# The Rabbit Hole of Munchausen by Proxy: Knowledge is Power

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## DISCLOSURES

The speakers have no financial or other conflicts of interest to disclose.

*"Try this—I just bought a hundred shares."*

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## Outline

- Case Presentation
- History
- Definitions and Language Use
- Impacts on Pediatric Care
- Pediatric Assessment and Management
- Psychological and Psychiatric Sequelae
- Profiles of Perpetrator
- Profiles of Child/Adolescent
- Mental Health Treatment
- Q&A

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## HISTORY OF MSBP/MBP

- Baron Munchausen (Karl Friedrich Hieronymous von Munchausen)
- 18th century
- Cavalry captain with a Russian army
- Excellent story teller

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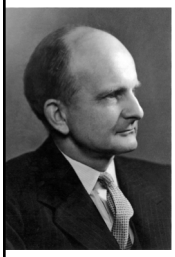
## HISTORY OF MSBP/MBP



1941--British neurologist (Asher) described Munchausen Syndrome

- Patients who:
  - Made up stories about their illnesses
  - Liked to be "sick" and in hospital
  - Hurt themselves to be hospitalized
- Goal: sympathy and attention

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## HISTORY OF MSBP/MBP

- 1975 C. Henry Kempe: Uncommon manifestations of the battered child syndrome
  - Human bites
  - Intentional poisoning
  - Withholding water causing hypernatremia
- Roy Meadow, Pediatric Nephrologist first coined this term (1977)
  - "The Hinterland of Child Abuse"
    - Reported two cases in which parents made their children ill in order to obtain unnecessary medical care
      - Hypernatremia from maternal induced salt intoxication in a 14 month-old boy
      - Hematuria and recurrent UTIs in a 6 year-old girl
    - "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."

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## IDENTIFICATION OF TRENDS

- Rosenberg reviewed 117 cases of MSBP to address whether there were trends which may help physicians:
  - Better characterize the syndrome
  - Understand the etiology
  - Aid in the diagnosis
  - Possibly prevent and treat MSBP

Rosenberg 1987

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## Rosenberg Criteria

- Illness in a child which is simulated (faked) and/or produced by a parent or someone who is *in loco parentis; and*
- Presentation of the child for medical assessment and care, usually persistently, often resulting in multiple medical procedures; and
- Denial of knowledge by the perpetrator as to the etiology of the child's illness; and
- Acute symptoms and signs of the child abate when the child is separated from perpetrator

*No mention of motivation of perpetrator
*Who are we diagnosing?

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## Munchausen Syndrome By Proxy/Munchausen By Proxy

- Never a formal ICD or DSM diagnosis
- Historically used in cases in where person diagnosed with FDIA (factitious disorder imposed on another) engages in falsifying a condition/illness in another
  - Victims of all ages
  - Animals
  - Intentional deception
  - Persists in the absence of external rewards

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## Munchausen Syndrome By Proxy/Munchausen By Proxy

**What's wrong with this terminology?**

- This form of child abuse is NOT a syndrome
- Encapsulates psychopathology of abuse and abuse of victim
- Who are we diagnosing?
- Who makes the diagnosis?
- Not useful with regard to evaluation and treatment
- Not useful to protect children


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## MEDICAL CHILD ABUSE

"Child receiving unnecessary and harmful or potentially harmful medical care at the instigation of the caretaker."

Unnecessary to identify the **intentions or motivation** of the caregiver to make this diagnosis

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## How is medical child abuse like other forms of child abuse?

- Presents in many different ways
- Severity ranges from mild to severe
- It is not an illness, but can result in illness
- Perpetrators of the abuse can have many different motivations
- Perpetrators often have experienced difficulties in their own childhood
- False history→lying

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## How is it different?

**The medical care system is the instrument of the abuse.**

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## MEDICAL CHILD ABUSE

- Exaggerators and Fabricators:
  - Reported symptoms did not happen
  - Specimen tampering
- Inducers:
  - Intentional suffocation
  - Poisoning
- Spectrum
  - Exaggerating signs of illness for FMLA
  - "Ground glass in formula to cause bloody emesis"

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**Table 1. Types of Falsification.**

| Type of Falsification | Examples |
|---|---|
| Producing false information | Providing false information about current symptoms and limitations in the child; the child's medical or other history; and prior findings, recommendations, or treatments. Examples include saying a child has seizures when there are none and providing altered diagnostic medical documentation. |
| Withholding information | Failing to provide pertinent information that would help to explain the child's presentation. An example is not informing the clinician that the child is vomiting due to poison that was just administered. |
| Exaggeration | Providing clinical information that is based on a genuine symptom of limitation, but is enhanced in order for the child to be seen as more severely ill or impaired than is true. An example is reporting more frequent or treatment-resistant seizures than truly exist. |
| Simulation | Altering biological specimens or medical test procedures to yield abnormal results. Examples include presenting contaminated urine samples, placing one's own blood in child's stool sample, or interfering with a diagnostic test to produce abnormal results. |
| Neglect | Withholding medications, nutrition, or treatments to exacerbate symptoms. An example is failing to administer seizure medication as prescribed. |
| Induction | Directly creating symptoms or impairments. Examples include poisoning, suffocating, starving, and infecting. |
| Coaching | Manipulating another to answer questions by clinicians and others in a manner that substantiates the false claims of the abuser. Adults and very young victims can be effectively coached to (knowingly or unknowingly) collaborate with the abuser and corroborate the false claims of the abuser. Examples are spouses who repeat what the abuser has told them to be true as if it were fact or a child victim who is *reminded* to report specific symptoms to the clinician. |

## Types of UNNECESSARY* care received:

- Medical Provider visits
  - ED
  - Hospitalizations
- Psychiatric evaluations
- Medications
- Noninvasive Tests
- Minimally Invasive Tests
- Invasive Tests
- Minor Surgery
- Major Surgery


*Caregiver history commonly dictates care provided to pediatric patients.

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## RISK and HARM


- Direct harm from induction of illness
  - Permanent physical harm
  - Death
- Receipt of unnecessary and invasive evaluations/interventions
  - Iatrogenic medical conditions
  - Permanent physical harm
  - Death
- Kept out of school
- Miss social/developmental opportunities
- Misperception of being excessively ill/disabled

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## WARNING SIGNS

- Reported symptoms/behaviors incongruent with observations
- Discrepancy between abuser's reports of the child's medical history and medical record
- Extensive medical assessments do not identify medical explanation for child's reported problems
- Unexplained worsening of symptoms or new symptoms correlating with abuser's visitation
- Laboratory findings do not make medical sense, clinically impossible/implausible, or identify chemicals, medications, or contaminants that should not be present
- Symptoms resolve/improve when child is separated and protected from influence and control of abuser
- Other individuals in home or caregiver have or had unusual or unexplained illnesses or conditions
- Animals in home have unusual or unexplained illnesses or conditions—possibly similar to the child's presentation (e.g., seizure disorder)
- Conditions/illnesses significantly improve or disappear in one child and then appear in another
  - Example: when another child born, the new child begins to have similar or other unexplained symptoms
- Caregiver reluctant to provide medical records, claims past records not available, refuses to allow medical providers to discuss care with previous medical providers
- Demands for testing and studies not clinically warranted
- Care sought at several institutions
- Abuser reports that other parent is not involved, does not want to be involved, and is not reachable

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## PRESENTING SIGNS

- Bleeding
- Seizures
- Central nervous system depression
- Apnea
  - BRUE (formerly known as “ALTE”)
- Diarrhea
- Vomiting
- Fever
- Rash

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**TABLE 1** Symptoms and Signs by System Involved

Allergic: food allergy, rash
Dermatologic: erythema, vesiculations from burns, lacerations, scratches, puncture wounds, eczema
Developmental: learning disabilities, attention-deficit/ hyperactivity disorders, neuromotor dysfunctions, pervasive developmental delay, psychosis
Endocrine: polydipsia, polyuria, hypoglycemia, diabetes, glycosuria
Gastrointestinal: abdominal pain, anorexia, diarrhea, dehydration, esophageal burns, vomiting, weight loss, bowel obstruction, gut dyskinesias, bleeding including hematemesis and hematochezia or melena, bleeding from nasogastric tube, bleeding from ileostomy, disorders leading to a need for parenteral nutrition
Hematologic: bleeding, easy bruising, anemia
Infection: fever, leukopenia, sepsis, septic arthritis, osteomyelitis; failure to resolve infections with antibiotics to which bacteria are susceptible; onset of new infection while the child is receiving antibiotics to which the bacteria are susceptible; unusual bacteria from the site of infection or infection with multiple simultaneous organisms of low pathogenicity
Metabolic: mitochondrial disorders, without positive testing
Neurologic: seizures, headaches, weakness, disorder of consciousness
Oncologic: leukemia, other cancers
Ophthalmic: recurrent hemorrhagic conjunctivitis, keratitis, eyelid swelling, unequal pupils, nystagmus, periorbital cellulitis
Orthopedic: limping
Otic: otorrhea, recurrent infections
Renal: hematuria, proteinuria, renal calculi, bacteriuria, renal insufficiency, hypertension, nocturia, hypernatremia, hyponatremia, hypokalemia, pyuria, renal failure
Respiratory: presentation with an acute life-threatening event, apnea including sleep apnea, cystic fibrosis, bleeding from the upper respiratory tract, intractable asthma, hemoptysis, cyanosis, hypoxia
Rheumatologic: arthritis, arthralgia, morning stiffness

*Flaherty et al. AAP Clinical Report, 2013*

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## VARIETY OF PRESENTATIONS

- 8 month-old with FTT
  - Mother withholding formula in the hospital, but reporting baby ate.
- 4 y/o with mastoiditis, hospitalized for 8 weeks with bacteremia
  - MOC putting spit and feces in IV
- 15 y/o boy referred for debilitating neurological condition
  - Mother and child stated his legs were paralyzed every morning when he awoke.
    - Would improve as the day went on and was able to participate in bicycle racing.
    - Condition not present during summer.
  - Numerous neuro evaluations: LPs, EMGs, imaging
- 4 year-old girl brought in for repeated evaluations by mother due to suspected sexual abuse.
- Diet severely restricted due to “multiple food allergies.”

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## OVERLAP WITH OTHER FORMS OF ABUSE/NEGLECT

- Prescribed medication intentionally not given with claims that illness persisted.*
  - Asthma
  - Infections
- Unusual hematologic disorder suspected by medical providers after mother repeatedly and secretly bruises her child with a hammer.

*Medical Child Abuse may occur in the setting of a true illness.

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## IT IS ALL IN THE DETAILS…

- "Vomited overnight X 3"—not good enough
- Who reported that they witnessed the child with symptoms or impaired functioning
  - At the time of onset?
- Names of past clinicians who made diagnoses of the child
- Exactly what education or clinical instruction has been provided to the caregiver and that caregiver's ability to understand the education or clinical instructions using the teach-back method
- Episodes of nonadherence or threatening/attempting to leave the hospital against medical advice
- Requests by the caregiver for specific assessments or interventions
- Episodes of unexplained equipment malfunctions or suspected tampering
- Other concerning behaviors.

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## Clinicians Caring for a Suspected Victim

- Gather all medical records from past and present treating professionals
- Make contact and regularly communicate with both parents (all caregivers)
  - Provide caregivers with ongoing education and feedback about findings and recommendations.
  - Ask all caregivers to repeat back the information provided to them
  - Carefully document all education and other discussions with the caregivers.
- Collateral data from school personnel and other independent observers with regular access to child
- Review suspected abuser's online social media activity
- Carefully devise evaluation and rehabilitation plans that systematically and objectively challenge claims made by suspected abuser or victim.
- **Meet with the other clinicians involved in care to compare data and coordinate plans.**
- **Alert other clinicians (verbally and in the chart) about poor reliability of symptom reports or behavior of suspected abuser, importance of relying upon objective data, proceed conservatively, and need to document well**
- Minimize school accommodations, prescriptions, and invasive testing and treatments.
- While devising evaluation and rehabilitation plans, consultation with an expert is recommended
- Report reasonable suspicion of child abuse and neglect to the proper authorities

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## KEY POINTS

- Think that it might be happening--missed MCA due to not considering the diagnosis
- Practice based upon evidence-based care
- Detailed history and then compare to what is seen medically
- Documentation crucial
- Toxicology
  - Medications present
  - Insulin/C-peptide
  - Other substances?
- Caregivers may start out exaggerating symptoms and then, over time, begin inducing illness
- Trust but verify
- Can be difficult for PCPs to make diagnosis
- Subspecialists
- Avoid fragmented care
  - Gatekeeper
  - Minimize numbers of physicians; especially at PCP office
- COMMUNICATION = SAFETY NET
- MDT MEETINGS (Pre-/Post CPS involvement)

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## Diagnosing Medical Child Abuse: Child Protection Team

- Record Review

**Table 3. Chronological Table of Patient Health Care.**

| Date | Patient/ BIB | Health Care Contact | Subjective Caregiver Reports | Objective Findings | Diagnosis/ Recommendations | Other |
|---|---|---|---|---|---|---|
| 9/17/17 | Alexis<br><br>BIB mom | Dr. Lee, Emergency Medicine, Memorial Hospital ER | Hx of constipation since birth. Followed by GI who advised her to go to ER. Reports 6 days of projectile emesis and food refusal. | NAD. Labs & vitals WNL. Exam benign except for mild diaper rash. KUB WNL. Eagerly took 4 oz. of formula from bottle. No emesis in ER. | *Diaper rash* – Advised mom to keep baby's skin clean and dry. Hydrocortisone cream prescribed. *AGE suspected* – Provided IVF and return if sxs persist. | Mom accurately summarized all guidance and agreed to plan. However, she did not remember the name of GI doctor. |

- Communication is key

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## Additional Diagnostic Strategies

- Search for evidence of illness fabrication/induction
  - Covert video surveillance
    - Privacy issues
    - Liability
- Separation of the child from the suspected perpetrator
  - Hospitalization
  - Alternate placement

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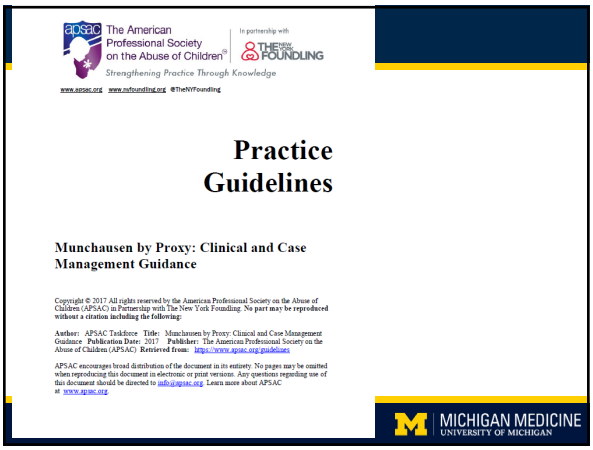


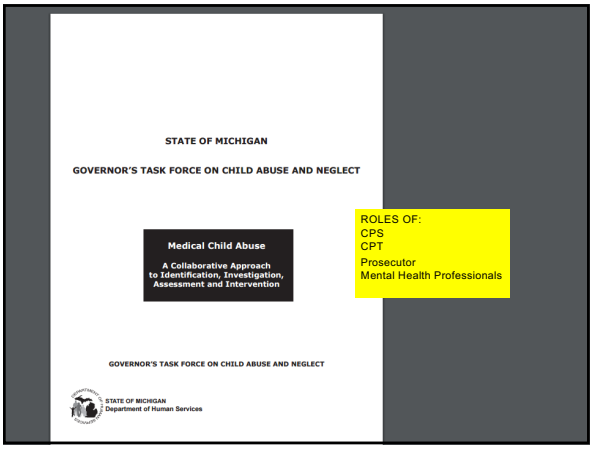


## COMMON GOAL: CHILD SAFETY

- PURPOSE
  - Coordination and collaboration of several disciplines and agencies in identifying and responding to cases of suspected Medical Child Abuse.
    - Assists professionals in understanding their roles.
  - Organized chronologically, using the time frame common to the detection and management of these cases.

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## OLDER VICTIMS and COLLUSION

- Older victims may collude with the perpetrator by confirming information provided by their caregiver about their medical histories
  - Fear of contradicting caregiver
  - Caregiver's persuasion over time
  - Believe they are ill with a mysterious disorder that providers cannot figure out
  - Aware that the caregiver's history is inaccurate, but fear caregiver's revenge or that no one will believe him/her.
- Reporting of symptoms directly from the victim
  - Consider induction of illness
  - "Blended case"
  - Other

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## Psychopathology of Perpetrators

- Often perpetrated by mother (96% in a sample of 796)
- Elusive
  - Requires detailed, painstaking enquiry and multidisciplinary involvement
- Chronic somatization and/or coexisting personality disorder (75%)
  - Mental illness may also be concealed from others including victim
- Most cases, caregiver records requested to determine:
  - Mental health disorder exists and if treatable
  - Whether reunification possible
  - Mental health, medical, social work, school and forensic records, interview all caregivers, past trauma, history of pathologic lying (pseudologia fantastica)

References: Bass 2011, Bools 1994, Sanders 2002, Yates 2017

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## Assessment of Perpetrator

**Assessment of the alleged perpetrator: preparation**

(a) Medical and nursing records of the child's mother:
  (i) hospital
  (ii) primary care (handwritten and typed).

(b) Medical and nursing records of all involved children.

(c) Social work records/reports/case conferences.

(d) Police records, videos.

(e) Legal documents:
  (i) statement of mother and father
  (ii) report of child's guardian.

(f) Interview with mother and father.

(g) Interview grandparents.

(h) Telephone interview with GP, social workers, paediatrician and guardian.

(i) Multidisciplinary case conference (ideal).

References: Bass 2011

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## Psychopathology of Perpetrators

- Demographics
  - Age 27.6 to 31.3 years (21-48)
  - 43% to 76% married
  - Variable involvement in healthcare (14 to 46%)
  - 54% unemployed and 25% were on long term disability benefit
- Trauma History
  - 85% experienced a loss or separation from a parent prior to age 11
    - Only 2 without loss of a parent via death, separation, incarceration
    - 33% in foster care
  - 30-54% exposed to severe abuse or childhood maltreatment
- Medication Use
  - 67% with asthma had inhalers (6 of 9) with 1 with factitious asthma on prednisolone
  - 3 receiving anticonvulsants, 3 with opiates for pain, 1 with diuretic for unclear reasons, 2 with diabetic care (1 with metformin and 1 with insulin)
  - Only 3 on antidepressant treatment

References: Bass 2011, Gray 1996, Adshead 2005, Yates 2017

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## Psychopathology of Perpetrators

- Medical History
  - 96% of mothers had extensive medical notes and problems
    - Care often chaotic with frequent changing of PCP
  - Despite high utilization, very little confirmed illness (15% with confirmed disease)
  - Most common diagnoses: epilepsy, asthma, diabetes
    - 3 of 5 did not have confirmation of epilepsy and other 2 with histories of early childhood seizure
    - 32% with NEE (Conversion Disorder)
    - 9 were diagnosed with asthma but not had disease confirmed by PFTs and 1 had an established record of factitious disease
      - All women receiving treatment for asthma also had a history of Conversion Disorder
      - Association of asthma, hyperventilation, NEE, dissociation
    - High rate of pseudocyesis (false pregnancy, 5 of 28)
  - High rate of obstetric complications (24%)

References: Bass 2011, Yates 2017

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## Psychopathology of Perpetrators

- Psychosocial and Forensic Information
  - 36% with forensic history: 6 with shoplifting, 2 for arson, 2 for police harassment
  - 61% referred to CAP services
  - Common: **disruptive behavior**, self harm, anxiety, depression, school refusal, eating disorder, encopresis, trauma/sexual abuse
  - Most had contact with adult psychiatric services
    - 21% admitted to psychiatric hospitals with half being involuntarily admitted
    - 71% received outpatient treatment
    - N=28, 54% self harm, 50% mood disorder, 75% personality disorder
      - Antisocial, borderline, histrionic, anxious/dependent
    - N=796, 31% factitious disorder on self, 19% personality disorder,14% depression
    - High rate of poor follow up
  - N=28, 57% with somatization (mean duration 16.1 years, 7-27, SD 6.1)
    - High utilization of neurologic, gastroenterological, obstetric and gynecologic
    - High utilization of emergency services and significant accidents
    - 64% with factitious illness
  - Only 10% with substance use

References: Bass 2011, Yates 2017

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## Psychopathology of Perpetrators

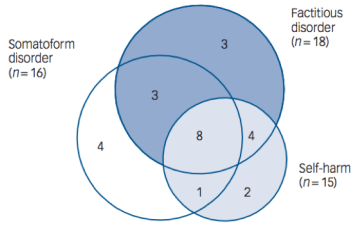


**Fig. 1** Association between factitious disorder, somatoform disorder and self-harm in the 28 participants.

References: Bass 2011

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## Psychopathology of Perpetrators

- Pathologic Lying
  - 61% with documented history, often starts in childhood or adolescence
  - Enduring personality trait or characteristic
  - At times related to stressful life events
  - Lies: compulsive, habitual, self-aggrandizing, chronic
  - Need
    - Desire to be cared for or to avoid vulnerability
    - Attention
    - Perceived as smart, caring, selfless, or in control
    - Manipulate and humiliate a powerful figure or spouse
    - Previous abuse or trauma ("victim to offender cycle")
    - Excitement of being in a medical setting
    - Control
    - Substance use


- PCP often unhelpful as information often disjointed, inaccurate or limited
- Children of parents with somatization have increased risk of medical utilization and abnormal health beliefs
- When mother confronted, maltreatment escalates with attempts to "prove" how ill victim is

References: Bass 2011, Craig 2002, Marshall 2007, Feldman 1997, Andersen 2018

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"I felt sick to my stomach that a mother could need attention so badly that she could injure her children."

"Usually the abuser grew up feeling unloved and unwanted, usually the victim of some form of abuse themselves"

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## Risk Factors in Perpetrators

**Risk factors identified in our sample of mothers for creating abnormal illness behaviour in children**

Remote risk

(a) Loss or separation from parent.
(b) Abuse/neglect.
(c) Foster care.
(d) History of lying in adolescence.
(e) History of self-harm.

Recent risk

(a) Current somatoform disorder.
(b) Current factitious disorder.
(c) In receipt of disability living allowance.
(d) Child missing school.
(e) Frequent visits to doctors (symptoms unexplained).

AND . . .

(a) Frequent moves of house (and GP).
(b) Parent requests disability living allowance for child.

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## Non-Perpetrating Caregivers

- Passive role
- Rarely attend hospital visits, clinic visits or cares
  - Understanding of care by perpetrator with minimal contact with providers
  - Providers rarely reach out to non-perpetrators
- Described as "traditional breadwinners" leaving "care and nurturing" to mothers
- Frequent travel needs or work that requires extended time away from home
- Oblivious to partner's abuse and specific details of child's apparent illness
- Strong doubt and denial, often getting enmeshed in perpetrators narrative and distrusting providers
- Can become facilitators of abuse by funding cares, facilitating transportation

References: Anderson 2018, Morrell 2012

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## Non-Perpetrating Caregivers

- Clear absence of fathers
  - Emotionally absent
  - Rarely attended medical visits
- Despite living together, evidence of serious marital problems
  - Provides insight into potential maternal intentions
    - "This could be a sick attempt to get attention from the children's absent fathers as well"
- Typically, when child sick parents come together to support child
  - In these families, mothers may find child's illness as a reprieve from existing marital conflict
    - Repeatedly trying to re-engage spouse into family life
  - Strong negative view of fathers
    - Accountability
    - Ignorance
  - Yet…
    - Often explained away father's lack of awareness
    - Absolution of non-perpetrating parent

References: Anderson 2018, Morrell 2012

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## Implications for Care Providers

- Be aware of potential medical child abuse particularly in parents with chronic somatization or factitious illness
- In youth with chronic somatization, increased health utilization, or abnormal health beliefs assess parental behaviors and psychopathology
- Gather collateral!
- Listen to your internal sense of concern or "when things just don't add up"
- Importance of care coordination and communication
- Need for high suspicion in parents who have a history of lying or misrepresentation of information


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## Clinical Pearls

- Often present as loving, caring and strong advocates
- Often "passive-aggressive"
- Suggest clinical disease in a variety of ways
  - "Our OP Neurologist is really concerned about seizure and asked us to tell you about getting a lumbar puncture or MRI… I'm really not sure what is going on but Dr. Smith is concerned, what do you think?"
- Hostile to some, pleasant and sweet talking to others
- Very aware of care dynamics and push boundaries/limits in a manipulative way to get what they want out of care, but then quickly becoming agreeable to ensure relationship with care providers not fractured
- Fabrication through misrepresentation of timeline, embellishing of symptoms, misrepresenting testing or information from others
  - Also fabrication by omission or partial disclosures
- Often overly agreeable and then quickly refuses aspects of care

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## Clinical Pearls

- Splitting providers
  - Be very careful of the caregiver who "butters you up" with compliments
  - "Thank you so much for looking into this, you are the first doctor to really care about my daughter"
- Frequently change providers or ask for discharge when not getting what they want
- Generally well spoken and couch requests and behaviors in societal norms
  - "I don't know what is going on, I'm just scared and want what's best for my son"
  - "I know my daughter well and that does not work for her"
  - "No one believes us and then they find something wrong, she is in pain and you are making her suffer"

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## Profiles of the Victims

- 75% under age of 5
- 64% were female
- Generally only one child in a sibship was a victim
- 71% had fabrication of illness and almost 46% with induction of illness (23% with both)
- 61% had received a neurologic diagnosis (seizure, ataxia, ADHD, anoxic episodes) with 9 of 17 mothers having neurologic symptoms themselves
  - 2 children in wheelchairs
- Referrals: 28% social services, 18% pediatrics, 18% school, 18% adult mental health services, 7% from family and 4% from CAP, 4% health visitor, 4% PCP and 4% self-referral

References: Bass 2011, Andersen 2018

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## Profiles of the Victims

**Adopt identity of being "sick"**

- Dependent personality
- Reinforcement from mother, family, school and health system
- Engrained in world view and response to physiologic and emotional distress
- Emotionally immature
- Medically savvy with significant medical language
- Significant habituation of illness response/somatization, aligning with perpetrator for a variety of reasons
- Requesting care in anticipation of "becoming sick"
- Risk avoidance and social isolation
- Increasing valuation of sick role and even engagement in traditionally pro-social advocacy groups
- Maintain positive view of mother and maintains similar worldview as mother (can vary over time)
- Often corroborates or is co-opted into deception and fabrication of illness either implicitly or explicitly (rare)
  - Folie a deux (shared psychotic disorder), can also occur between the perpetrator and healthcare providers
  - Often the perpetrator is well aware of their actions and their intentions, usually with malintent
  - Youth may truly believe they are ill
- View individuals who confront victim about fallacy of presentation as "evil", "unhelpful"
- Dissociative, poor insight, limited capacity to cope with distress, alexythymic
- May not have discrete psychiatric illness, if do often disruptive behavior disorders, anxiety or mood disorders

References: Shapiro 2011, Bass 2014, Tatu 2018

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## Profiles of the Victims

- Referrals: 28% social services, 18% pediatrics, 18% school, 18% adult mental health services, 7% from family and 4% from CAP, 4% health visitor, 4% PCP and 4% self-referral
- Ailments are commonly fabricated or induced apnea, seizures, bloody stools, emesis, rashes, dehydration, fevers, lethargy and cardiopulmonary arrest
- Greater in tertiary care centers
  - 1/3 of 155 infants who suffered repeated ALTE
- Mortality rates up to 10%

References: Andersen 2018, Feldman 2004, Truman 2002

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## Screening

- Multi-site study at Cincinnati Children's, NYU, Wake Forest
  - Goal: Screening for early identification of medical child abuse
  - Items chosen based on published characteristics of medical child abuse
    - Caregiver
    - Patient
    - Illness information
  - Each item in instrument scored with 1 point if positive
  - Tested by reviewing hospital charts from child protective services from confirmed medical child abuse patients
    - Compared results with charts of children with admissions for apnea, emesis, diarrhea, seizures not diagnosed with medical child abuse
  - 19 cases and 389 controls for analysis
  - Initial 46 questions, determined 26 items showed statistically significant difference between case and control patients
    - An instrument of 15 items maximized area under the curve in the receiver operating characteristic curve
    - Score of 4 or greater had a sensitivity of 94.7% and specificity of 95.6% ($p<0.05$) in detecting medical child abuse

References: Greiner 2013

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## Screening

TABLE 2 MCA Screening Instrument (15-Item)

| MCA Screening Items | OR | 95% CI | P |
|---|---|---|---|
| Caregiver has features of Munchausen syndrome (multiple diagnoses, surgeries, and hospitalizations, with no specific diagnosis) | 46 | 9.9–211 | <.0001 |
| Caregiver had received counseling/psychiatric care | 8.9 | 2.4–27.9 | <.0001 |
| Caregiver has personal history of child abuse | 72 | 7.2–738 | <.0001 |
| Caregiver leaves hospital against medical advice or insists on transfer | 18 | 3.7–87.5 | <.0001 |
| History of cyanosis | 4.8 | 1.9–12.4 | .0497 |
| Care at >1 hospital in 6 mo | 3.5 | 1.2–12.8 | .0176 |
| Consults with ≥1 subspecialist | 8.8 | 2.9–27.2 | <.0001 |
| Illness abates when patient out of care of primary caretaker | 89 | 16.4–485 | <.0001 |
| >1 episode of apnea postdischarge from nursery | 4.5 | 1.8–11.5 | .0007 |
| Bruising or trauma to face/neck | 73 | 7.2–738 | <.0001 |
| Prescription/request for apnea monitor | 9.4 | 3.5–25.2 | <.0001 |
| Chronic diarrhea with or without vomiting >2 wk | 4.7 | 1.2–17.7 | .0135 |
| Chronic vomiting/diarrhea without definite diagnosis | 10.1 | 3.4–29.0 | <.0001 |
| Erratic drug levels | 10.8 | 1.0–124 | .0181 |
| Toxic drug levels on >1 occasion | 46 | 3.9–528 | <.0001 |

References: Greiner 2013

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## Care Dynamics

- Frequent disbelief/denial from family and healthcare providers
- Perpetrators may see children as "objects" to meet their needs
  - Concerned more about hospital staff perception than child's well being
  - Enjoy hospital environment, feedback as "exemplary caring mother"
  - Providers sense of failure and desire to "save" child, appease distressed mother
  - Clinicians and staff can become avoidant, callous, hostile or apathetic
  - Influenced by societal views of the mothers (under detected)
- Increased risk of child becoming future perpetrator

References: Anderson 2018, Fulton 2000, Schreier 2004

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## Online Perceptions

- 356 posts from 348 members explored and coded online posts via open-thought discussion on internet forum for viewers of televised show about medical child abuse
  - Qualitative analysis to develop contextual understanding, adopt interpretive stance and understand processes through interactions
- Information gathered:
  - Social perceptions about the non-perpetrating partners
  - Phenomenon of medical child abuse
  - Resistance faced by those who attempt to report it

References: Anderson 2018

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## Online Perceptions

Diagnostic difficulties
- 37 self reported cases of medical child abuse
- Most made multiple attempts to contact social services, police and dismissed
  - *"… my mother-in-law railroaded the whole session, sprouting some amazing lies and cover-ups"*
- Seek aid through online support
- Support previous findings of diagnostic difficulties
  - *"The perpetrator is too convincing. She has fooled every kind of expert you can imagine."*

Social perceptions
- Term "Munchausen by proxy" minimizes impact on victim
  - "Excuse" for the behavior as focus should move toward the victim
    - *"…heinous form of child abuse…not something that you have…something that you do!"*
- Female perpetrators perceived more negatively than males
- Society can exhibit extreme aversive reactions to medical child abuse
  - *"They should just be sterilized and removed from society so they can't abuse their children"*
- Victims reported mothers successfully maintained image of caring parent
  - *"She is a master manipulator… She had the doctors wrapped around her little finger."*
- Resistance towards investigating
  - *"I would like to know HOW you can prove that a mother has this disorder."*
  - *"I have tried everything and no doctor or professional believes me."*

References: Anderson 2018

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## Online Perceptions

**Perpetrator justice**

- Most felt that a prison sentence was too lenient
- Many comments about forcibly preventing perpetrator from having any more children through court-ordered hysterectomy
- Small group against "inhumane" punishments yet still advocated for disproportionate punishment compared to male offenders of abuse
- Several comments about death penalty in cases of severe or fatal medical child abuse

**Causation**

- Perpetrators are "inherently evil"
- Small number believed there is heritable component

**Perception as "creeps" and "monster-like creatures"**

- Dehumanization - societal coping and understanding

References: Anderson 2018

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## Mental Health Treatment

- Early Awareness and Identification
- Screening and Clinical Suspicion
- Obtain Collaterals
- Document, Document, Document!
- Education of Care Team and other Non-perpetrating family
- Environmental Supports and Removal from Perpetrating Caregiver

**Multidisciplinary Team**

- Psychiatry
- Psychology
- Social Work
- Nursing
- Pediatric Hospitalist and Subspecialists
- PCP
- Child Protection Services
- Child Protection Team
- Legal
- Risk Management
- Ethics
- Security
- Child Life
- Spiritual Care
- Rehabilitative Services
- Pharmacy

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## Mental Health Treatment

**Psychotherapy**

- Patient
  - Trauma-informed
  - Cognitive Behavioral Therapy
  - Biofeedback
  - DBT
- Mother
  - Psychodynamic
  - Interpersonal
  - DBT
  - Trauma-informed
  - CBT
- Other Family
  - Psychoeducation
  - Trauma-informed
  - Family Therapy
- Marital counseling


References: Kozlowska 2012

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## Mental Health Treatment


**Goals**
- Understand family dynamics, psychological factors, who is involved in induction of symptoms and understand the function of the symptoms in the family system

**Potential outcomes**
- Reduction or disappearance of symptoms, return to functionality/schooling, improved parenting behavior

**Rehabilitation**
- Focus on functionality and not limitations
- Utilize underlying motivations that align with healthy treatment

**Psychiatric care**
- Care as usual, no specific interventions routinely used
- Gather collateral and communicate collaboratively
- Be judicious with medication use and avoid polypharmacy
- Avoid invasive interventions, invasive diagnostics, splitting, fueling over pathologizing symptoms
- Report or reach out to local authorities when suspicion (does not always lead to report but raises alarms and monitoring)

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## Case Presentation

Hospital Course:
- Transferred to Hospital C for further care
- Laboratory evaluation, Head CT, MRI/MRA all normal
- Events were NEE, confirmed by EEG (captured)
  - Mother instructed not to place fingers in patient's mouth or attempt to insert oral airway during NEE, instructions repeated as mother performing activity repeatedly during stay despite directions otherwise
  - NEE more common in AM, especially upon getting out of bed, bathing, and breakfast
- Subjective weakness, sensory deficits not consistent with neurological etiology
- Presentation consistent with Somatic Symptom and Related Disorder
  - Concerns about maternal influence on symptom presentation
- Only physical disease: Developed viral URI (+rhinovirus-enterovirus; Day 3)
  - CXR and UA negative
  - Last fever Day 3, RPAN negative Day 10

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## Case Presentation

**Consultations:**
- Psychiatry Child Adolescent
- Psychology PED
- Neurology PED
- Dietitian
- Social Work
- Child Protection Team-SW
- Physical Medicine and Rehab PED
- Physical Therapy
- Occupational Therapy
- Speech and Language Pathology
- Bedside Music & Art Therapy

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## Case Presentation

- Persistent constipation & history of feeding difficulties:
  - Extensive work-up negative
  - First gastric emptying scan suggestive of gastroparesis (borderline)
  - Subsequent upper GI shows normal anatomy and emptying time
  - Celiac testing negative
  - Received milk of molasses enemas without issue
  - On NJ but tolerating PO. OT/SLP evaluated and cleared for swallowing
    - Mother tampering with cares, selective with cares, refusing medical instructions
- Transferred to PM&R Service for one week rehabilitation
  - Inconsistent findings
  - Strengths in areas that would not be expected if she had a neurological injury (as mom was concerned about) and weaknesses in areas typically seen with malingering (TOMM delayed recall = 9; PPVT SS = 30)
- Medical Symptom Validity Test (MSVT) to assess her effort and memory
  - Suggestive of poor effort and invalid performances
  - "Strongly indicative of knowing the correct response but choosing the wrong responses intentionally."

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## Case Presentation

- Inconsistent care and providers
  - Care fragmented (7+ institutions), disjointed, communication by word of mouth
- Polypharmacy, Invasive Intervention, Potential for Iatrogenic Injury
  - Extensive testing with frequent repeating of studies at maternal urging
- Maternal and provider frustration
  - Mother partially accepting of diagnostic information and cares
  - Maternal care-seeking behaviors
  - Splitting of providers
  - Poor care coordination and communication
- Collateral from other providers
  - Maternal information not consistent with documentation and collateral
  - Mother fired OP PCP on Day 6
  - Alternate PCP concerned about misinformation and maternal influence on symptoms
- Not accepting of diagnoses, conceptualization, cares
  - Asking for discharge to home to pursue other providers
  - Mom attempted to schedule invasive surgical interventions at another national academic institution under false pretenses
- CPS report being filed 2 days prior to discharge

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## Case Presentation

**In rehabilitative therapies:**

- Performance extremely variable depending on patient mood, who present, and type of activity
- Fairly consistent when doing things she enjoyed, with no deficits and improved fine motor control, louder speaking voice and appropriate cognition

**At discharge:**

- Stand-by assist for all mobility
- Get up with furniture assist from laying down to wheelchair
- Ambulate with walker for short distances
- Wheelchair provided due to inconsistent performance and fall risk
- ADL performance variable, with stand-by-assist to max assist
- Max assist for bathing especially with lower extremities, hair and back
- Mother interfering with PT, OT, SLP involvement often refusing patient partake in cares, bathing patient, mobilizing patient against medical advice, refusing oral nutrition

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## Case Presentation

**Recommendations:**

- Establish PCP with close, regular follow up and coordination of care
- Mental health follow up scheduled for psychiatric care and psychotherapy
  - ROI to coordinate cares with OP mental health provider
  - ROI for school counselor for re-entry into school and coordination
- Follow up with PM&R, PT, OT, SLP, Neuropsychology
- Refeeding plan:
  - Promote 2 different foods per meal, at least 3 bites of each food
  - 3 meals per day
  - Gradual increase in volume and variety of foods
  - Goal of removal of NG/NJ
  - Not to get a gastrostomy tube under any circumstance at this time

**Result:** Patient removed from home and mother lost maternal rights, patient received comprehensive care in a group home and returned to full baseline functioning with no ongoing medical concerns after 6 months

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# Questions?

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