced illness and the child’s state of health and ill health, or after a legal fact-finding hearing has taken place,\textsuperscript{79} and sometimes in the process of management of perplexing presentations, an adult psychiatrist might be asked to assess the caregiver (panel 7).

Establishment of whether the caregiver can acknowledge the concerns of others and accept some responsibility for harming the child is important. Such establishment will have a major effect on management recommendations and outcome and willingness to engage with professionals in the long term.\textsuperscript{79}

**Panel 6: Possible explanations for the medical response to signs alerting to fabricated or induced illness**

- Concern about missing a treatable disorder in the child
- Usual practice of working with parents
- Difficulty of withstanding pressure from the mother to continue to investigate and treat the child
- Discomfort of disbelieving or suspecting a parent, especially if this might prove to be unjustified
- Doctors’ dependence on the history of the child’s problems given by the parent or parents
- Difficulty of saying explicitly that doctor is mystified about child’s presentation
- Doctors with interests in particular diseases might want to rise to the diagnostic challenge
- Doctors working in private practice are likely to work in isolation with little communication with other professionals
- Increasing medical subspecialisation, with poor communication between specialists, risks having no identified clinician with overall responsibility for the child\textsuperscript{44}
- Doctors might want to avoid complaints against them and therefore continue to follow the parents’ requests
- Doctors might be uncertain when to mention suspicion, what to say to parents, and what to write in the medical file
- Pursuing concerns about the possibility of fabricated or induced illness is very time consuming
- Some doctors are reluctant to initiate a child protection process within which they will have little control and about whose benefits they might have doubts

The use of standardised measures can be helpful in some cases. These measures, which include the relationship scales questionnaire\textsuperscript{72} and the parental bonding instrument,\textsuperscript{73,74} can provide an indication of attachment security of the parent. The adult attachment interview is a well-validated method for the measurement of attachment organisation in adults, but needs training for administration and rating.\textsuperscript{77} The dynamic maturational model has been used to code assessments of attachment in both adults and children and adolescents.\textsuperscript{67,77} The structured clinical interview for DSM-IV-TR axis II personality disorders\textsuperscript{78} is a diagnostic technique; the standard assessment of personality\textsuperscript{79} is a screening technique, and document-derived assessment\textsuperscript{34} can provide useful information.

This assessment will lead to an understanding of the caregiver’s mental health, including possible autism spectrum disorder, for which there is a screening instrument.\textsuperscript{9} Some parents with this disorder might present with beliefs about their child’s health that are difficult to corroborate (panel 3). Predisposing and maintaining factors for the fabrication or induction of illness in the child should also be sought. Most importantly, the assessment will also show the degree and quality of acknowledgment of abuse by the caregiver, their partner and wider family, and their willingness and individual capacities to engage in a programme of risk management and treatment. Some risk factors have been identified that should alert the clinician to the potential risk a caregiver might pose by involving a child in abnormal illness behaviour.\textsuperscript{29}
Further steps after ascertainment of fabricated or induced illness

Whether the child might at a future time return to the care of the perpetrating parent is dependent on two main issues. First, overall parenting capacity should be assessed in relation to the child in question and other children in the family on the basis of possible other difficulties in the parent–child relationship, not related to fabricated or induced illness.8 The second issue is the caregiver’s response to treatment offered.

Therapeutic needs of the child

Children whose health and daily life and functioning, including education and peer relationships, have been adversely affected by fabricated or induced illness, will need active rehabilitation. The child and siblings will need a truthful narrative to explain the caregiver’s actions, and, when applicable, the reasons for separation from her. They will also need sensitive support for the possible loss of a primary caregiving relationship with their parent. Older children might feel guilty and complicit, and some children have great difficulty in accepting the fact of illness fabrication by their parent.

Therapeutic needs of the family

This section is written from the perspective of a heterosexual nuclear family, because this pattern is the most common. The father needs individual help to process the new awareness of his family, in particular the abuse of his child or children, and any possible feelings of guilt for his previous absence of awareness, or of his support of the mother. He will need additional support if he assumes the role of the main caregiver, particularly if he had been excluded from involvement in his child’s day-to-day physical and emotional care.85,86

Siblings will often have been relatively neglected whilst the caregiver focused attention on the “sick” child. They might feel excluded and angry, especially if their mother leaves the family. The remaining family together need help in the formation of a different family with a now well child. An important aspect of this work is the construction of a narrative of their experiences. Work with the child and family would appropriately be done by child and adolescent mental health services. Pragmatic interventions encouraging engagement of the family, problem solving, and formulation sharing (with use of assessments of attachment) have been described in the treatment of complex presentations involving exaggerated or fabricated symptoms in children.82,87–89

Therapeutic needs of the perpetrating caregiver

Perpetrating caregivers will need therapy to address the harm they have caused, its effect on the child, and possibly the effect of the loss of that relationship. Therapy should address feelings of guilt, shame, and sometimes associated suicidal feelings. When feelings of guilt and shame are wholly absent, the perpetrator’s capacity to mentalise the effect of harm on the child should be questioned and explored. As for all psychological treatments, successful treatment needs both engagement and commitment. Personality pathology is treatable, but many perpetrators report having experienced extreme neglect and abuse, and have little capacity for self-reflection, making meaningful engagement in psychological therapy difficult, especially if they continue to display deceptive behaviour. Furthermore, individuals who use denial and cannot admit their behaviours present almost insurmountable obstacles to psychological treatment. The initial focus of therapy should include the individual’s acknowledgment of the harm they have caused to any child in their care. Panel 8 shows some of the psychological characteristics that present obstacles to psychological treatment.
Very few specialist services can provide treatment for both perpetrator and child in cases of this nature.19 The parent will often be rejected by regular psychological treatment services as being too disturbed, yet they are often not disturbed enough to reach criteria for the intervention of forensic services. Most parents will need treatment for somatoform, mood, or personality disorders, usually of the emotionally unstable, borderline type. Ample evidence exists to show that personality pathology responds to treatment regimens that address affect and arousal regulation, such as dialectical behaviour therapy and mentalisation-based therapy.19 Although many patients report reductions in symptom severity, improvement in social and vocational function is more difficult to achieve.44

Prognosis
Prognosis is dependent on a multitude of complex factors, but in general, a better outcome for reunification of carer and child is associated with acknowledgment by the carer of the illness fabrication or induction, willingness to work and cooperate with helping agencies, the capacity of the treating team to work with a psychiatric formulation, and the presence of specific stressors at the time of the abuse.95,96 Very few studies have been done of reunification of families. Reunification is dependent on clear evidence of the caregiver’s positive response to treatment, within timescales appropriate for the child’s developmental stage and managed within a child protection framework.97 This finding was shown in a small follow-up study of 17 children from 16 families (12 with induction of illness, four with fabrication, and one with tampering of samples).98 Reunification requires careful consideration, as in 20% of cases the abuse recurs if the child remains with the parent/abuser.99

Future perspectives and key points
Fabricated or induced illness should be identified early before the child comes to serious harm, and professionals should be alert to the features that should prompt them to suspect this disorder. Because the illness can take place in many diverse settings and involves workers from social work, education, legal, and medical domains, early recognition should be included in the continuing professional development of all doctors and other professionals. In the UK the General Medical Council has made progress by encouraging doctors to communicate more freely with one another.100 Simple guidelines for recognition published by NICE18 are recommended (panel 6) and should be widely promoted.

Another key issue is assessment of these cases for the court. Experts in child protection have come under criticism in the UK.101 Clinicians involved in this specialty need substantial expertise and experience, and assessment should not, in our opinion, be undertaken in isolation. Training and peer supervision of the so-called expert witnesses are needed. There is scope for interdisciplinary collaboration between Royal Colleges of Psychiatrists and Paediatrics and Child Health.

More collaborative research is needed in this specialty,102 which has so far been scarce. Many questions remain,1 such as what distinguishes perplexing presentations that do not develop into fabricated or induced illness from those that do, and what is the relative prevalence of the two?2 could an international database be established?3 what is the prevalence of this disorder in educational settings?4 why do some mothers with chronic somatoform disorders involve their children in this behaviour and not others?5; and how does the internet contribute to this disorder?21,24

A case exists for the establishment of more proactive networks to support professionals in the early identification of parents and children before harm to the child takes place. For example, recommendations state that regular hospital-based multidisciplinary meetings be established to discuss cases and share information between disciplines. These meetings should involve a designated child protection doctor for the hospital, hospital paediatricians, the local community paediatrician, nurses and social workers, and an adult consultation liaison psychiatrist with experience of these presentations.105 Involvement of hospital legal teams might also be needed.

Contributors
CB and DG conceptualised the Review. CB did the literature search and wrote the first draft. DG wrote the section on perplexing presentations and assessment, and contributed to later refinements and additions to the final draft. Both authors contributed figures and approved the final submitted version.

Conflicts of interest
We declare that we have no conflicts of interest.

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Beyond Munchausen Syndrome by Proxy: Identification and Treatment of Child Abuse in a Medical Setting

John Stirling, Jr, MD, and the Committee on Child Abuse and Neglect

ABSTRACT
The condition widely known as Munchausen syndrome by proxy comprises both physical abuse and medical neglect and is also a form of psychological maltreatment. Although it is a relatively rare form of child abuse, pediatricians need to have a high index of suspicion when faced with seemingly inexplicable findings or treatment failures. The fabrication of a pediatric illness is a form of child abuse and not merely a mental health disorder, and there is a possibility of an extremely poor prognosis if the child is left in the home. In this statement, factors are identified that may help the physician recognize this insidious type of child abuse that occurs in a medical setting, and recommendations are provided for physicians regarding when to report a case to their state’s child protective service agency.

INTRODUCTION
In the oft-quoted paraphrase of Hippocrates, the physician is admonished to “first, do no harm,” and not without good reason. Even when necessary, diagnostic tests are at best inconvenient and frequently invasive or painful. Therapy is not without risk either, because it often involves hospitalization, drugs, or surgery. When the diagnosis is elusive and diagnostic efforts become more aggressive, the physician must always weigh risks to the patient against the benefits of an accurate diagnosis. Nowhere does this calculation become more important than in the rare circumstance in which the patient’s caregiver fabricates the signs or symptoms of the disease in question, in what has traditionally been called Munchausen syndrome by proxy.

DESCRIPTION
The fictitious Baron von Munchausen was an extravagant raconteur, whose fanciful narrations of his imagined exploits made his name in literature. Physicians have borrowed his name to describe a group of patients whose complaints are fabricated but so convincing that they are subjected to needless hospitalizations, laboratory tests, and even surgery. The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) refers to Munchausen syndrome as “factitious disorder” (300.19), and motivations for this bizarre behavior continue to puzzle both medical and mental health professionals.

In 1977, Meadow first described cases in which the apparent symptoms of Munchausen syndrome were instead projected onto a dependent child as a parent fabricated symptoms and even signs of a nonexistent illness. When the fabrica-
tions involved a dependent individual like this, the condition was likened to Munchausen syndrome experienced “by proxy,” and the diagnosis of Munchausen syndrome by proxy entered the medical lexicon. In the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, the condition is proposed as a new category called “factitious disorder by proxy.”

There is no typical presentation for this condition. Suspicions may arise when parents misinterpret or exaggerate normal behaviors, and true cases range from apparent fabrication of reported symptoms to outright fabrication of signs of disease. Caregivers may report signs and symptoms that are undetectable to the medical observer, or the child may demonstrate signs that defy medical interpretation. In case reports, a wide variety of situations have been called, appropriately or inappropriately, Munchausen syndrome by proxy, including the following examples:

- A mother takes her child to the doctor for frequent evaluations for sexual abuse, even in the absence of objective evidence or history of abuse.
- Mothers insist their children be treated for attention-deficit/hyperactivity disorder although there is no evidence to make the diagnosis.
- A parent starves her child because she wrongly believes he has multiple food allergies.
- Physicians suspect an unusual hematologic disorder after a mother repeatedly and secretly bruises her child with a hammer.
- A parent purposely suffocates her child and kills him during a hospitalization for “apnea.”

It is difficult to imagine how such varied conditions can be included in the definition of a syndrome. In some cases, the caregiver has merely exaggerated the child’s symptoms; in others, the caregiver has imagined them. In the worst cases, the signs and symptoms of illness have been induced by the caregiver’s intentional actions. In some patients, the consequences are minor; in others, the consequences are fatal. Indeed, the only things common to the presentations catalogued above are the caregivers’ insistence that something was wrong, an absence of pathologic findings sufficient to explain the described signs or symptoms, and consequent harm to the child.

**TERMINOLOGY**

Use of the term “Munchausen syndrome by proxy” has led to much confusion in the literature. For example, some experts insist that the term be applied only when the parent is seeking medical care because they are somehow personally compelled to relate to the medical care system, whereas others say the parent’s motivation is not important. Although the original description referred to harmful medical care, subsequent authors have extended the appellation “Munchausen syndrome by proxy” to cases in which the only harm arose from medical neglect or noncompliance or even educational interference. In addition, there remains confusion about who should make the diagnosis of Munchausen syndrome by proxy: a psychiatrist or pediatrician? Is it a diagnosis applied to the parent or the child? Is it a pediatric or a mental health diagnosis? These ambiguities become especially important when medical personnel present their diagnosis to other professionals or to juries in seeking to protect a child victim.

To alleviate confusion, the American Professional Society on the Abuse of Children has recently made a more explicit distinction between the abuse (pediatric condition falsification) and the presumed motive behind most such cases (factitious disorder by proxy). This distinction has the advantage of replacing an eponym with more descriptive nomenclature, a recent and welcome trend in medicine. Whatever it is called, it is important to remember that harm incurred when a caregiver exaggerates, fabricates, or induces symptoms of a medical condition may still simply be termed “child abuse, which happens to occur in a medical setting.” This appellation reminds us that the focus of our intervention should always be to identify and minimize harm to the child regardless of the motivation of the perpetrator.

**DEFINITION**

Whether it is called Munchausen syndrome by proxy, pediatric symptom falsification, or simply child abuse, what remains as the central issue of importance is that a caregiver causes injury to a child that involves unnecessary and harmful or potentially harmful medical care. To make the diagnosis, the physician must ask 3 questions:

1. Are the history, signs, and symptoms of disease credible?
2. Is the child receiving unnecessary and harmful or potentially harmful medical care?
3. If so, who is instigating the evaluations and treatment?

If the child receives excessive, unnecessary medical care merely because the physician is overly compulsive or, worse, incompetent, then abuse is not a consideration. If the child is getting the unnecessary medical care because the parent is systematically misrepresenting symptoms, purposefully making up symptoms, manipulating laboratory tests, or even purposefully harming the child to create symptoms (eg, by poisoning or suffocation), then continued medical care itself may become abusive. The medical staff, in pursuing an ever-more-elusive organic diagnosis, may lose sight of its ultimate implausibility. One needs 2 circumstances to make the diagnosis in this form of abuse: harm or potential harm
to the child involving medical care and a caregiver who is causing it to happen.

The motive of the caregiver, although useful to the therapist, is unimportant in making the diagnosis of abuse. In no other form of child abuse do we include the perpetrator’s motives as a diagnostic criterion. For example, a man can sexually abuse a child for a variety of reasons, but his motivation is irrelevant; the child still carries the diagnosis of sexual child abuse. A mother might violently physically assault her infant because she is fed up with the child crying, she is intoxicated or drugged, or she earnestly thinks that is the way to get the infant to behave and start eating, but it is still called physical child abuse.

Child abuse is a pediatric diagnosis, one that describes what is happening to the child. Motivation of the perpetrator often becomes an issue when society considers incarceration, treatment, or reunification but not when the physician makes the medical diagnosis of child abuse.

**DIAGNOSIS**

Diagnosis of fabricated disease can be especially difficult, because the signs and symptoms are undetectable (when they are being exaggerated or imagined) or inconsistent (when they are induced or fabricated). Researchers may differentiate between exaggeration and fabrication or induction of symptoms, but action taken by the clinician must be determined by the perception of harm or potential harm to the child.

Regardless of the exact nature of the duplicity, health care professionals can be seduced into prescribing diagnostic tests and therapies that are potentially injurious. This is easier than one might think. After all, absolute certainty is a rare thing in medical diagnosis, and physicians have all known empirical therapy to be effective. On occasion, though, the well-meaning but misguided pursuit of an ever-more-elusive diagnosis or effective treatment can lead medical staff into an ethical dilemma. Potentially harmful medical care can range from a diagnostic search that subtly encourages and enables a caregiver’s delusion through a full spectrum of invasive tests and medical or even surgical interventions. Alternatively, a child may present to the doctor with a common diagnosis but one that seems resistant to an increasingly aggressive array of treatment regimens. The common factor in all is the failure to consider factitious disease in the differential diagnosis, although it is often more likely than the arcane diagnoses being pursued so assiduously.

Child abuse is not a diagnosis of exclusion. On the contrary, when a clinician suspects that a disease has been falsified, this hypothesis must be pursued vigorously and the diagnosis must be confirmed if the child is to be spared further harm. In seeking to determine if signs and symptoms of a disease have been fabricated, the physician should make every effort to gather information from all those involved and make other professionals aware of the concerns. Care of children who are victims of factitious disorder by proxy often involves a variety of medical personnel, from primary care physicians and medical subspecialty consultants to dietitians, physical therapists, and social service workers, and each has a unique perspective. Nursing and support staff can frequently contribute to making the correct diagnosis by reporting their observations of, and experiences with, the child and family to the supervising physician. It should be stressed, however, that the falsification of a medical condition is a medical diagnosis. Although multidisciplinary input can be very helpful in diagnosis and essential in treatment, psychologists, social workers, and others are not in a position to make or confirm this diagnosis.

Occasionally, more information about the maltreatment is needed before a diagnosis can be reached. When it is suspected that no true disease exists and it is felt that harm to the child is imminent, the use of covert videotape surveillance has been recommended.15–17 Such surveillance may capture a parent’s misbehavior, as when a child is being physically abused in the hospital. It may fail to confirm reported symptoms when they are being exaggerated or exonerate a suspected caregiver when a disease truly exists. In any event, video surveillance cannot be considered a gold standard or held as the only way of diagnosing this insidious form of child abuse. When videotaping is used, adequate safeguards such as continuous surveillance and a well-understood plan of action must be present to prevent further injury.

**TREATMENT**

By recognizing that this problem is a form of child abuse taking place in a medical setting, a clear role is delineated for the system that is currently in place in our states to protect children. Child protective services agencies are mandated to keep children who are abused—sexually, physically, or psychologically—safe regardless of whether the abuse occurs in the home or the hospital.

When considering treatment for child abuse taking place in a medical setting, the basic principles used in any other type of child abuse case should be applied:

1. Make sure the child is safe.
2. Make sure the child’s future safety is also assured.
3. Allow treatment to occur in the least restrictive setting possible.

For example, if an overanxious mother who has insisted on too much medical care for her child is willing to cooperate with the physician and learn when it is appropriate to seek care, the child can safely be treated within his or her family setting. In contrast, if a mother has repeatedly suffocated her child, the “least restrictive
setting” that would guarantee the child’s safety would most likely be permanent out-of-home placement.

If the parent’s care-seeking is harming the child but the parent refuses to cooperate with the physician in limiting the amount of medical care to an appropriate level, the state child protective services agency should be informed. If the parent persists in harming the child, medical child abuse should be reported in the same way as physical and sexual child abuse. Any time that a dependent child is being hurt by an adult’s action, child protective services should become involved.

A list of possible interventions follows, from the least restrictive to the most restrictive. Some of these options require action by outside agencies (child protective services, private counselors, law enforcement, etc).

1. Use individual and/or family therapy while depending on a primary care physician to be “gatekeeper” for future medical care utilization.

2. Monitor ongoing medical care usage by involving people or institutions outside the medical practice to alert the physician gatekeeper about health care issues. For example, in the event of a child protective services investigation, or with the parent’s consent, the insurance provider can be alerted to inform the primary care physician or medical home about visits to other professionals. Another example would be having the parent authorize the school to call the physician any time the child is absent or have school officials agree not to excuse any absence without the physician’s approval.

3. Admit the child to an inpatient hospital setting or a partial hospital program, where his or her actual signs and symptoms can be monitored (as opposed to the signs and symptoms reported by the parent). This admission is a very important resource if the parent tends to exaggerate or lie about the child’s pain or disability. A program that treats the whole family can then work to define the child as normal in the parents’ eyes.

4. Involve child protective services to obtain dependency, either in or out of the home, to control overuse of medical resources and gradually reintroduce the child to the caregiver’s home while monitoring the child’s safety.

5. Place the child in another family setting permanently.

6. Prosecute the offending parent and incarcerate him or her, thus eliminating access to the child.

The physician’s role in options 4 through 6 would be to report the case to the appropriate authorities, carefully document the abuse, and, if needed, testify on the child’s behalf in courts of law. Obviously, options 3 through 6 will be required only in the most extreme or persistent cases of medical abuse.

**CLINICAL ADVICE**

When physicians diagnose and manage cases of child abuse in the medical setting, the following clinical advice will help ensure a more successful outcome of the case:

1. Whenever possible, have a pediatrician with experience and expertise in child abuse consult on the case, if not lead the team. This may help to reduce “false-positive” misdiagnosis and better identify actual cases.

2. Review all the medical charts pertinent to these complicated cases. Abusing parents often seek medical care from a variety of sources and may change physicians frequently. It is important to involve all the treating physicians in the process. Primary care and subspecialty physicians should work together to identify parents who seek excessive medical care. They should communicate regularly about the degree of medical care utilization and reach consensus on management. Cooperation of all the involved physicians is not only critical to good patient care, but it can also keep the parent from becoming confused or deliberately playing one doctor against another.

3. Work with a hospital- or community-based multidisciplinary child protection team. Such teams bring a variety of skills and viewpoints to the treatment process and provide expert consultation for the primary care physician in child maltreatment and child protection.

4. When a “more restrictive” response is needed, do not hesitate to involve the state social service agency responsible for protecting children from abuse. If the physician has access to a multidisciplinary child protection team, the team can help coordinate efforts to protect the child and facilitate communication with the state child protection agency.

5. Involve the whole family in the treatment. Their entire view of illness and health in their lives has to be adjusted. Ongoing family issues must be addressed to guarantee the future safety of the victim and any other children in the home. Therapists may use effective behavioral management techniques to change the child’s dysfunctional behaviors, when appropriate.

**SUMMARY**

What has been known as Munchausen syndrome by proxy may be better described as pediatric condition falsification or simply child abuse that occurs in a medical setting. In aggressively seeking an elusive diagnosis, physicians can sometimes cause harm to their patient and must remain aware of this possibility. The pediatrician who suspects that signs or symptoms of a disease are in fact being fabricated should concentrate on the harm or potential harm to the child caused by the actions of that caregiver and the efforts of the medical personnel to
diagnose and treat a nonexistent disease. Proper diagnosis of fabricated disease involves thorough evaluation of medical charts, clear communication among medical professionals, and, often, a multidisciplinary approach. A focus on the motives of the caregiver, although useful in therapy, is unnecessary for the diagnosis of this form of child abuse.

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My Mother Caused My Illness: The Story of a Survivor of Münchausen by Proxy Syndrome

Mary Bryk, RN, BSN* and Patricia T. Siegel, PhD‡

ABSTRACT. Objective. Münchausen by proxy syndrome (MBPS) is a form of child abuse in which a parent fabricates or produces illness in a child. Although the medical consequences of MBPS have been well described, there is no detailed published account of what it was like to grow up in a family where the mother systematically induced serious illness. This article describes one victim’s childhood experiences.

Methods. The medical history was obtained from a review of the original medical records, notes from the primary physician, discussions with two physicians who provided treatment, and several meetings with the victim and the victim’s therapist.

Results. This article chronicles the actual experiences of an MBPS victim through 8 years of medical abuse at the hands of her mother, reveals the victim’s account of what happened to her, describes what her family was like, details the long-term consequences on emotional and physical development, identifies the factors that influence recovery, and details the impact on family relationships.

Conclusions. Child maltreatment and MBPS need to be part of the differential diagnosis when the clinical picture is atypical or does not appear medically plausible. The consequences of MBPS are psychological and physical and impact the entire family. Suggestions to assist health care providers recognize, assess, and report cases of suspected MBPS are provided. Pediatrics 1997; 100:1–7; abuse, fabricates, victim.

ABBREVIATION. MBPS, Münchausen by proxy syndrome.

Münchausen by proxy syndrome (MBPS), first described in 1977 by Professor R. Meadow, is a form of child abuse in which a parent, usually the mother, systematically fabricates information about their child’s health or intentionally makes the child ill. Some of these children suffer a degree of physical and psychological damage, either from outright harm or from painful procedures, unnecessary medications, or hospitalizations ordered from unwitting physicians. This form of abuse differs from other forms of child maltreatment in several ways: the perpetrator is almost always female and usually presents as a model parent, there is little or no indication of family discord, and the abusive behavior is clearly premeditated, not impulsive or in reaction to the child’s behavior.

Although the medical consequences of MBPS have been well described, there are few articles that describe the long-term psychological impact of MBPS on its victims. Only one article describes MBPS victims as adults. To date, there is no detailed published account of what it was like to grow up in a family where the mother systematically induced serious illness. This article chronicles the actual experiences of a MBPS victim through 8 years of medical abuse at the hand of her mother. The medical history, obtained from original medical records and notes from the primary physician (J. Scholl. Notes covering the medical course of the case between 1961 through 1964, personal communication, 1993), details the impact on family relationships. The specific passages that illustrate the warning signals and significant aspects of the disorder associated with the MBPS are in italics. We conclude with

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The first author is one of the subjects described in Dr Libow’s 1995 article.
suggestions to help health care providers recognize and treat children victimized by this form of child maltreatment.

THE MEDICAL HISTORY: THE DOCUMENTED TRUTH

In the summer of 1961 a 2-year-old girl was referred to an orthopedic surgeon because a trivial injury to the right ankle had not healed. Examination revealed mild swelling with no laceration or evidence of a fracture. The leg was splinted. Over the next 4 months the swelling continued and the child began to have spiking fevers. Two castings of the leg and a course of antibiotics did not totally resolve the problem. A hematologist was consulted and diagnosed mild thrombosis. A bone biopsy was done. The pathology report described evidence of reactive fibrosis and hemorrhage, cause unknown. Repeated radiographs revealed no evidence of osteomyelitis. The hospital record indicates a total of 28 hospitalizations, 24 surgeries, multiple blood transfusions, dozens of radiographs, several incision and drainage procedures, as well as skin and bone grafts. Numerous courses of different antibiotics were used. Temperatures were frequently recorded in the 103° to 105°F range. One report indicated the child was hospitalized after a febrile seizure at home. After each discharge from the hospital, the child was closely followed as an outpatient with various and continuous medications; yet she continued to have spiking fevers.

Between the ages of 2 and 4, the infection was limited to the right leg. The initial diagnosis was cellulitis. Eventually, this became chronic osteomyelitis, although the child never followed a typical course and repeated radiographs never revealed evidence of osteomyelitis. Several incision and drainage procedures were performed because of frequent temperature spiking and swelling. Response to antibiotic therapy was poor. Eventually, irrigation tubes for antibiotic treatment were inserted in the tibia.

At age 4 and weighing 24 pounds, the child suffered a spontaneous spiral fracture of the right femur while in the hospital. The medical records for this hospitalization show the mother’s handwriting on the nursing notes, medication sheets, and intake and output records. The child was discharged home in traction with a pin through her right heel. For the next 7 years the pin tract remained infected and drained continuously. Amputation of the right leg was considered and discussed with the parents after informal consultation with a physician from another hospital. The infection responded to the next course of antibiotics.

When the child was 5, the left limb became involved after a fall while playing. A cast for a broken left wrist was placed at the physician’s office. One week later the wrist was severely swollen and required an incision and drainage procedure. There was evidence of infection but radiographs were negative for osteomyelitis. The wrist responded to antibiotic therapy over the next several months of treatment.

At age 6, the third limb was involved and the child presented with what appeared to be cellulitis of the right arm. Radiographs revealed no evidence of osteomyelitis. Two incision and drainage procedures were performed over the following 3 weeks and the severe temperature elevations dropped. Cultures again revealed bacterial infection and a course of antibiotics was initiated. At age 7, the child was brought to the emergency department with skin slough on her arm. The skin defect involved three quarters of the right arm and there were contractures of the elbow. The infection persisted for another eight months and there was significant loss of muscle mass. Two skin grafts were performed over the next few years but motion still remains restricted. At some point in time when the child was 8 years old, the left leg also became infected. The medical record indicates that the physician remained puzzled as to how the osteomyelitis traveled from the right to left leg.

When the child was 10 her medical condition dramatically improved. Three corrective surgeries were performed over the next 4 years; one to repair the right tibia, another to correct an internal foot rotation, and the third for skin grafting to the right arm. No further incidents of osteomyelitis occurred. Height and weight remained at or below the fifth percentile until midadolescence. Final adult height and weight falls in the average range.

MY STORY: THE PAINFUL TRUTH

I was raised in a small college town in the Midwest. I was the middle child, with a sister 20 months older and a brother 7 years younger. My mother was a registered nurse with a bachelor’s degree. She did not work until I was a teenager. My father never completed college. He worked for a pharmaceutical company and did carpentry work on the side. We lived with my grandmother, who was a microbiologist and worked for the same company as my father, in a middle-class neighborhood.

The first page of my 400-page medical record begins when I was 2 years old; the year was 1961. My parents reported that I had fallen down a flight of stairs and twisted my right ankle. Six weeks after the incident I was still limping, my foot was swollen, and there was a large bruised area over my ankle. Our family physician made a referral to an orthopedic surgeon who was to become my primary physician for the next 8 years.

An initial diagnosis of cellulitis was made. After several weeks of not responding to antibiotics, an incision and drainage procedure and biopsy were done of the area. The results of the report read “sections of periosteum exhibit chronic inflammation with fibrosis and old hemorrhage. No evidence of specific etiologic agent.” What the physicians who were treating me didn’t know was the injury to my ankle was no accident; the cause—repeated blows with a hammer by my mother.

My earliest memory of abuse is between the ages of 2 and 3. I was in the high chair with the tray pulled tightly to my chest. I could barely breathe, let alone move. My left leg was tied to the leg of the high chair with a dish towel. My hands were bound to prevent me from pulling at my mother’s hair. She was very angry at me for fighting her. Her words were always the same and repeated frequently over the next sev-
eral years: “I’m doing this for your own good. The doctor wants me to do this treatment to make you better.” As the blows of the hammer were hitting my foot all I could understand was the pain. I tried hard to escape her grasp. This made her even more angry: “If you don’t hold still, it will take even longer.” I came to believe it was my fault she was angry. I was not a good girl. I needed to try harder to please her so she would love me.

My mother’s “treatments” were scheduled three times a week, always after the midday news. Once I started school, the time changed to late afternoon. By picking me up a half hour early from school, a “treatment” could be completed before my sister walked home. During school breaks my sister was sent to a friend’s house or outside to play. When neighbors asked about the cries coming from our house it was explained that I was being difficult during dressing changes.

Once incisions were made to drain the infection, my mother not only used a hammer to create the swelling, but also used a sharp instrument to probe and contaminate my wounds with potting soil and coffee grounds to prolong the infection. My medical record indicates the wound cultures always showed the same organisms: *Pseudomonas aeruginosa*, *Proteus mirabilis*, and *Escherichia coli*.

By the time I was 2½ years old I had several open and draining wounds on my right leg. Because my mother was a nurse I was often released early from the hospital and continued having intravenous therapy at home. My mother was allowed to provide total care for me during my hospitalizations, including giving medications and charting in the hospital records.

I turned 3 years old when my ninth hospitalization occurred, because I developed sepsis. A system was set up to continuously irrigate my leg with antibiotic solutions. I was responding well to treatment after a month long hospital stay, when my next “accident” occurred. Although still in the hospital, but in my mother’s care, I suffered a spiral fracture of the right femur. The nursing note (in my mother’s handwriting) states “started to walk, took a couple of steps when a crack was heard and leg hung. Doctor notified.” I was placed in traction with a pin through my right heel. This pin tract would not heal for the next 7 years.

It was during this hospitalization that I began to understand that my mother’s “treatments” were different from the way the other nurses treated me. I became truly terrified of her and understood the extent of her power over me. Her love was connected to hurting me and keeping me sick. She threatened that if I told the truth no one would believe me. I would be taken away from my family forever. It was enough of a threat to keep me silent for 30 years.

There were times when my right leg was casted by the physician. This did not stop my mother from putting things down my cast and using a hammer on my exposed toes and knee. The swelling would force the physician to take the cast off. One time my mother used the hammer to smash the cast until it was soft. She then told the doctor I never listened to her and was always running, jumping, and playing on my right leg.

After a while my mother started to attack my left leg too. I was forced to use a wheelchair or to remain in bed. Meanwhile the doctors continued to puzzle over my case. Why did I not respond to antibiotics? Why was the osteomyelitis now showing up in another extremity? My mother had them running in circles.

I was 6 years old when I truly gave up hope of ever being rescued. My mother poured boiling water in the incision on my right arm, bandaged it up and waited till morning to take me to the emergency room. The staff was well acquainted with me because I was taken there one or two times a month for blood transfusions due to anemia.

This time I came into the emergency room hysterical screaming “Don’t let her hurt me any more.” Everyone thought I was reacting to my arm wound and I was given a sedative. I lost three-fourths of the skin on my arm and had a large gaping deep wound for the next 2 years. What in fact was a third degree burn was documented in the medical chart as “skin loss due to severe infection.”

I was in fourth grade when I realized I would have to save myself. I was very ashamed and too frightened to ask for help. Sometimes I thought I would lose my mind having to pretend that everything was okay. All I ever heard was how wonderful my mother was and all that she was sacrificing for me (some friends and relatives still speak of her as if she is a saint). Who would ever believe me if I told the truth?

One afternoon, as my mother was preparing for one of my “treatments,” I stood up to her and said I was going to tell my teacher and doctor. I don’t know why she backed down, but she did. Maybe it was because I was physically stronger and fighting her more frequently or it could have been because my brother, who was 3, was an easier target. Only my mother knows the real reason.

The abuse did stop and “miraculously” my medical condition improved dramatically. For the first time in 8 years I had full use of both my legs. Although I still had to endure several corrective surgeries over the next few years, the worst was over. To this day, however, the two size difference in my shoe size and the massive scars that cover my arms and legs are a constant reminder of my mother’s distorted love (Figs 1-4).

MY BROTHER: THE HURTING CONTINUES

When the abuse ended for me I was filled with guilt because my little brother became my mother’s next victim and began to manifest similar symptoms. For 2 years, he had problems with “osteomyelitis” in his knee. Because I was so afraid I could not bring myself to tell anyone. I felt I had let my brother down. He was alone, frightened and unprotected, just as I had been.

I was suspicious that my mother was hurting my brother from the beginning. One day I caught her in the act. It was a warm sunny day, all of us were in the backyard playing in a wading pool. My mother called for my brother to come inside. He began to cry and refused to go. My mother picked him up and
carried him inside. My heart was racing and there was a knot in my stomach. I heard a dull thud and knew she was using the hammer on my brother. I turned to my sister who was very quiet. “Did you hear that?” My sister slowly shook her head no. The noise continued. I had to do something. I raced inside and saw my mother sitting on top of my brother’s chest just like she used to do to me. The hammer was poised in her hand. I immediately screamed at her to stop. She yelled at me to get back outside. I begged her to stop hurting him. The hammer whizzed past my head hitting the wall behind me. I was so scared I did as I was told. I went back outside and sat with my sister in the wading pool and sobbed.

My brother has admitted to me that mother abused him but has not discussed it with anyone else in the family. He has spent many years a lost soul, wandering from job to job, starting and never completing college classes. He was a binge drinker and abused drugs for a while. A few years ago he embraced religion and is currently studying to be a minister.

MY SISTER: SCARED OF THE TRUTH

As far as I know my sister was never abused. She staunchly supports my mother and adamantly denies any knowledge of what my mother did to me and my brother. Although she was often at school or sent to friends or neighbors when my mother was abusing me, there were many times she was just outside the door and must have heard my screams. But she never wanted to know what was going on. She was probably scared too. Today she is a very angry adult who does not seem happy or content with her life. In the past her anger overwhelmed me and made me feel guilty because I felt I was somehow responsible. Now I realize that her anger is not my problem. Perhaps someday she will open her eyes and confront what really happened. Maybe then she will be free to find happiness.

MY FATHER: HE WOULD NOT HEAR THE TRUTH

As a child, I loved the Disney stories. Tales of good versus evil and of happy endings gave me hope for the future. I desperately wanted my father to be my knight in shining armor. He was supposed to rescue me but he never did.

In the beginning, I thought my father was unaware of what my mother did to me, otherwise he would have stopped her. However, I learned differently when I told him what my mother was doing and he didn’t believe me.

Sunday was family day and the only day my father was at home. After church we often took drives into the country. One Sunday, while waiting in the car for my mother, I started to tell my father about how mother used a hammer on my leg. My sister in the back seat began to scream, “She’s lying, mommy would never do that.” Tears were streaming down her face, her hands clamped tightly over her ears. My
father immediately confronted my mother who became teary-eyed and denied everything. My father turned to me and gave me a severe lecture about not lying and told me to never mention the subject again. I learned several lessons that day; the conditions of my father's love, the ease with which my mother could manipulate situations to her advantage, and how easily she could deceive others into believing her.

To this day my father denies any knowledge of my mother's abusive behavior and does not believe me.

**MY MOTHER: THE TERRIBLE TRUTH**

My mother uses illness as a way to gain attention and approval. Her bizarre behavior has significantly damaged several lives, including her own. For the last 15 years she has had “problems” with thrombosis and cellulitis leading to severe infection in her right leg. Despite the use of antibiotics, the infections come and go and she has relied on several prescription analgesics for pain. In the early 1980s, one physician told my father he felt my mother’s leg wounds were self-inflicted. Mom, of course, denied it. Dad believed her and found her another physician.

In the fall of 1989, my mother was arrested for falsifying prescriptions. She was addicted to pain killers and had been calling different pharmacies with bogus controlled substance numbers to get more medication. One pharmacist became suspicious and called the police. An attorney friend of the family convinced the judge my mother would enter a drug rehabilitation program and the charges were dropped. I was recently told my mother’s “condition” had deteriorated further and she may become confined to a wheelchair. Her physicians were considering amputation. I talked with her physician and told him I suspected she is causing her own illness.

*My mother is an incredible liar and a powerfully deceptive actress. It is amazing what she has gotten away with over the years. Although I have forgiven her for abusing me, I continue to be angry for the way she continues to abuse herself and for how she manipulates family and friends. Although I could never have a trusting relationship with her, I still yearn to know a mother’s love. To date, unfortunately, she denies ever abusing me, my brother or herself. Also, many family members, friends and neighbors continue to view her the model mother. She has the love and support of my family of origin and much that she predicted has come true; my father, sister and brother are lost to me and my children. But she has not won. I am stronger than ever and have successfully built a new life based on truth and love.*

**THE YEARS AFTER THE ABUSE: THE UNSPOKEN TRUTH**

The first year after my mother stopped abusing me I was filled with constant fear and anxiety that she would resume her “treatments.” As time passed I became more confident and outspoken at home and my teen years were filled with constant power struggles with my mother. I often had the upper hand because I had a secret she did not want revealed. Her way of dealing with our relationship was to try and keep me dependent, to demean me, and destroy my self-esteem. My illness was rarely discussed by the family and the message I received was “be grateful you survived and remember you owe it all to us.” I was told I would never amount to anything and no matter what I did, I could never please my parents. I graduated in the top 5% of my high school class but my parents felt I would fail in college. I earned an academic scholarship but was told not to speak of it because it might offend my sister. I first left my family at age 18 when I decided to attend college 3 hours away from home. I had no car so visits home were infrequent. This distance allowed me to grow as an individual and to begin to learn about myself apart from my family’s influence. Once I graduated from college, I continued to live away from home and because I had limited interactions with my family I continued to grow stronger emotionally.

I met my husband when I was 25 and already working as a nurse. He knew nothing of my abusive history until one weekend while visiting my family I impulsively confronted my mother after she showed me a large bruise on her thigh. I recognized the bruise as similar to those she gave me with a hammer and accused her of self-inflicting the bruise. She became hysterical, started to cry, and went to my father for support. My father continued to defend her even after I was able to show him the hammer she kept hidden in a bedroom drawer. We left my parents with nothing resolved. My parents never mentioned the incident again. During our drive home, my hus-

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Fig. 4. Significant calf asymmetry with loss of tissue and scarring on the right.
band asked about my childhood but I told him I was not able to talk about it. He said “One day you will have to deal with your past and I will support you when ever the time is right for you.” It was not until the birth of my first child that I was strong enough to challenge the demons from my past.

**MY RECOVERY: THE TRUTH STILL HURTS**

Each time I review my medical records, I go through a period of mourning for a childhood lost. In the name of sickness and at the hands of medicine, I am disfigured with permanent physical scars. Because of distorted motherly love, I continue to battle deep emotional wounds. It is likely that my experiences with illness, pain, and hospitals were influential in my decision to choose nursing as a career as I have always felt a deep sense of wanting to help others. However, my mother also played a part; she used to tell me that “if nursing was good enough for her, it was good enough for her daughter.” I guess I was still trying to please her and earn her love by “being good” and “doing what she asked.” I am glad to report, however, that my nursing career has proved very rewarding and I have enjoyed personal satisfaction in working with and helping patients.

I am also fortunate to have a healthy, loving marriage and two wonderful daughters. I was 30 years old and a mother for the first time when I realized I needed to seek professional help to deal with my mother’s abuse. It happened one day while I was holding my infant daughter in my arms and became overwhelmed by the feelings of love and protection I felt for her. It was the first time I admitted to myself how abhorrent my mother’s behavior was. My impetus to enter therapy was a strong desire to be healthy in my relationship with my own daughter. I didn’t want my emotional scars to be passed on to her. I was also lucky enough to have a husband who loves me and is very supportive.

Therapy was not easy. Although I always had memories of what my mother did to me, I had never talked to anyone about it. To speak out loud and relive these memories brought to the surface feelings I had spent thirty years trying to stifle. Along with individual therapy I also attended group therapy with other female survivors of childhood abuse. There, I learned I was not alone in my pain. Therapy was a safe place to vent feelings and learn how to set boundaries. The final piece of the puzzle was learning that the abuse I suffered had a name. I had always felt that my experiences were different from others in the group and I finally understood why; the medical abuse I experienced was a deliberate, premeditated act; the physical abuse that other group members experienced was more impulsive and reactive. My recovery progressed rapidly from then on.

I currently have no contact with my family and have built a life separate from them. To have any relationship with them I would have to deny everything that happened to me. Although it is painful to lose these relationships, I feel strong in knowing I can never go back to playing the role of victim ever again. Every day when I look in the mirror, I am hauntingly reminded of my abuser. The physical resemblance and the massive scars are constant reminders of what I have survived. By telling my story I hope children who are victims of this terrible abuse will be better understood and will have a better chance of survival. Health professionals need to take responsibility in recognizing this sadistic illness. Departments of social service and the judicial system need to look at their policy of keeping families intact. Every child deserves to be loved unconditionally by someone who can be trusted. In my case, the woman who gave birth to me does not deserve to be called “mother” and should not have been allowed to raise children.

**DISCUSSION**

When the abuse reported here was perpetrated, neither factitious illness nor MBPS had yet been described in the medical literature. Thus, physicians could not have been expected to consider MBPS. However, the medical record and physician notes did frequently indicate a sense of puzzlement and bewilderment by the unusual clinical course of the illness. Although medical etiologies need to be ruled out in circumstances such as these, it is also important to consider environmental and psychosocial factors when the clinical presentation does not seem medically plausible. Both child maltreatment and MBPS need to be part of the differential diagnosis when the clinical picture is atypical. You can’t diagnose it unless you think of it. Once considered, “look with new eyes” at the entire case and the medical record. All medical symptoms and diagnoses the mother reports should be substantiated by lab or test results. Records from all involved physicians and hospitals should be obtained and reviewed. Also, it is important to remember the child may be more vulnerable to abuse while in the hospital, so either find a reason to restrict visitation or have a sitter in the room. The interviewer also needs to determine if other children in the family are vulnerable to medical abuse. Infants and preschool children should be considered at highest risk. Another family member (father, grandparent) needs to be interviewed separately and asked about the child’s symptoms without revealing the information given by the mother. Nonmedical information provided by the mother should also be checked because fabrication can occur in multiple areas. Inquiry regarding the mother health is also important because she may have a history of fabricating or inducing symptoms in herself. Remember, however, not to alert the mother of your suspicions throughout the course of the assessment. Finally, we recommend that health care providers consult the Child Protection Team when MBPS is suspected. These teams are typically staffed with pediatricians, pediatric psychologists, and social workers familiar with hospital policy and procedures regarding child maltreatment as well as with the special circumstances involved in assessing, diagnosing, and reporting MBPS. These multidisciplinary teams can provide concrete suggestions for confirming MBPS, help initiate the necessary legal action after the diagnosis has been established, formulate a treatment/intervention plan for the mother,
outline a monitoring system to protect the child in the future, and establish criteria for reunification.

**CONCLUSION**

The details presented in this case underscore the need to develop sensitive means of identifying and treating children who are victims of MBPS and serve as powerful reminders to directly talk with, and listen to, young patients. This child victim knew from a very early age that her mother’s “treatments” were different. Yet, her mother’s threats and her father’s rejection and denial proved too overwhelming to allow her to directly ask for help. Had one health care provider talked with her privately and won her trust, perhaps she would have been able to talk about the things her mother was doing. When there is suspicion of foul play or MBPS, referral to a mental health professional familiar with child maltreatment could help provide the supportive environment and trusting relationship that children need to begin revealing the truth. In the case presented, a childhood was lost, sibling relationships were irreparably damaged, and an entire family was torn apart by the failure of many systems to respond to this tragedy.

**ACKNOWLEDGMENTS**

We thank Drs Howard Fischer and Alan Gruskin (Children’s Hospital of Michigan), and Judith Libow and Herbert Schreier (Children’s Hospital of Oakland) for reviewing the manuscript and for their helpful suggestions. We are also grateful to Dr James Scholl for kindly providing a copy of his original personal notes used in a 1964 case presentation.

**REFERENCES**


**GOODBYE TO ALL THAT**

The Spencer Method of handwriting was taught in America until after the Second World War. Aging pupils recall it with bittersweet memories of a past when moral certainty still seemed possible.


Submitted by Student
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 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 *factitious disorder* 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. 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.

**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>Case 1</th>
<th>Birth</th>
<th>13</th>
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</thead>
<tbody>
<tr>
<td>Age onset (mo)</td>
<td>Age Diagnosis (mo)</td>
<td>Feeding aversion</td>
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<td></td>
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<td>Occupational therapy, video swallowing study</td>
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<td>Food IgEs, food elimination</td>
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<td>Constipation since birth</td>
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<td>Barium enema</td>
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<td>Failure to thrive, including height, weight and OFC</td>
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<td>Tube feeds, thyroid labs, pancreatic elastase, stool fats, stool culture, metabolic &amp; mitochondrial disease screening, GH IGF-1, IGF binding protein</td>
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<td>Reflux</td>
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<td>UGI, pH probe, NM gastric emptying, upper endoscope</td>
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<td>Developmental delay</td>
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<td>Cardiac echo, monitoring Neurology exam</td>
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<td></td>
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<td>Tongue tie, noisy respiration</td>
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<td></td>
<td>ENT exam, nasopharyngoscopy</td>
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<td>Developmental delay</td>
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<td>Developmental evaluation</td>
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<td>Fatigue, myalgia-motor regression (bedridden)</td>
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<td>Hypoventilation-sleep apnea</td>
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<td>Sleep study</td>
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<td></td>
<td>Failure to thrive, gut dysmotility disorder, constipation</td>
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<td>Swallowing study, upper &amp; lower endoscopy, gut CMV testing</td>
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<td>Chronic bladder spasms/pain</td>
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<td>Renal US, VCUG</td>
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<td>Undefined neurologic/metabolic/mitochondrial disorder</td>
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<td>Anemia</td>
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<td>Iron studies, epo level, coagulation and thrombophilia testing</td>
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<td></td>
<td>Hypoglycemia</td>
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<td>Case 2</td>
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<th>Treatment efforts</th>
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<td>Laxatives, suppositories</td>
<td>Resolved, no treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nasogastric/gastric tube feeds, high calorie formula</td>
<td>Resumed normal growth</td>
<td></td>
</tr>
<tr>
<td>103</td>
<td></td>
<td>H2 blockers, PPIs</td>
<td>None, no treatment</td>
<td></td>
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<td></td>
<td></td>
<td>None</td>
<td>Normal</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>None</td>
<td>Normal</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>Speech, OT/PT</td>
<td>Rapidly improved</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Gabapentin, methadone, AFOs</td>
<td>Normally ambulatory within 3 days</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Oxygen nasal cannula &amp; bipAP</td>
<td>Weaned to room air</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>NG, laxatives, gastrostomy/Nissen, TPN (multiple 2° line infections)</td>
<td>Weaned to oral feeding, lines removed</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Onybutrin, narcotics</td>
<td>Resolved off medications</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Co-enzyme Q, l-carnitine, l-thyroxine, vitamins</td>
<td>Resolved off meds, except still thyroid dependent</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Gabapentin</td>
<td>No seizures off meds</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Iron, vitamins</td>
<td>Responding to iron</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Tube and parenteral feeding</td>
<td>Not present</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>g-tube, lansoprazole, ondansetron, senna, polyethylene glycol, Mother self referred for port-a-cath</td>
<td>Achieved full oral feeds, rapid weight gain, no constipation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home health aids &amp; nurses through palliative care</td>
<td>No dystonia or hemiparesis events</td>
<td></td>
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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></td>
<td></td>
<td>Wheelchair, but can do</td>
<td>Walking with walker, on baclofen,</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>transfers, autism</td>
<td>mitochondria medications stopped,</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>program,</td>
<td>spasticity persists,</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>mitochondrial</td>
<td>entered school</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>disease cocktail,</td>
<td></td>
</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>oral baclofen,</td>
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<td></td>
<td></td>
<td></td>
<td>botulinum toxin,</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>home schooling</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>kindergarten work</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>MR brain (mild</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>peri-ventricular</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>leukomalacia) &amp; spine</td>
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<td></td>
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<td></td>
<td>MR spect scan brain</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Multiple EEGs + 48 h EEG</td>
<td>Levetiracetam, valproic acid</td>
<td>No seizures, still on valproic acid 9 months later</td>
</tr>
<tr>
<td>Seizure disorder</td>
<td></td>
<td></td>
<td></td>
<td>Oxygen by cannula continuous</td>
<td>Severity resolving, rapidly off oxygen</td>
</tr>
<tr>
<td>Hyperventilation, central autonomic dysregulation</td>
<td>Pulmonary, psychiatry consultations, echocardiogram, blood testing</td>
<td>Oxygen by cannula continuous</td>
<td>Albuterol, glycopyrrolate, fluticasone, montelucast</td>
<td>Off all but PRN albuterol, rare use</td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>Pulmonary consultation, laryngoscopy, bronchoscopy, MR chest</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Obstructive sleep apnea, hypoxia</td>
<td>Sleep study</td>
<td>Oxygen</td>
<td></td>
<td>Resolved. Off oxygen</td>
<td></td>
</tr>
<tr>
<td>Medication allergies</td>
<td>Maternal history</td>
<td>Avoidance</td>
<td></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>Epidural medication</td>
<td></td>
<td>Improving off treatment</td>
<td></td>
</tr>
<tr>
<td>Recurrent pain</td>
<td>Pain consultation, epidural catheter for medications</td>
<td>Use of pacifier, clonidine, Prozac</td>
<td></td>
<td>Resolved, off medications</td>
<td></td>
</tr>
<tr>
<td>Eye deviation</td>
<td>Ophthalmology consultation, visual evoked potentials</td>
<td>None</td>
<td></td>
<td>Not present</td>
<td></td>
</tr>
<tr>
<td>Heart concerns</td>
<td>Cardiology consultation, EKG, Holter monitor</td>
<td>None</td>
<td></td>
<td>No disease</td>
<td></td>
</tr>
<tr>
<td>Proteinaceous renal stone</td>
<td>Renal US, mildly high Ca/Cr ratio</td>
<td>None</td>
<td></td>
<td>No disease</td>
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</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
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 fabricate illnesses). These blogs described graphic procedures and symptoms, often followed by strong fears of impending child death, fears which were not supported by language and complex stories to exaggerate their children’s illnesses or completely fabricate 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 Bass and 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 caretaker’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 intercurrent 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.

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 as 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


Beyond Munchausen Syndrome by Proxy

To the Editor.—

As experts in Munchausen syndrome by proxy (MSBP) maltreatment, we are writing in response to “Beyond Munchausen Syndrome by Proxy: Identification and Treatment of Child Abuse in a Medical Setting.”1 We commend the American Academy of Pediatrics for addressing this form of maltreatment, which is underrecognized. However, we do have several concerns about this position statement. Of these concerns, the most important is the remark that, although multidisciplinary input is important, the physician is the only professional who can actually make the diagnosis of MSBP.

We differ with this conclusion for several reasons. Most basically, MSBP is a much wider phenomenon than just “a form of child abuse taking place in a medical setting.”1 Manifestations of MSBP can be seen in schools, mental health facilities, nonprofit organizations, churches, the legal system, child protection agencies, the home, and the community at large. Likewise, physical symptoms are only a part of the spectrum of MSBP, with other kinds of “problems” (eg, psychological symptoms and other behaviors) that are exaggerated, fabricated, or induced in some cases.

The methodology involved in confirming or disconfirming MSBP includes the gathering of records from many sources (not just health care), conducting specialized interviews of a variety of professionals and nonprofessionals, and performing an overall information analysis, the last conducted by, or with the assistance of, a professional who has specialized knowledge and experience in this field.2 The task of identifying the discrepancies that may be present among all these sources, and answering the medical questions that arise, often requires input and clarification from physicians, but the investigation as a whole need not be done solely by them. In fact, most physicians do not have the time required for a thorough, appropriate investigation. Although the authors stated that “child abuse is a pediatric diagnosis,”1 it is not solely a pediatric medical diagnosis. Issues of motivation and circumstance are always important in determining that a given physical condition is the result of deliberate abuse (or neglect), as opposed to accident, ignorance, or other possible causes. All states and many other nations reflect this fact by assigning maltreatment investigations to child protective agencies and, within hospitals, to multidisciplinary/multiagency child protective teams.

The statement that “psychologists, social workers, and others are not in a position to make or confirm this diagnosis” overlooks the legal requirement for these professionals and others, to report suspicions of child maltreatment to child protective authorities. These professionals receive training in the assessment of child maltreatment, may incur legal penalties if they fail to report, and must act in accord with their professional ethics. Given the overall shortage of professionals with expertise in MSBP, it is often necessary that a counselor, social worker, or other nonphysician make the assessment and lead the multidisciplinary/multiagency team. In such circumstances, involved professionals should make every effort to work with an MSBP professional of whatever discipline and/or to obtain education from an MSBP professional in this specialized kind of maltreatment.

We believe that it can be dangerous to delay the reporting of suspicions of child maltreatment, including MSBP, as suggested by the authors’ “list of possible interventions.”1 Our experience has been that many situations of MSBP respond very poorly to “individual and/or family therapy,” which may even be contraindicated as an early step in MSBP. Attempts by a physician to “gatekeep” or “monitor” are thwarted easily by perpetrators of MSBP who involve multiple caregivers (“doctor-shop”) or even flee to another area when suspected. The extent of MSBP maltreatment perceived by the primary caregiver may be only the tip
of the iceberg if, unknown to the pediatrician, other providers or agencies are also being deceived. Absent the supervision and power of the courts, it is likely that perpetrators will not tell the whole truth, genuinely cooperate with medical gatekeeping, or even remain available to the physician.

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REFERENCES

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In Reply.—

In committing to write a report on the falsification of pediatric medical conditions (Munchausen syndrome by proxy [MSBP]), the Committee on Child Abuse and Neglect knew that it was wading into a definitional swamp of confusing notions about this type of child abuse. The response from Feldman, Light, Lasher, and Sheridan, all of whom are respected and competent professionals, sheds light on the necessity for ongoing debate.

The committee set out with 2 objectives. One was to clarify the sometimes bewildering terminology that is applied to these cases. We pointed out that the issue for the medical provider is the falsification of a pediatric condition, more than the state of mind or motivation of the perpetrator. We are concerned about the harm that can be done to a child in the medical setting with medical personnel as the unwitting instrument of the abuse. Although some authors have applied the term to someone who lies about the nonexistent illnesses of a fictitious child over the Internet or a woman who falsifies the illness of her dog,1–3 our discussion was limited to medical presentations, as in the original patients with Munchausen syndrome. In such cases, the medical professional is, in fact, the only member of the team who can determine if the condition truly exists and thus “make” the diagnosis. Nowhere is it contended that the medical professional is able to investigate the case without help, nor is it felt that only the physician must lead the team. We certainly agree with the authors that child abuse is not only a medical diagnosis. Nonetheless, we maintain that the diagnosis of factitious disease remains a medical one.

Our other objective was to remind pediatric providers of their role in the ongoing management of these cases. Many presentations that suggest MSBP fall short of a report to child protective services, and many of those reported need not be removed from the home. One response will not be appropriate for all. To this end, we offered a number of progressively restrictive management options, with multidisciplinary team involvement high on the list. Clearly, at the more severe end of the spectrum, this type of abuse is as serious as any and use of the child protection system is absolutely necessary.

In their response to our article, Feldman et al again underline the importance of a multidisciplinary approach to the difficult diagnosis of MSBP and remind readers that there is an “overall shortage of professionals with expertise in MSBP.” We can certainly not disagree with either statement. What was stressed in our article is the need for pediatricians to remember that parents’ histories may be unreliable and to maintain vigilance.

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Unconventional Solution: A Marketing Approach to Solving Health Literacy Disparities

To the Editor.—

We read with interest the recent report from Sanders et al6 in regard to the association between caregiver’s health literacy and the use of child health services. Their finding raises an important question about the true role that health literacy plays in health outcomes.

A large body of research suggests that health illiteracy does not completely account for suboptimal outcomes. For example, some studies found that illiteracy