

## Summary - Complex Medical Needs and Medical Child Abuse Mary Beth Hollinger, RN, MSN

Hollinger's presentation will focus on utilizing safe and effective strategies to navigate the health care system for patients and family members with complex medical needs. Meeting the needs of adults or children with complex health needs is becoming increasingly difficult especially as accusations of Medical Child Abuse become more common. The goal of this discussion is to help families stay together through better understanding and improved communication with medical professionals.

For this presentation, the term **Medical Child Abuse (MCA)** is used as a global term to include Munchausen Syndrome By Proxy, factitious disorder, somatoform, and conversion disorder (slide 8).

The goals and objectives are threefold:

1. Increase understanding of the challenges that medical professionals and families face when caring for medically challenging, chronically ill children.
  2. Increase understanding of the factors that contribute to allegations of Munchausen Syndrome by Proxy (MSBP), Medical Child Abuse (MCA), somatoform, or factitious disorder.
  3. Learn strategies to help communicate instead of alienate, thus fostering better care.
- Objectives (slide 9):

1. Review challenges medical professionals and families face today which may impact the medically complex family and the care they receive.
2. Review relevant literature to note trends, including current medical school and law enforcement training.
3. Discuss common red flags for labels of MCA, Munchausen Syndrome, and MSBP and how families' voices can be heard, but not suspected.

**What is Mitochondrial Disease?** (slides 10-13) Mitochondrial disease can be described as failure of cells to make enough energy to power a body, creating a condition where the body's "batteries are low." When energy for the cells becomes critically low, a body begins to show various signs and symptoms of stress or failure. When the batteries of electronic devices fail, all the "apps" can be affected, translating to any number of body systems (apps) with dysfunction. What sets Mito apart from other diseases and creates confusion is the fact that symptoms can occur in any system, at any time, and with any degree of severity. Even within the same family carrying the very same genetic mutation and the same diagnosis, the symptoms may still vary significantly between affected family members. Adding to a complex presentation, symptoms in the same patient can vary from one day to the next, or even from minute to minute. In the past, Mito was diagnosed only in children, but adults are being diagnosed as well, entering the door with a very long, complex, and often perplexing medical history. The mode of inheritance can be varied as well, adding to the difficulty in pinning down a diagnosis. Mitochondrial disease is very complex.

### **Definitions** (slides 20-27)

- **Munchausen Syndrome By Proxy (MSBP)** is a diagnosis or allegation given to a parent who purposefully harms a child for external gain, such as a parent seeking and gaining attention from staff and family when a child is in the hospital. The child suffers from unnecessary medical procedures and treatments or direct injury by the perpetrator. The child's health improves when removed from the parent(s). A forced separation from a suspected offender is often used to confirm MSBP, relying heavily on the child's health improvement after separation. The perpetrator is considered to have a mental illness. Although an exceedingly rare condition, allegations of MSBP in the Mito community are not rare, pointing to the need for much better communication between parents and the medical community.
- **Munchausen Syndrome (MS)** is a type of factitious disorder, or mental illness, in which a person harms him or herself, due to a desire to be seen as ill or injured.
- **Somatoform Disorder** is a psychological disorder in which psychological stress is displayed as physical symptoms. Symptoms have no clear medical explanation, but rather supply either internal or external gains.
- **Medical Child Abuse (MCA):** Terminology has shifted over the past 10-15 years, which has increased the number of allegations against parents. MCA focuses on the victim, regardless of the intent, good or bad, of the parent. A form of child abuse, MCA is defined as a child who receives harmful or potentially harmful treatments at the instigation of the parents. MCA is also called overmedicalization and is the opposite of medical neglect. MCA is more inclusive, broader, and much easier to prove, with no need to assess if symptoms improve when separated from the parent(s).

**How does mitochondrial disease begin to look like Medical Child Abuse?** (Slide 29 & 30) Families, medical personal, and to some degree, child protective agencies interact, working for what is best for a child, yet bringing their own distinct personalities and perspectives to the table.

### **Physicians** (slide 31)

- Time constraints - too busy, limited time slots to see complex patients
- Insurance pressures - \$\$
- Science-driven knowledge base - evidence, research, patients need this knowledge
- Sees patient in the moment, which may not reflect the whole child
- Complex patients with a progressive disease
- Human emotions - frustration, anger, sadness
- Communication skills
- Mito knowledge base is often poor in general doctors
- Personality - understanding vs. arrogant

### **Hospitals** (slide 32)

- Complex, huge
- May feel disorganized
- Poor communication between doctors, often forcing parents to relay information. For example, the neurologist asks, "What did the GI doctor say?" instead of obtaining the records from the GI office.
- Problems magnified between multiple institutions
- Insurance pressures

### **Child/Patient/Family with Mito** (slide 34)

- Multiple medical problems - many systems, many doctors
- Variable symptoms & variable intensity of symptoms
- Some with strong knowledge base
- Many with rich Mito experience with self/child, which is extremely valuable
- Scared, angry, frustrated, exhausted, hostile, lonely
- Multiple family members may be affected which multiplies all the issues and pressures
- Search for Mito friendly doctors which can appear to be "doctor shopping"
- Helicopter Moms - new term played out in the media with negative connotation

### **Child Protective Agencies** (slide 35)

- Overworked, understaffed
- Do not understand Mito
- No review/hearing before a child is removed (guilty until proven innocent)
- Courts and CPS agencies take doctor's word over parent's word

The pressure from outside institutions, such as schools, professional programs, medical and law schools, social media, and nursing care, PT/OT, finances, and the media, impact doctors, families and CP agencies (slides 36-51).

**Medical schools** teach the definitions explained above as well as a perpetrator profile, most often describing a clever mother who "tricks" a trusting and unknowing doctor.

- primary caregiver (99% female/mother)
- educated, middle class, friendly with staff
- knowledgeable about medical conditions
- maybe a health care professional who also know how to advocate
- uses multiple medical caregivers & facilities
- demands specific treatments (IVs, medications, etc.)
- presents multiple symptoms which don't seem to fit known diseases
- unexplained sibling death
- child improves in the absence of the caregiver
- block proposals to stop treatment
- mitochondrial disease workup

For example, a parent enters the ER with critically ill child, knowing what has worked in the past, and immediately demands, "My child needs D5W, run at 1½ times maintenance!" The staff has not even examined the child, which can set up a difficult

situation. Another situation occurs when medical staff want to decrease or stop a certain treatment that parent feels has brought their child back from the brink or has helped their child live a more normal life. Fearful of a relapse, parents may block this treatment plan, even if the child may be ready to move on to this level of care. Parents know how hard recovering from a relapse can be for child with mitochondrial disease, creating feelings of fear and vulnerability.

### **Media and Law Enforcement**

- taught that Medical Child Abuse is the same as Child Abuse
- obtain extensive social history from all contacts as well as social media sites, seeking evidence about how you view your child. Does a balance of posts exist with both the ill child and the child doing normal activities? Private messages and private posts are examined. Posts will be compared with doctor's descriptions and written notes. Common themes of concern contain distortions, attention seeking, exposure of the child to public view when in the hospital or when ill, rather than a balanced view of the child. Poor attitudes to medical professionals and media and fund raising requests are also carefully examined.

**Media's** power should not be underemphasized - newspaper articles, books, and TV programs generally exaggerate and sensationalize the incidence of Medical Child Abuse

**Schools** - allegation can begin with schools.

- IEP's (Individual Educations Plans) and 504 plans, along with other medical needs, are costly to schools and can be ignored by the schools, creating tension.
- Need vs. Helicopter parent?

**PT/OT and Home Care** - Often parents best supporters!

- See the child's variability of symptoms over time and measure parameters which can be helpful to parents when parents are trying to seek help.
- Like teachers, spend a great deal of time with the child and can speak to family dynamics, rendering their "snap shot" of the child more like a long exposure, panoramic view.

### **Summary of Red Flags** (slide 52)

- social media
- G-tubes, ports and feeding tubes (always get a 2nd opinion!)
- Presentation that does not match presented history
- Multiples: specialists, hospitals, medicines
- IEP and 504 plans
- Poor communication between doctors
- Mothers - single, educated, medical field, strong advocate
- Making frequent or unnecessary demands, inflexible
- Fundraising

## **Medical Professionals' Role in Preventing False Accusations of Medical Child Abuse**

- Continue the quest for knowledge and research. The knowledge base regarding Mitochondrial Disease is still poor with few experts. Understand the variability of symptoms with mito. Mitochondrial patients will need to see many different medical specialists.
- Allegations of MCA almost always come from a conflict which then "sparks" the issue (slide 56).
- Listen and respect the experiences of the family (slides 57 - 58).
- Empathy - understand parents' fears. It takes time to fully explain situations to the point that the patient/family truly understand.
- Take the time to explain the plan to the point of *understanding*.
- Communicate more effectively with other doctors and health care professionals.

## **Preventing and Facing Allegations - A Plan of Action!**

Parents and patients DO have control!

1. **Retain a Lawyer** well versed in Child Protective cases when facing child removal (or danger of child removal) (slide 62). Do not sign anything without the lawyer's approval. The state will provide you with a lawyer if you cannot afford one.
2. **Gather Supports.** Ask for letters of support from trusted sources (slides 63 - 64), including family, teachers, coaches, doctors, home care nurses or therapists, schools, etc. Many facilities prevent employees from openly supporting an accused family until called to appear in court, so it becomes vital to reach out quickly. Insurance companies can be of help because they often require written documentation from the doctor in order to grant approval, stating why a test or procedure was medically necessary.
3. **Gather Medical Documentation**(slides 65-66)
  1. Past Medical History - obtain past medical records to document when, why and who ordered tests, procedures and medications, any results, and both doctor's and nurse's notes.
  2. Keep meticulous current medical and CPS contact documentation, including what is discussed, who is in attendance, plan if presented, and date and time.
4. **Play Nice!**(slides 67-68)
  - a. When parents are worried and stressed, emotions can turn to anger and hostility. Remember to choose words carefully, and to not swear nor yell.
  - b. Avoid hostility directed at staff!
  - c. Avoid unnecessary demands (medical or educational).
  - d. Do not constantly talk about the child or self in the "sick role," but also talk about the child's "normal" activities - what he or she did at school or with friends. Blogging can offer emotional support, but also balance posts with discussions about the positive things and normal activities.
  - e. Avoid being rigid with new treatment plans. Be open to new ideas for treatment. Choose battles carefully. Allow others to see your child struggle at times and then work together to find a solution to the problem. Get the professionals on your team - all wanting to do what is in best interests of child.
  - f. Be respectful to all and have patience with new staff.

**g.** Have a support person with you for doctor appointments and during hospital stays. Attend appointments as a medical team. In court, for example, when a mother attends an appointment and then tells the father what the doctor said, the father's decisions and point of view are considered tainted. But when that father listens directly to the doctor, he is viewed as having come to his own, independent decisions, which is a much stronger stand in a court of law.

### **Communication is key!** (slides 68-73)

- Report symptoms as honestly and accurately as possible, being very specific.
- Request a team meeting as soon as tensions begin to build.
- Prioritize problems and address one concern at a time. Do not expect that 12 complicated issues can be addressed in one 15 minute appointment. Schedule a second appointment or request a longer appointment.
- If "firing" multiple doctors, seek insight with a social worker, parent liaison or other third party for insight.
- Advocate - YES! Aggressive - NO! Parents know their child and adults know their bodies and need to advocate for the best care possible, even if it causes conflict. Understand your medical rights.
- Be mindful of all that is stated, posted or written! Talk with a trusted friend rather than venting on social media.
- When a caregiver has reached his/her emotional or physical limit, find someone to step in. Use stress reduction techniques.

### **Prevention** (slide 74)

- Work with the most knowledgeable medical team.
- Get a copy of medical records or use a communication log, noting all treatments, diagnosis, medications, etc.
- Force provider communication - Do not speak for doctors. Sign releases to encourage communication.
- Obtain all orders in writing and bring written orders with you to the ER.
- Obtain second opinions for all major procedures.
- Let others see your child sick.

False accusations of MCA can have a long lasting negative impact on families - separation, routines disrupted, children suffer setbacks. Parents distrust and/or avoid medical care, socially withdraw, and doubt their parenting skills, all which can impact the ongoing care of the child (slide 76).

**Summary** (slides 77-80) Everyone is under tremendous stress (patients, parents & health care providers). Personalities and communication styles clash, and a spark is ignited. Communication is the key. Support each other. Show compassion - do not just react.

When dealing with complex medical situations, it is often a good idea for health care professionals and families take a "time out" before acting, such as calling child protective agencies or filing a complaint against a doctor. Time often tames emotional

levels and can increase understanding. When the media gets involved, the situation escalate quickly as both sides tend to dig in their heels, unwilling to retract their position. Reassess the situation before reacting. These situations are not about placing blame and offer a chance to work on communication skills.

When accused, parents often say, "But I'm a good mother," but being a good parent is not a shield against allegations. Parents need to be proactive and continue to work on effective communication. Be mindful of what is said and let the child speak for himself/herself as much as possible. If parents and health care workers communicate, cases of false Medical Child Abuse accusations should decrease and parents can navigate the health care system with only the best interests of their children to worry about.