

Medical Child Abuse: What Have We Learned in 40 Years?

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Abstract

Purpose of review The realization that caretakers could harm children by getting unnecessary and harmful or potentially harmful medical care began 40 years ago with the first paper on what Meadow called Munchausen by proxy. This article reviews the evolving understanding of this form of child abuse and discusses ongoing controversies including as follows: what to call it, whether it is rare or common, who gets the diagnosis, is there a profile of a perpetrator, is the motivation of the perpetrator important, and how treatable is the condition.

Recent findings Several recent policy guidelines are available detailing current recommendations for evaluation and treatment. Pediatricians tend to conceptualize this phenomenon in child abuse terms and refer to it as medical child abuse (MCA). Mental health professionals continue to use the deceptive behavior of the perpetrator as the organizing principle.

Summary Medical and mental health professionals are working together to develop treatment strategies. Clarity regarding the ongoing controversies suggests avenues for future research.

Introduction

Medical child abuse (MCA) is defined as a child receiving unnecessary and harmful or potentially harmful medical care at the instigation of a caretaker [1]. The term, MCA, joins a long line of descriptive labels beginning with what Meadow called “Munchausen syndrome by proxy [2].” Despite an awareness of this entity for

over 40 years, the medical community has yet to standardize the approach to identifying and treating this set of harmful behaviors affecting children. Yet, controversy remains regarding a number of questions. What makes it different from other forms of child maltreatment? What should we call it? Is it common or rare? Is it a

manifestation of child maltreatment or an adult mental illness? Is there a profile of a “Munchausen mother?” Does it matter what motivates her? And, most importantly, is MCA treatable? This review addresses where the field stands on these controversies and also offer suggestions for further research.

What makes it different?

We can attribute some of the confusion to Dr. Meadow. In his original paper, he introduced several of the contradictory threads [1]. He subtitled his paper, “The hinterland of child abuse,” suggesting it was not at all common. He clearly labeled it as a form of child abuse but near the end of the paper notes: “None can doubt that these two children were abused, but the acts of abuse were so different in quality, periodicity, and planning from the more usual non-accidental injury of childhood that I am uneasy about classifying these sad cases as variants of non-accidental injury.” With this statement, he gave the medical community permission to consider this type of child maltreatment different from all other forms. He was partly right about MCA being different in one important way—physicians are involved in children being mistreated. In other forms of child maltreatment, physicians can separate themselves and objectively evaluate what is happening to children. With this type of abuse, physicians and the medical community are involved, and initially unknowingly, the diagnoses, associated evaluations, and therapies may contribute to harm inflicted on these children.

What should we call it?

Physicians’ involvement in MCA cases leaves them uncomfortable when describing objectively what happened to the children. Physicians may be compelled to come up with descriptive terms that, in effect, absolve them from responsibility. They were lied to. This is true. Caretakers mislead physicians and compel medical personnel to recommend and execute potentially harmful medical treatment by exaggerating, fabricating, or inducing symptoms in their children [1]. Not only do some caretakers psychologically, sexually, or physically abuse their children, some also do things in the medical environment that put their children in harm’s way from inappropriate medical care. What should we call this? As medical providers coming to terms with our unwanted complicity, we may be tempted to focus on the prevarication rather than the harm to the child. On the other hand, in order to move past the feelings of having been lied to and instead focus on helping the children, we can simply call it medical child abuse.

How common is it?

Over the decades, the awareness of this form of child maltreatment has grown from unimaginable to being sensationalized through popular entertainment. Books, motion pictures, television programs, and even popular songs have all featured children harmed in this way. In the early days, we saw individual case reports, one more interesting than the next as we came to terms with the variety of ways the doctor/parent/patient relationship could be abrogated. By 1987,

Rosenberg pulled together 117 case reports and began to characterize the children being harmed and the caretakers who elicited the harmful care [3]. But she maintained it was “rare,” an assertion that continues to be made today. Researchers went on to collect series of cases of children with a specific illness such as polymicrobial sepsis [4], unexplained apnea [5], or seizures and pseudoseizures [6]. More recently, subspecialists have documented the multiple ways children seen in their clinics may be harmed as a warning to colleagues [7–9]. Case reports have been appearing in the literature from all around the world including Turkey [10], Saudi Arabia [11], and Japan [12]. Today there are well over a thousand cases reported.

But is it rare or common? The answer to this question depends on the definition used. A strict definition such as the one by McClure et al. in Great Britain leads to a conclusion that Munchausen syndrome by proxy (MSBP) is quite rare, occurring in just 0.5 children per 100,000 population per year [13], an estimate derived from accounts of physicians reporting children smothered or poisoned in Great Britain. More recently, Ferrara and colleagues evaluated 751 consecutive admissions to a children’s ward in Rome, Italy, and found 4 cases of MSBP for a rate of 0.53% or roughly one for every 190 admissions [14•]. In Seattle Children’s Hospital, we are asked to evaluate 40–50 children for possible medical child abuse each year. In 40 years, we have come a long way from thinking this form of child maltreatment is “extremely rare.”

Who gets the diagnosis?

The question of who carries the diagnosis is a bit more complicated. Consensus exists that MCA involves harming children. Most people would also agree that getting a physician to administer unnecessary care is “abnormal.” The confusion centers on where to put the emphasis. Pediatricians and other primary care providers tend to focus more on the abuse of the child while mental health professionals seem more interested in the parent. Recent guidelines make room for both approaches [15•, 16•, 17•, 18–20].

The names people choose for this behavior reflect their primary interests. Those using “medical child abuse” emphasize the similarities MCA has with other forms of child maltreatment. Authors using “pediatric condition falsification” or other similar designations focus on characteristics of (e.g., lying) and treatments for abusers.

Diagnosing the child

“Medical child abuse” clearly labels the behavior as abuse and states the medical connection explicitly. It makes no more claim to a medical diagnosis than does other forms of abuse. Physical or sexual abuse are not medical diagnoses of a specific illness as much as events in the life of the child which can have medical consequences. The same is true for medical abuse. As an event or series of events, it can be described as occurring on a continuum of severity from mild to moderate to severe. At a certain point along that continuum, as with other forms of child maltreatment, representatives of the community at large determine a need to intervene to protect the child from further harm. All forms of child maltreatment share this property. Mild forms of physical abuse such as spanking

are common while severe presentations such as abusive head trauma are much less common.

A mild presentation of MCA may involve an anxious mother who takes her child to the doctor on a weekly basis with few symptoms of illness. The child may undergo multiple exams, miss school, and might get unnecessary testing to “treat the parent.” The treatment for this type of abuse would seldom involve legal intervention nor perhaps even a report to social services but would require the medical treatment community to reorient the parent in a way to normalize the doctor/parent/patient relationship.

Continuing to focus on the child, a moderate presentation of MCA may involve a child whose parent lies about witnessing seizures resulting in the child being placed on antiepileptic medication. The unnecessary prescribed medication and other seizure precautions may have a significant but not life-threatening impact on the life of the child. In such a case, social services should be involved and a treatment plan would include close supervision of the family and discontinuation of potentially harmful medical treatment.

At the severe end of the MCA spectrum are the children whose lives are put at risk by medical treatments such as unnecessary surgeries, indwelling lines, and treatments with potentially life-threatening side effects such as the administration of intravenous immunoglobulin. A mother who smothers a child to death has committed murder. If the child lives, the crime is assault or attempted murder. If the child lives but is subjected to numerous invasive medical treatments as a result of the behavior of the parent, in addition to the assault, he or she has also been medically abused.

If a child has experienced unnecessary and harmful or potentially harmful medical care at the instigation of a caretaker, no matter where along the spectrum from mild to severe, medical providers need to intervene to bring the unnecessary medical care to a halt. In the process, as with other forms of child maltreatment, physicians as mandatory reporters provide information to child protection agencies who decide if the threshold for abuse has been superseded and when the child needs protection from his or her caretaker.

While they may speculate about the motivation of a parent, pediatricians and family practitioners have a primary responsibility to the children. They are the front line and must be ready to identify and treat the whole spectrum of MCA behaviors. They will likely see many more mild and moderate cases than the severe ones that end up in news accounts and in court. For providers, the rationale behind why a parent lied in order to ensure their child would be subjected to potentially harmful therapies is less of a priority compared to the need for providers to stop harmful medical treatments.

Diagnosing the perpetrator

Psychologists and psychiatrists, however, often begin their involvement further along in the treatment process when social services and courts are determining if parent perpetrators can be deemed safe caretakers for their children. They are motivated to evaluate the psychological makeup of the offending parent. For psychologists, terms like factitious disorder by proxy (FDP), pediatric condition falsification (PCF), caregiver-fabricated illness in a child (CFIC), or factitious disorder imposed on another (FDIOA) naturally direct them to focus on the adult perpetrator.

We base most of what we have learned about adults perpetrating MCA on published cases rather than population-based inquiry. Publication bias skews the findings in the direction of more severe presentations. Two recent studies using different methodologies came up with similar descriptions of perpetrators of moderate to severe abuse. Bass and Jones conducted in depth psychiatric assessments on 28 mothers referred (primarily from family court) for recommendations about management [21]. They found histories consistent with somatoform disorder (57%), fabricated symptoms in themselves (64%), and pathological lying (61%). The women had significant histories of childhood physical and sexual abuse. Yates and Bass conducted a systematic review of 796 published cases to look at perpetrator variables [22•]. They used the MCA definition (unnecessary and harmful or potentially harmful medical care at the instigation of a caretaker) and applied it retrospectively. The 796 perpetrators were overwhelmingly female (97.6%), mothers (96.6%), and married (75.8%). Fabricated symptoms in themselves were present in 30.9% of the histories. Thirty percent had a history of childhood maltreatment; mental illnesses such as depression, personality disorder, and substance/alcohol abuse were common. While findings like these do not confirm a specific psychiatric diagnosis, they do lead us to conclude that perpetrators of moderate to severe MCA had unfortunate childhoods and have a strong propensity to lie.

The standard for psychiatric diagnoses is the Diagnostic and Statistical Manual - Fifth Edition (DSM-V) [23]. The 2013 revision included an entry for factitious disorder imposed on another (FDIOA) as distinct from factitious disorder imposed on self (FDIOS). Regrettably, the definition of this disorder carries us far afield from defining MCA as a form of child abuse. The primary feature of FDIOA is the intentional deception involved in the falsification of signs and symptoms of illness in another. The perpetrator's motivation is the key factor. Though creators of this diagnosis moved away from "wanting to assume the sick role by proxy," they still were compelled to describe a particular motivation in the perpetrator. Note that a child victim is not required to make the diagnosis. In fact, FDIOP has been described with adults or animals as the focus of the deception [24]. It has even been invoked when only imaginary people or animals are lied about as in FDIOP over the Internet [25]. Forensic psychiatrists are sometimes asked by courts if the perpetrator of MCA meets criteria for FDIOP. While undoubtedly some do, it seems more important to ascertain if a child has been harmed and what must be done to stop the abuse.

With regard to the question—who gets the diagnosis?—we actually have come a long way. We do not need a psychological diagnosis in the caretaker to describe the effects of a parent's behavior as child abuse and treat it accordingly. We also have learned a lot about the background of parents who abuse their children medically and can even, in rare situations, give them a DSM-V diagnosis, but having a diagnosis in the parent adds little to the treatment for the child victim.

Is there a profile of a “Munchausen mother?”

Many have tried to assemble a profile of an MCA mother. Review articles continue to include lists of attributes, but more recently, there is invariably appended a warning that none of the listed characteristics is pathognomonic.

The recently published practice guidelines prepared for the American Professional Society on the Abuse of Children (APSAC) did away with the “profile section” altogether [15•].

While not addressing specifically the profile question, Petska and colleagues called attention to the difficulties using maternal behavior to diagnose MCA [26•]. They compared the behaviors of mothers of children with complex medical conditions to mothers of children being medically abused. Using case examples, they demonstrated considerable overlap in maternal responses and behaviors.

So much effort has been expended on constructing a profile of a perpetrator because physicians would want to identify the person who is going to lie to them before it happens as this may benefit the potential child victims and also spare the medical profession from the pain and shame involved in MCA. However, knowing if a person is lying or might lie in the future is not an easy task. The APSAC guidelines cited research that health care personnel “including mental health experts do no better than the general public in determining through an interview whether someone is lying [15•].”

Rather than listing characteristics of a potential perpetrator, a more useful strategy would be development of a screening instrument that would identify MCA as it is occurring. Several attempts have been made [27, 28•]. Mash and colleagues sought to ascertain risk factors distinguishing MCA from failure to thrive (FTT). They compared 17 documented cases of MCA where gastrointestinal symptoms predominated with 68 controls. They identified several risk factors which predicted MCA with 100% sensitivity and 96% specificity. Parents who reported more than five organ systems involved in their children’s illness, absence of a confirmed genetic disorder, more than five allergies (and unusual allergies), and refusal of service from a hospital-based nutritional team were significantly more likely to have MCA diagnosed.

Efforts like this focus on patterns of parental behavior that put children at risk for unnecessary care rather than personality characteristics of individual caretakers. Clinicians still need to appreciate that we cannot predict who will harm a child. Our job is to remain open to the possibility and, when we discover abuse, act to bring it to a halt.

Is the motivation of the perpetrator important?

The building consensus is that, as helpful as it might be to know why someone might perpetrate MCA, actually identifying a clear and consistent reason is difficult. The earliest reporters of MCA events postulated the mother must be psychotic to put their child at such risk [29]. For several decades after Meadow’s initial report, writers searched for mothers “wanting to assume the sick role by proxy.” In reality, parents seldom admitted to this motivation; instead, they maintained they were just following doctor’s orders. Some wanted to be the best mother they could be by getting the best medical care for their children. In discussing the motivation issue, the APSAC guidelines emphasize parents meeting their own needs ahead of those of their children. “Needs cited by those who have admitted to this behavior have included the need to receive care and attention; to be perceived as smart, caring, selfless, or in control; to manipulate and humiliate a powerful figure, to manipulate a spouse; or, for the excitement

of being in a medical setting [15•].” Needless to say, these representations of motivations could describe parents who medically abuse their children but might also apply to many mothers who do not.

We can all agree, however, that understanding why the perpetrator parent acted to cause the harm to her child is just as important in MCA as it is with other forms of child abuse. We need to know “why” to help provide for ongoing safety and to determine if the child will be safe in the home or if the perpetrator must be removed for the sake of the child and any siblings.

After 40 years, have we decided what constitutes treatment?

As is the case with other forms of child abuse, with MCA, the treatment involves as follows: Identifying abuse is taking place, stopping the abuse (the harmful medical care), providing for ongoing safety, reversing the harmful consequences of the abuse, and preserving the integrity of the family whenever possible [1]. As the severity of the abuse increases, more resources may be required. Mild abuse can often be managed in the physician’s office. In general, moderate abuse will likely involve child protective services and severe abuse, in addition, will also activate the legal system.

In reality, treatment of MCA varies widely from community to community. In some areas of the country, physicians remain largely unaware that parents can bring harm to their children in this manner. Social service agencies and police departments are unprepared to assess or intervene legally. In other locales, and particularly in some children’s hospitals, there is a concerted effort to identify and respond to MCA. Child protection teams in some hospitals routinely follow published protocols [15•, 20, 21, 30]. The general sequence of response includes the following: (1) suspicion of MCA, (2) extensive review of medical care received and parental behaviors observed based on medical records and collateral documentation, (3) getting consensus of the medical community that the treatment response must change dramatically, (4) enlisting the perpetrator and the patient’s family in rewriting the treatment contract, (5) stopping the harmful care and ameliorating the effects, (6) guaranteeing ongoing safety, and (7) getting psychological treatment for perpetrators. At any point along the treatment process, as needed, the involvement of child protection and legal services can be activated.

Understandably, most published accounts of treatment focus on situations where perpetrators are unwilling or unable to cooperate in rewriting the treatment contract to include only needed medical interventions. These situations might lead to removing the parent from the home, termination of parental rights, or even incarceration of the perpetrator. Incarceration is rare and occurs primarily when there is clear evidence of induction of illness, i.e., when the child is the victim of assault [31•].

Some institutions are including the response to MCA as a quality improvement issue. In Seattle Children’s Hospital, for example, the realization that children were receiving gastric tube placement in the absence of clearly documented inability to eat prompted a protocol requiring inpatient admission to observe feeding in a controlled environment (not just taking the mother’s word

for the child's inability to feed normally). This effort has resulted in significant reduction in gastric tube placement.

Other hospitals have recognized the utility of collaborative pediatric, child psychiatric inpatient or day hospital programs to treat medically ill children who have comorbid psychiatric illness or family dysfunction [32•]. These programs are able to evaluate a range of alleged symptoms and effect the modification of distorted belief systems around delivery of medical treatment. They have the advantage of being medically oriented but also constructed to meet the psychological needs of the entire family.

The answer to the treatment question is, yes, MCA is treatable if it is addressed as a manifestation of child abuse. Mild cases are easier to treat. Moderate to severe presentations can provide significant challenges, and in rare situations, successful treatment may even result in the perpetrator being incarcerated [31•].

Conclusion and areas for further research

This review of controversies surrounding MCA suggests some areas of study. For example, it would be useful to conduct population-based epidemiologically sound surveys to establish the extent of mild, moderate, and severe presentations. Before this can happen, we need clear definitions of what constitute each category and research establishing interrater reliability.

Surveys of basic knowledge of MCA in medical, social service, and law enforcement communities can address the variability of awareness in different settings. Establishing a baseline of awareness can lay the groundwork for future educational efforts.

Protocols such as the gastric tube example cited above can be implemented for a range of pediatric entities where real illnesses can be mimicked by parents leading to children receiving unnecessary care. A list of these illnesses is quite long but includes some difficult to diagnose conditions such as mitochondrial disease, chronic Lyme disease, postural orthostatic tachycardia syndrome, and chronic fatigue syndrome. Children truly suffering from these conditions need and deserve appropriate treatment. Those who do not can be crippled for life from inappropriate treatment. Developing protocols to distinguish between the two groups benefits everyone.

Compliance with Ethical Standards

Conflict of Interest

Thomas A. Roesler declares that he has no conflict of interest.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

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