

Munchausen-by-Proxy

Also known as Medical Child Abuse

The following information was extracted from a symposium talk by Sumit Parikh, MD and other experts. Additional comments were provided by Drs. Russell Saneto and Mark Tarnopolsky.

Munchausen-by-Proxy, also known as Medical Child Abuse (MCA), is a mental disorder in which a parent (usually the mother) abuses her child by creating or falsifying medical symptoms, or by seeking unnecessary medical care for the child, in order to gain attention and sympathy. The parent may exaggerate, misrepresent, or fabricate symptoms or test results, which can lead to the child undergoing numerous hospitalizations, invasive tests, needless therapies, and even surgeries. Some physicians who have a particular interest in unusual disorders may be eager to test and diagnose a child with complex, persistent, and confusing symptoms, often feeding the problem.

Physicians, especially pediatricians, are taught to listen to and trust parents, as a means of more quickly diagnosing a sick child. But the reality is that some parents do misrepresent information to their child's physicians. Sorting out whether there actually is an underlying disease, despite possible suspicions about the parent, can be a daunting task. There are no easy answers or solutions.

No provider enters a medical relationship suspecting MCA. There are certain "red flags" that physicians note when dealing with a difficult case that often raise suspicions. These include, but are not limited to, the following:

- No explanation for a persistent illness
- Symptoms/results don't fit the case; don't make sense
- Symptoms don't occur when witness is present; only the parent sees them
- Symptoms don't respond to appropriate and adequate treatments
- Numerous doctor visits or hospitalizations
- No medical documentation of alleged illnesses/symptoms
- Change in symptoms to another organ system when testing of one system is completed/negative
- Conflicting information from various medical sources
- Embellishing or over-exaggerating symptoms & test results
- Refusal to leave the child's bedside
- Symptoms improving in the hospital and returning at home
- Requests from the parent to not send results or consultation notes to the primary care pediatrician
- Multiple tests ordered by experts being normal
- Insistent requests to repeat minimally abnormal tests even if subsequent tests are normal
- Frequent attempts to contact "World Experts" to garner support for a diagnosis
- "Doctor shopping" especially in regards to a primary care pediatrician
- Being evaluated at multiple centers
- Experts stumped
- Parent enthusiastic about invasive testing

The last several bullet points in particular can cause trouble for the parents of children with mitochondrial disease. In an effort to get a diagnosis for their child, parents of patients with possible mitochondrial disease may undergo a “diagnostic odyssey.” They relentlessly pursue a diagnosis via the internet, checklists, and multiple doctors. They may see non-existent symptoms, request too many tests, visit too many doctors, embellish or exaggerate, and use medical labels/terms. While these parents may not actually be guilty of MCA, their actions and responses can make a physician suspicious, and bring the parents’ integrity into question.

Additionally, there is a concern about the overuse of a mitochondrial disease label by parents and physicians. Mito symptoms can overlap with other symptoms, and can be secondary to other medical/metabolic disorders. Mitochondrial disease can be an easy diagnosis for an MCA parent to reference.

Parents may assume that the first reaction of a physician is to report the parents to Child Protective Services. However, this is often not the case. Many facilities use a Child Advocacy Team approach. The team often includes physicians from several specialties, nurses, social workers and lawyers. The cases are evaluated in detail. These teams try very hard to be objective and not have an agenda going into the situation. If a concern of symptom over-reporting is raised, they may:

- Sit down and talk with the parents (may involve talking to each parent separately).
- Teach parents to accurately describe symptoms, and not over-report/embellish information.

When a physician suspects MCA, they will often first contact the primary care pediatrician to see if they have similar concerns and if they are aware of all of the testing/referrals that have been made with the child. If a concern exists regionally, a team meeting as described above is often pursued to decide whether it is necessary to notify child protection services.

Reporting suspected MCA is not always the simplest or best solution, but in some instances or hospital systems it may be the only option to get the parents’ attention and response to the doctor’s/team’s concerns. It is a difficult moral and ethical dilemma. While only a small percentage of reported cases actually turn out to be MCA, the accused “vocal minority” makes it seem that the problem is more common than it is. Any stress placed on the family is with the intent of the safety and protection of the child. Bearing in mind that there is a difference between suspicion and confirmation of MCA, it may be necessary to separate the child from the parent and monitor the child’s health after separation. The future of the child’s safety must be assured, and the whole family may be involved in the treatment.

In order to avoid a mistaken diagnosis of MCA, recommendations include the following:

- Give full & accurate disclosure of information
- Avoid exaggerations
- Keep an organized copy of all medical records and share them openly with providers

- Have a letter from the principal provider stating the diagnostic dilemma of the patient.

In conclusion, the goal of medicine is to diagnose, treat, and enable the patient to return to their best state of health. Again, no provider begins a clinic/hospital visit with MCA in mind. However, when “red flags” appear, providers are legally, morally and ethically obligated to involve child advocacy teams and/or report their concerns to the local agencies responsible for the protection of children (and adults). Uncommon diseases can present the provider uncertainty about the signs and symptoms within a clinical situation. Repeated unexplained situations compound the dilemma a provider faces. Both care providers and patients and their families need to be open and proactive in all phases of medical care. The topic of MCA is sensitive and filled with emotion on both sides. Developing a dialogue between families and providers may help reduce a false MCA diagnosis.

Disclaimer:

The above information is not considered to be official hospital policy. Each hospital has its own policy for dealing with suspected child abuse cases, and such policies may vary widely.