

A Review of Munchausen Syndrome by Proxy

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Munchausen syndrome by proxy was described 35 years ago,¹ and yet it remains a complicated, controversial, and confusing condition. The term was initially limited to circumstances in which a caregiver surreptitiously injured the child or the child's symptoms were fabricated, both leading to unnecessary or potentially harmful medical care.

Over time, the spectrum of Munchausen syndrome by proxy (MSP) has expanded. Clinicians frequently use the term to describe cases in which a child's medical symptoms are emphasized and exaggerated by an unsatisfied adult caregiver, which enters the child into a pattern of increasing tests and interventions. At some point, and usually only in retrospect, physicians realize the medical care itself was not medically justified and caused real or potential harm to the child.

Primary care physicians are uniquely positioned to identify potential warning signs of MSP. Whether the child's illness is inflicted directly by the family, or through unnecessary tests ordered or performed by health professionals, early recognition of risk factors and interruption of

family and physician behaviors can stop an increasingly dangerous situation for a child. We will discuss elements of the contemporary health care system, which may facilitate "over medicalization" that places the child at risk for injury. Heightened awareness of the role health care providers' play in perpetuation of some cases of MSP may help reduce morbidity and mortality.

BACKGROUND AND OVERVIEW

MSP is a clever reference to Baron K.F.H. von Munchausen, an 18th century minor nobleman who embellished his insignificant military adventures into tales of heroic adventure.² In the 1950s, British psychiatrist Richard Asher coined the term "Munchausen's syndrome" to de-

CME EDUCATIONAL OBJECTIVES

1. Define Munchausen syndrome by proxy (MSP) and provide a more specific classification scheme that accurately reflects the spectrum of this disorder.
2. Determine the clinical characteristics of the specific subtypes of MSP.
3. Clarify the role played by the medical provider in MSP and challenges posed by our modern health care delivery system.

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scribe adults who presented histrionic and deceptive medical stories that confounded physicians.³ The phrase “Munchausen syndrome by proxy” was introduced in 1977 by British pediatric nephrologist Roy Meadow. He described two children with a fictitious illness; one with “hematuria” with mother’s blood found in the urine and another who died from salt poisoning.¹ The words “by proxy” emphasized the roles of the perpetrator and victim: the adult had the pathological need to embellish or deceive the health providers and the child was the “proxy” victim.

MSP is a form of child abuse. Like other forms of abuse, there is a spectrum of presentations from mild to severe, and the diagnosis should be recognized regardless of the motivations or intentions of the caregiver. Realizing that MSP results in significant pediatric morbidity and mortality is fundamental to understanding the urgent need for recognition and management.

CLINICAL SPECTRUM

MSP is not a single condition but a clinical spectrum. Even Meadow’s original description included two types of caregiver actions: 1) the parent inflicted the illness (by salt poisoning); and 2) the parent fabricated the symptoms (contaminated child’s urine with blood).¹ Subsequently, similar cases were described in the literature, leading to attempts to establish diagnostic criteria.²

MSP is defined by the following characteristics: 1) a child’s illness is fictitious or induced by a caregiver; 2) interaction with the health care system results in multiple medical tests and procedures; 3) denial by the caregiver as to the cause of the child’s illness; and 4) symptoms abate following separation of the child from the caregiver.² These characteristics are found in most forms of child abuse. What makes MSP a unique form of child abuse is the active role health care professionals play in the initiation and perpetuation of the syndrome.⁴

Different terms for subtypes of MSP have been introduced as nomenclature that is more precise and descriptive.

Factitious Disorder by Proxy

A psychiatric diagnosis in the perpetrating caregiver who falsifies or fabricates the child’s signs and symptoms to meet her underlying, self-serving psychological need to have or be associated with a chronically or seriously ill child, is diagnosed with factitious disorder by proxy (FDP);⁵⁻⁷ the emphasis is on the pathology of the adult.

Pediatric Condition Falsification

Pediatric condition falsification (PCF) is a form of child abuse in which an adult exaggerates, fabricates, or falsifies a child’s clinical signs or symptoms to a degree that a clinical illness is perceived by the treating physician, which leads to invasive medical care.⁵ The emphasis is on the inaccurate medical history.^{4,5} An underlying psychiatric disorder in the adult may or may not be present. Other possible motivations include material benefits (eg, housing, nursing care), attention, malingering, and the desire to hurt another adult.

Medical Child Abuse

A recent and useful concept described by Roesler and Jenny is that of “medical child abuse” (MCA).⁸ They propose this definition: “Medical child abuse occurs when a child receives unnecessary and harmful or potentially harmful medical care at the instigation of a caregiver.” The definition is based solely on harmful acts inflicted upon the child and acknowledges the role of health care providers in causing harm to the child. These authors argue the term “MSP” should be discarded as it is confusing, imprecise, and encumbered with 35 years of social and legal nuances. They believe different forms of child abuse should be described with specific terms that explain the harm to the child.

For example, when the child is harmed directly by an adult as a means to cause or mimic a disease (eg, suffocation, poisoning, impact-causing bruises), the causation of injury should be recognized and properly labeled as physical assault on a child. When harm to the child is not actually inflicted by the parent, but caused by repetitive invasive acts by health care professionals responding to reports and demands of parents or guardians, the proper terminology is MCA.

While the diagnostic label of MSP remains in common use, it is without an International Classification of Disease-9 (ICD-9) code. The term is recognized by professionals in the child protection and legal systems. MSP unites a variety of clinical conditions in which a child is harmed by a caregiver directly or through the caregiver’s interaction with members of the health care profession.⁹

CLINICAL CHARACTERISTICS

In the classic MSP scenario, there are three intertwined constituents: 1) the child with persistent symptoms that defy medical explanation; 2) the adult caregiver, typically, but not exclusively, the biological mother; 3) the physician, often a hospital-based specialist, eager to understand and ameliorate confusing persistent symptoms.⁴

Common threads unite the varied presentations of MSP. Patient symptoms are out of proportion to physical findings and do not respond as expected or established treatments. The case is considered “unusual” or “atypical.” Additional studies fail to uncover a satisfactory cause for the symptoms. The caregiver may be appreciative but not satisfied or reassured, prompting the clinician to pursue additional investigations or consultations to find the cause for the symptoms. The intricate interaction between the unreassured parent, the child’s perplexing symptoms, and the treating physician can lead to a child’s harm from unnecessary tests and

treatments including surgery or invasive medical procedures.

Three Forms of MSP

Presenting signs or symptoms in MSP are now recognized to take three forms: 1) covert injury induced in secret by the caregiver; 2) fabrication of symptoms by the perpetrator; and 3) symptoms neither induced nor fabricated, but emphasized and exaggerated by the caregiver who is not reassured, which prompts additional medical tests, interventions, and procedures.

Covert Injury

Covert injury to a child occurs in many ways. One classic example is poisoning the child with salt, phosphorous, ipecac, insulin, laxatives, sedatives, or antidepressants.¹⁰ Substances can be injected subcutaneously or intravenously causing inflammation or infection. Physical injury, such as bruising or burns, can be construed as a bleeding disorder or immunodeficiency. Complaints of recurrent apnea or apparent life-threatening events should raise the possibility of suffocation.¹¹ Evaluation requires a search for toxins or other agents causing harm to a child. Rarely, appropriately arranged covert surveillance efforts are indicated to assist in the diagnosis.^{10,12}

Fabrication and Falsification

Fabrication or falsification of symptoms is challenging to identify. Physicians expect medical history from the family to be truthful. Fabrication of symptoms is often not initially included in the differential diagnosis of challenging or confusing clinical problems. Yet thoughtful skepticism is necessary if the medical history does not match objective findings. As one example, multiple diapers filled with “blood” should be associated with some degree of tachycardia or fall in hematocrit. If these objective findings are absent, surreptitious placement of red dye or animal blood should at least be considered.

Spectrum of health care seeking by parents

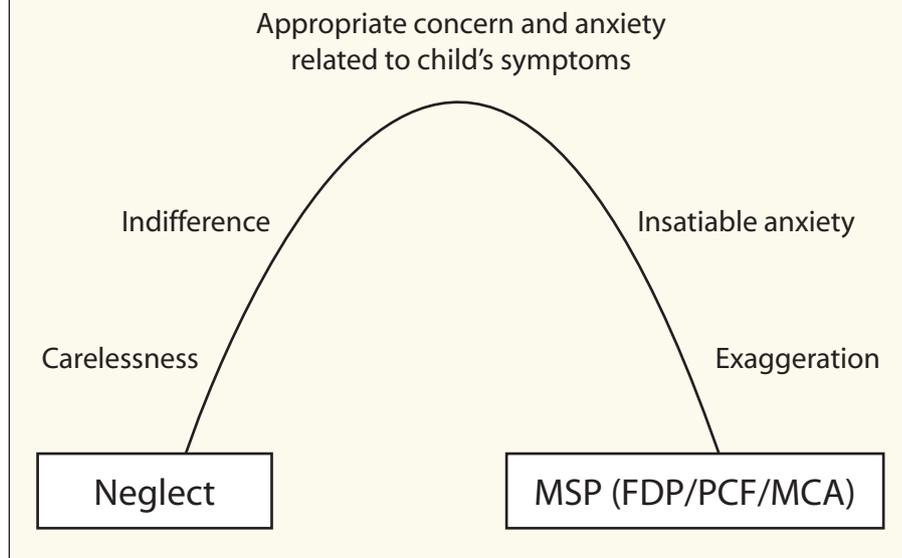


Figure 1. Spectrum of health care seeking by parents. FDP = factitious disorder by proxy; MCA = medical child abuse; MSP = Munchausen syndrome by proxy; PCF = pediatric condition falsification. (Adapted from Eminson and Postlethwaite.¹³)

When a reasonable diagnostic evaluation does not produce the expected findings associated with the clinical presentation, a pause in diagnostic pursuits coupled with a re-examination of the known facts may at least raise the possibility of false information or clandestine actions.

Exaggerated Symptoms

Exaggerated symptoms reported by an “un-reassurable” caregiver pose a significant challenge. Exaggeration of symptoms is in the eye of the beholder and is not, by itself, an unreasonable method for parents to use when they are concerned for the welfare of their child.¹³ Cases often begin with a legitimate medical problem, and the child may have a diagnosed medical condition.

Over time, unexplainable or confusing symptoms develop that persist or evolve despite reasonable diagnostic and treatment strategies. The caregiver, or at times the physician, is not reassured and becomes worried about “missing something” when reported symptoms persist. Either case can lead to further evaluation

and interventions beyond those reasonably justified by objective findings. Physicians become caught in a pattern of providing or prescribing an escalation of health care, to the point of causing actual injury to the child (see Figure).¹³ The term that best describes the harm to child under these circumstances is MCA. Resolution depends upon recognition that the child is being injured by unnecessary medical care and refusal by physicians to continue in a care plan that is abusive for the child.

HEALTH CARE SYSTEMS AND MSP

We propose that a number of forces are evolving in the health care delivery system that may facilitate the role of medical professionals in MSP. Much of this section reflects the experiences and opinions of the authors.¹⁴

Electronic Medical Records

While counterintuitive, electronic medical records (EMRs) may obscure an accurate medical history in a number of ways. First, multiple EMR systems do not interface well. Records from incongruous fa-

cilities are often reviewed in summarized notes rather than original data, increasing the likelihood of incomplete information. Second, EMRs can be massive, particularly for chronically ill children. Data can be cluttered with copied information inserted for documentation and billing purposes obscuring critical observations and thought processes. Third, physician and nursing notes generated by “copy and paste” behaviors can be carried forward without reference to the original author or observer. Fourth, the ubiquitous use of “templates” and predetermined drop-down lists to document the history and physical examination leave limited opportunity to include nuanced assessments of personal interactions and observations.

Limited Access to Complete Records

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 established rules giving individuals added control over their protected health information. Written consent is necessary for information sharing. Access to past medical information for a child is difficult without cooperation from a parent. For concerns of child maltreatment, HIPAA specifically allows information disclosure to appropriate child protection authorities for purposes of investigation, but this applies only after a formal report of possible child abuse had been filed.¹⁵

HIPAA has also made it challenging to communicate through published case reports. Publication of clinical experience requires patient/family consent, unless the case can be completely de-identified. As a result, families are more likely to give permission to report conditions erroneously mistaken for abuse, rather than descriptions of unusual forms of child maltreatment, which were so fundamental to the understanding of the original concept of MSP.

Risks of Diagnostic Tests

Biochemical and diagnostic test results can enlighten or mislead.¹⁶ Risks

associated with increased testing include over-interpretation of incomplete data, fearful perception of significant disease based on nonspecific abnormal values, and re-enforcement of anxiety with inconclusive results. Increased numbers of tests increases the risk that a misleading test result will result in injudicious and dangerous interventions.¹⁷ Examples include risks associated with inappropriate cardiac imaging,¹⁸ variability in interpretation of abdominal radiographs,¹⁹ and unnecessary surgery.^{20,21}

Increased reliance upon tests to establish a diagnosis is coupled with the observation that the skills required to perform an expert history and physical examination may be less emphasized^{22,23} despite evidence of their importance.²⁴ The plethora of laboratory tests and evaluation procedures, coupled with parent expectation for further testing, makes increased utilization of biochemical and diagnostic tests likely. Normal test results may not provide reassurance, but heighten anxiety that a rare or undiagnosed condition can yet to be found with the next round of testing.

Drive for Patient Satisfaction

Respect for parent/guardian satisfaction is important. Families have legitimate concerns and care plans should address those concerns. However, caregiver-driven care can overemphasize the concern of the adult over the safety of the child. Without objective standards for assessing health care quality in many areas, the “consumer grade” serves as a surrogate marker. A demanding unsatisfied parent expects to “find the problem” through multiple medical consultations, additional diagnostic studies, and even invasive procedures, which may not be medically indicated.

Acquiescing to parental demands is the preferred course for multiple reasons: 1) there is less pressure on hospital administration and staff when parents are satisfied; 2) physician’s are less anxious

about litigation for “missing something”; 3) there are financial incentives associated with increased testing and consultations; and 4) the belief that “you are never wrong if you do something.”

Physician skill, experience, and confidence are needed to make a reasoned, medically sound, and hopefully evidence-based judgment that further testing or interventions are not indicated and may be a source of unnecessary harm to a child.

Impact of Internet

The Internet allows caregivers to perform their own research, and create expectations of which tests and management interventions are indicated. This challenges the clinician to balance the child’s needs with parental demands. Social media can also be used by dissatisfied families to punish physicians or hospitals. It can also be used by the perpetrators of MSP to project public images of caring and concern in order to generate sympathy from the medical staff and the public at large. The reaction to what is disseminated on social media can be unpredictable, since the fundamental concept of MSP — that excessive or unnecessary medical or surgical interventions can harm a child — is complex and not intuitive. This can make dispelling misinformation difficult, and might result in harm to the reputations of medical personnel and their institutions.

Fractured Care

The child with real or perceived complex medical complaints is often directed to multiple hospital-based subspecialists. Communication among treating physicians has become less verbal, more electronic, and often unidirectional. Hospitalists have replaced the primary care physician in many institutions, potentially disrupting continuity of care and observation. In-hospital care conferences attended by multiple subspecialists are difficult to arrange. In complex cases, no one member of the treatment team may be in the position to question the need

or appropriateness for planned tests or procedures. Additionally, increased availability of subspecialists facilitates “doctor-shopping.”²⁵

It is often after MSP enters the differential diagnosis that questions arise regarding the appropriateness of prior medical care. Physicians understandably become defensive or feel victimized. Treating physicians may become angry and resentful with peers for suggesting they played a role in the child’s disease. We believe there are warning signs that might identify a child at risk for MSP, but it requires personal communication among treating physicians willing to offer critical assessment of the care plan.

CONCLUSIONS

MSP is a form of child abuse that presents along a continuum from mild to severe. For severe cases, in which the child is clearly being harmed by actions caused or instigated by adults, the appropriate response is to engage the child protection and legal systems. Such “text-book” cases carry a poor prognosis without removal of the child from the caregiver. Detailed management discussions are beyond the scope of this article, but are referenced.^{13,26-28}

The expanded concept of MSP provides a more hopeful approach. The requisite first step is recognition that physicians and the health care system can be part of the problem and can unintentionally serve as agents of harm to the child. Sometimes, medical treatments unknowingly reinforce harmful, covert acts committed by caregivers. In other cases, it is the physician who harms the child by performing unnecessary medical interventions in response to unreassured caregivers. Multiple authors have begun to highlight the role of the health care system in general and physicians in particular in these disorders.^{8,29-31}

Our observations about the complexities of the evolving health care system may resonate with other physicians who

worry about the potential harm caused by providing children with unnecessary or unjustified medical care. Reflecting on these factors may empower physicians to interrupt and possibly prevent some patterns of abuse. Appropriate actions include recognition of pathology, coordination of a medical team approach that refuses unnecessary interventions, and a primary focus on the medical needs and safety of the child patient rather than on adults. ■

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