Munchausen Syndrome
by Proxy

Pediatric Condition Falsification, Factitious Disorder
by Proxy, Child Abuse in the Medical Setting, Medical Child Abuse

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Objectives

At the end of this presentation, the learner will be able to:
- Recognize a range of symptoms that may be seen in cases of medical child abuse
- Summarize at least two challenges in making a medical child abuse diagnosis
- Review American Professional Society on the Abuse of Children (APSAC) practice guidelines for MBP

Disclosure

I have no financial relationships with any commercial interests.
TV series based on extreme case of Munchausen Syndrome by Proxy

The Act: Trailer (Official) A Hulu Original

The Name

1786 Rudolf Raspe published "The Surprising Adventures of Baron Munchausen"
Based on his "imaginative tales"
Tales were about his travels
1977 Roy Meadow described two cases of pediatric patients with illnesses caused by their mothers
- A mother put her own blood in the urine of her baby
- A mother fed her toddler excessive amounts of salt
Meadow coined the phrase, "MSBP"

Recent/Current Names

Pediatric Falsification Syndrome (PCF)
Caregiver Fabricated Illness in a Child (CFIC)
Medical Child Abuse (MCA)
Factitious Disorder Imposed on Another (FDIA, a DSM-5 diagnosis)
Statistics

Incidence is estimated between 0.5 - 2/100,000
More specifically, in children under 16 the range has been estimated to be about 0.4/100,000
In children under 2 the estimate is 2/100,000
Most children are under age 5 years
Average age at diagnosis is about 14 months - 2.7 years
Time it takes to make the diagnosis is 15 months - 5 years
35-50% of siblings have been abused prior to identification of the index case

Who Are the Perpetrators?

93% are mothers or female caretakers
85% have training or a relative with training in health care or day care
This may change with things like WebMD that allows anyone to become somewhat medically savvy

Spectrum of “Disease”

Hyper-vigilant parent/vulnerable child
Exaggeration of symptoms
Withholding treatment or nutrition
Mild fabrication of symptoms
“Evidence Tampering”/more significant fabrication of symptoms
Severe symptom induction
Coaching/manipulating the child
Why/How

Psychological needs of the caregiver take precedence over the needs/well-being of the child
- Caregiver need to receive care/attention
- Caregiver need to be perceived as smart, caring, selfless, “in control”
- Caregiver need to manipulate or control a powerful figure
- Caregiver need to manipulate a spouse/significant other

Some caregivers who do this also induce symptoms in themselves and/or have their own history of being a victim.

Types of Symptoms

Neurologic - abnormal movements, seizures, altered mental status, paralysis
Respiratory - “BRUE,” apnea, breathing difficulties, coughing up blood
GI - vomiting, diarrhea, feeding problems, reflux, blood in emesis or stool, need for G-tubes, colostomy, enteral feedings
Metabolic/Endocrine - abnormal electrolytes, often sodium or glucose
Eye Problems
Past

Presentation

Child presents with a history of symptoms that were observed by the parent, but not seen by medical providers
Symptoms are plausible and difficult to disprove
Often the child started out with an underlying condition (e.g. GERD)
Usual evaluation and treatment does not produce results that satisfy the caretaker
The child continues to present for evaluation of the same, increased or new symptoms
Medical Evaluation
Generally normal or positive for benign condition
Parent requests more tests
May initially seem satisfied with medical evaluation
Child returns with same, more exaggerated or different symptoms
Caretaker insists that the providers are missing something when the evaluation continues to be normal
Parent requests (demands through pressuring providers) more extensive evaluation
Medical providers get pressured into more tests, more treatments, more procedures, often surgeries

Medical Intervention
Parent/child continue to present with symptoms that are usually not seen by medical staff
Child may be hospitalized to more carefully evaluate symptoms
Medical staff may think this will "rule out" the possibility that the parent is causing the symptoms
BUT as many as 70% of "perpetrators" perform acts while the child is in the hospital

How Do They Do It - Some Examples
Smothering
Poisoning with toxins, medications, other substances (e.g. salt)
Adding blood to body fluids/stools
Inserting or forced ingestion of foreign bodies
Injecting local matter, dirt or other "infectious substances" into catheters, wounds
Applying toxic substances to eyes or skin
When to Consider the Diagnosis

Signs and symptoms observed by health care providers are different from caregiver’s description and/or symptoms only seen by the “caregiver of concern”

Medical evaluation does not reveal a source for the child’s symptoms

Laboratory or other studies that do not make sense - examples - a central line infection caused by a bacteria only found in soil, glucose or sodium values not seen in medical conditions

Child returns to medical attention frequently with similar escalating symptoms in spite of medical evaluations that are not able to treat or resolve the symptoms

In a hospitalized child, symptoms return or escalate at time of planned discharge

Discrepancies between caregiver’s report of other medical evaluations and the actual reports by other providers

Case One

A 2-year-old girl, CT

At age 9 weeks presented to the PED with history of fever at home and shaking episode - eyes rolled back, brief shaking

Seen in the Pediatric Emergency Department (PED) and was admitted. During that admission (48 hour “rule out sepsis” type admission) the mother’s friend told a nurse on the unit that her mother was making her sick. Social Worker was consulted. Mother and infant were watched very carefully but no other red flags at that time

Family History: An older brother was said to have had a complex medical problem (cared for at another hospital) as a baby

CT - cont’d

6 months later, “no show” for neurology appointment

One month later an EEG was done and normal

5 additional PED visits for rash, crying, abdominal pain, blood in stool

2 Dermatology visits for rash

2 Peds GI visits for constipation

One Dermatology “no show”
CT - 2017
4/17 Dermatology no show
5/17 Canceled Peds GI
5/17 Neurology no show 6 days later presented to PED with history of seizure; Neurology consulted gave Diastat for home use
5/23/18 Seizure at home - mother called
5/24/18 Seizure admit
5/25/18 Discharge and readmit for perioral cyanosis and lethargy
6/19/18 EEG showed right sided slowing
6/25, 6/26, 6/28 History of seizure at home - mother called to report

CT- 2017 cont’d
7/11/18 Seizure, MRI done and normal, Klonopin added
7/14 Seizure, Keppra added
7/16 PED for seizure, Keppra increased
7/18 Klonopin changed to Ativan during flu like illness, more Diastat provided
7/19 - 7/20 Cyanosis after seizure, led to admission
7/24 PED, cyanosis/lmp spell initially at PCP’s office (began in the parking lot, low HR, pallor by the time she got into the office) - admitted

When To Be Suspicious: Child Risk Factors
Child is 5 or under at the time of onset of symptoms
Frequent contact with the health care system
Symptoms are only witnessed by the mother/caretaker
Symptoms are vague, confusing, multiple
Symptoms not relieved by usual treatment
There is a sibling with complex medical problems or a deceased sibling
Father is distant/not too involved
Child deteriorates when discharge is planned
When To Be Suspicious: Parent Risk Factors

Appears caring, concerned, comfortable in the medical setting; makes friends with medical staff and other families in the hospital setting

Consistently pushes for more tests, procedures, hospitalizations

Has a higher than average amount of "medical savvy"

Seems to view and describe the child as the sum of his/her medical record

Becomes hostile/aggressive when challenged

Brings the child to multiple medical settings for second opinions

Making the Diagnosis

It's HARD!!!

Requires a detailed review of the medical records (all available records)

Short cuts such as looking at only discharge summaries is not sufficient

All providers must communicate with one another as parent will often misrepresent evaluations

Requires partnership between health care staff and Child Protective Services

CT - Hospital Admission

Placed in Long Term Monitoring room with portable video camera as part of a neurology evaluation for possible seizure disorder

7/25 - Monitor goes off twice - Patient sitting up and crying when RN gets into the room

7/26 - Mother in bathroom with patient, calls for help, nurse finds patient on the floor, pale, hypoxic and bradycardic when she puts her on the monitors

Improved with O2
A Delicate Balance

Need enough information to know if the child is at risk

The child may be at risk for harm while the medical staff try to get this information

Requires hypervigilance on the part of medical staff

Requires extensive documentation

CT - the final chapter

Techs viewing the video (not in real time) from 7/25 see disturbing events

Twice, about 15-20 minutes apart, when the mother is in the room with her daughter

First, the camera is moved so only the patient’s legs are seen

A blanket at the end of the bed is pulled up toward the head

Next a muffled cry is heard along with seeing the patient kicking, seems to be trying to get up

Then the cry gets very loud

Patient sitting up and crying when RN gets into the room

CT

There is a second similar episode minutes later, also seen on the video

The video events are reported to medical staff, a CPS report is made

Complications include the concern of whether the video is enough to be sure the mother has hurt her child

Questions include what to do next as far as allowing the mother to have access to the child, law enforcement involvement, allowing the investigative team access to the video (involves legal department)

The decision was made to remove the mother from the Children’s Hospital

Patient (and siblings) were placed with a relative, no more spells have occurred
A 29-year-old woman pleaded guilty on Wednesday to strangling an 18-month-old.
The District attorney’s office says that Jane Doe had admitted back in July to intentionally suffocating the child, causing a temporary loss of consciousness. There was no information given on the child’s current status or Jane Doe’s relation to it.

Thoughts?
When should providers have become concerned?
What happens if the call to CPS is made too soon?
How do you balance getting enough information for CPS to be able to remove the child with keeping the child safe?
Where do we draw the line between overly concerned parent and MSBP?

AAP Recommendations
Start with these 3 questions:
- Are the history, signs and symptoms of disease credible?
- Is the child receiving harmful or potentially harmful medical care?
- If so, who is instigating the evaluation and treatment?
AAP Recommendations

Review ALL the records
Make a chronological summary of all medical contacts
Look for:
  - Use of multiple medical facilities
  - Excessive and/or inappropriate pattern of utilization including procedures, medications, tests, surgeries
  - Pattern of missed appointments or leaving AMA
  - Misrepresenting opinions/diagnoses by other medical providers

AAP and APSAC Recommendations

Get all the key providers in the room at the same time to review concerns
Include nursing and others professionals involved
Include professionals who care for the child in the home
Contact outside facilities/providers to get their information directly from them - do not rely on information provided by the caretaker/family
Include school/day care staff
Often getting everyone together allows a real view of the big picture
Avoid aggressive testing, procedures, treatments while the medical “investigation” is going on
Alert all clinicians of the concern

Documentation

Should include who provided the history of symptoms the child has
Who was present with the child at the time symptoms occurred
What interventions took place
Any concerning behaviors on the part of caregiver or child
Any requests by caregiver for specific, extensive, unusual or excessive medical assessments, testing or treatment
Treatment recommendations that have been provided to the caregiver (preferably in writing and signed by both the provider and the caregiver with copies to each)
Any episodes of equipment malfunction or suspected tampering with equipment
Any communication with other professionals involved/relevant to the case
Making the CPS Report

Important to include the concern about MSBP in the report
In Monroe (and other) counties this will make the case a high priority
In Monroe County this means it will go to the Impact Team (CPS and Law Enforcement co-investigate)
Once the report is made it is usually necessary for the medical team to work closely with CPS
They may require more documentation than usual to be able to keep the child (and siblings) safe

AAP Recommendations

It is often beyond the ability of the medical staff to “diagnose” the parent
Focus on how the situation is affecting the child
Remember that the possible ways this can present seems to only be limited by the creativity of the caretaker and her/his willingness to place the child at risk, including harming the child

Case Two

13-month-old girl admitted with:
Loss of developmental milestones
Self-injurious behavior
Weight loss
Recurrent otitis externa
Corneal abrasions
Symptoms initially got worse in the hospital
Case Two - Services Involved

Neurology
Ped ID
ENT
Ophthalmology
Genetics
Developmental Pediatrics
Toxicology
Child Abuse Team

Case Two

Discharge Diagnosis: Sensory Processing Disorder
Returned a week later - readmitted
Corneal abrasions much worse
Concerning behaviors on the part of the mother and her boyfriend
Considered covert video surveillance (Patient placed in Long Term Monitoring room but never monitored)
Child Abuse Team reconsulted
CPS involved
Patient discharged to a foster home

Case Two

Mother was contacted by someone on Facebook
Woman who had a similar thing happen to her daughter
She was dating the same man at the time
The man’s mother worked in an ophthalmology office
This got better when they broke up
The ophthalmologist remembered her and that her case was the only other one like it he had seen
Since discharge she has continued to improve although her long term vision prognosis is not good
Case Two
Is this case different from the "usual profile"?
How does this affect how the medical team manages it?

Covert Video Surveillance
Privacy issue
Legal issues
Technical issues
Safety issues
Estimated to make the diagnosis in 50% of cases
Estimated to diagnose a medical problem in 10% of cases

Covert Video Surveillance
In case two, the mother and her boyfriend actually thought they were being video-recorded
The child stopped "getting worse" when they were moved into that room
Separation
Also can serve to make the diagnosis
Requires true, safe separation
Hard for CPS to make this happen
Hard to maintain it
Safety of other children in the home must be considered

Long Term - Medical Sequelae
Blindness
Brain injury
Death-Mortality is 8-10%, but as high as 30% in cases of poisoning
GI effects (remnants of G-tube, altered gut function, fundal plication)
Hearing loss
Injury to arms/legs
Removal of organs
Scarring

Long Term - Psychosocial
In one study 1/3 of children were returned home
Another 1/3 were still exposed to the offending caregiver
1/3 were placed away from the offending caregiver
Estimated that if the child returns, the rate of further abuse is 40%
In one study, 25% of siblings had died and 60% of siblings had similar illnesses
Psychological injury and becoming an adult with fabricated illness or a parent who causes this in their child is common
Summary

MSBP is a complex medical, psycho-social disorder

More common than we think

May begin with a medical condition that “morphs” into MSBP

Medical providers should ask these questions when considering the diagnosis:
- Are the history, signs and symptoms credible?
- Is the child receiving unnecessary evaluation or treatment that may be harmful?
- If so, who is instigating the medical evaluation and treatment?

It often takes communication and cooperation of the medical team to get to the point of making a CPS report.

It requires communication and cooperation between the medical team and the CPS investigative team (may include law enforcement) to have any chance of providing a safe environment for the child.