

## Vulnerable Child Syndrome or Medical Child Abuse? A Medical Provider's Guide

Suzanne P. Starling, MD  
Clinical Professor of Pediatrics  
University of California San Diego  
Medical Director, Chadwick Center for Children & Families  
Rady Children's Hospital San Diego



## Case Presentation

- 21 month old girl with repeated presentations for medical care
  - 3 inpatient admissions
  - 20 ED visits
  - 25 calls to pediatrician's office
  - At least once a month visits to PCP
- Same or similar symptoms reported each time – cough with posttussive emesis, leading to choking with reported cyanosis
- Episodes reported by mother unwitnessed by medical personnel or other relatives

## Case Presentation

- Mother very anxious
- Poor social supports
- Mom's father died when she was 10
- Other children in household without serious health problems
- Child had RSV bronchiolitis with apnea at age of 2 months

## Vulnerable Child Syndrome

## Definition

- Coined in 1964 by Green and Solnit-describes a physically healthy child who is viewed by a parent as being at greater than actual risk for behavioral, physical, and developmental diseases
- The parent's altered perception usually follows a serious illness, hospitalization or life-threatening event
- VCS occurs when a child's physician and family have discordant perceptions of the child's health

## Prevalence

- In 1995 community prevalence estimated at 10%
- No new prevalence data are available, but estimate would be much higher
  - More medically fragile children
  - More NICU graduates
  - More genetic diagnoses

### Red flags for the Pediatrician

- Frequent calls or urgent-care visits
- Excessive parental concern over minor medical problems
- Care-seeking from multiple sources
- Parent body language and tone of voice are very nervous

### Other Manifestations

- Parents exhibit anxiety when separating from child
- Separation anxiety leads to sleep disorders for both child and parent
- Parent delays start of school for child
- Parent can't set limits on child
  - Permissive
  - Excessive limits

### Child Vulnerability Scale

- In general my child seems less healthy than other children the same age
- I often think about calling the doctor about my child
- When something is going around my child usually catches it
- My child seems to have more accidents and injuries than other children
- I often have to keep my child indoors for health reasons
- I am concerned that my child doesn't look as healthy as he should

- My child doesn't seem to have as much energy as other children the same age
- I am concerned about the circles under my child's eyes
- I often check on my child at night to make sure he is all right
- I sometimes worry my child will die
- I feel anxious about leaving my child with a babysitter or at daycare
- I am sometimes unsure of my ability to care for my child as well as I should
- I feel guilty when I have to punish my child

### Maternal Risk Factors

- Miscarriages
- Infertility
- Maternal illness during pregnancy
- Maternal tendency toward somatization and OCD
- Maternal loss of a child of a similar age

### Child Risk Factors

- Prematurity and low birth weight
- Hospitalization as a young infant
  - Even minor illness like jaundice
- Feeding problems early in infancy
  - physician changes formula
- Positive screening tests
  - In sickle cell screening, many parent confuse trait with disease
  - PKU false positives
  - Cardiac murmurs

### Familial Risk factors

- Parental anxiety and depression
- Parental low self esteem
- Parental loss of a close family member as a child
- Parental loss of close friend or family member as an adult
- Lack of social supports

### What is NOT associated with VCS?

- Socioeconomic status
- Education of parent
- Sex of the child

### Vulnerable Child Syndrome vs. Parental Overprotection

- VCS is related to more medical visits
  - Stems from medical issues in child or parent
  - Can result in children with behavioral issues such as defiance and noncompliance
- Parental overprotection is not related to excessive medical visits
  - Stems from a psychiatric issue with the parent, often related to their own upbringing
  - Can result in anxiety disorders in the child, impaired social relationships, and dysthymia

### VCS Manifestations after Infancy

- Hospitalization of an older child may lead to VCS
  - Minor head trauma
  - Asthma
  - Gastroenteritis
- Children often are kept home from school inappropriately and restricted in their activities

### Case Presentation

- A five month old female diagnosed with a seizure disorder was admitted with 5<sup>th</sup> episode of apnea and cyanosis
- Apnea and cyanosis have never been witnessed by hospital personnel, despite multiple hospitalizations and ER visits
- Extensive previous workups have never revealed underlying medical cause

### Case Presentation

- Mother was witnessed holding her hand over the lower half of her daughter's face
- Hospital personnel concerns for mother inappropriately holding pacifier in child's mouth vs. suffocating her

## Case Presentation

- Child moved to monitoring room
  - no episodes captured by covert video surveillance (CVS)
- Child Protective Services notified that medical child abuse was possible
- Continued CPS monitoring recommended
- Child died one month later

## Case Presentation

- 1½ years later, mother's new baby presents to hospital with apnea, cyanosis, possible seizure
- Symptoms never observed by hospital personnel
- Extensive workup did not reveal underlying medical condition

## Case Presentation

- Mother is not anxious during the baby's medical procedures
- Mother states that she's "worried that the baby has the same symptoms as the child who died", but displays no worried affect
- Mother is diagnosed with pseudoseizures and has been hospitalized several times in the past few months

Is this VCS?

## Medical Child Abuse

(formerly Munchausen Syndrome by Proxy or MSBP)

## Medical Child Abuse

Definition: A child experiencing unnecessary and harmful or potentially harmful medical care at the instigation of a caretaker

Medical Child Abuse: Beyond Munchausen Syndrome by Proxy, Thomas A. Roesler & Carole Jenny, 2009, American Academy of Pediatrics Press ISBN: 978-1-58110-136-2

## Advantages of using the term Medical Child Abuse

- It's a pediatric diagnosis- affirms behavior as type of child abuse
- Motivation of perpetrator is just as important as it is for any other type of child abuse
- Easy to invoke the existing child protection system
- Easier to explain to lay people than MSBP

## Reviewed 115 cases referred for MCA

- 75.7% determined to be cases of MCA
- 26% of children never had an illness documented
- 74% received care excessive medical care

### Types of unnecessary care received

- Unnecessary medical visits- 81
- Unnecessary psych evaluations- 33
- Unnecessary medications- 74
- Unnecessary invasive tests- 46
- Unnecessary minor surgery- 33
- Unnecessary major surgery- 21

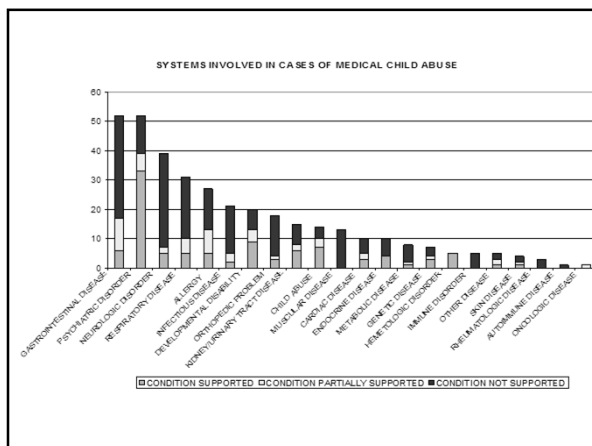
Medical Child Abuse: Beyond Munchausen Syndrome by Proxy, Thomas A. Roesler & Carole Jenny, 2009, American Academy of Pediatrics Press ISBN: 978-1-56110-136-2

## Type of MCA

- Exaggerated symptoms 89.7%
- Fabricated illness 73.6%
- Fabricated test results 8.0%
- Induced illness in the child 26.4%

## Symptoms at Presentation

Apnea  
Feeding difficulty  
Diarrhea  
Seizures  
Bleeding  
Cyanosis  
Hypoglycemia  
Behavior problems (ADHD)  
Asthma  
Allergy  
Fever  
Pain



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

- It 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

### What about the lying?

- People lie to their doctors about lots of things
  - Drug seeking behavior
  - Malingering
  - Food intake
- Perpetrators of all forms of child abuse lie
- Pediatricians are such nice people

### How is medical child abuse different from other abuse?

The medical care system is the instrument of the abuse

### Management of MCA presenting in the office setting

- Develop a medical plan for a child and contract with a parent to comply with the plan
- Report the family for medical neglect if the parent is unable to comply with the plan
- Have a meeting with CPS to discuss your concerns over a particular case
- Consult with a child abuse pediatrics specialist

### MCA Treatment Options

- Counseling from primary care physician
- Referral of parent for meds/psychotherapy
- Involve outside agencies to monitor care
- Involve third party payers in limiting care
- Treatment in partial hospital setting
- Admit to inpatient facility to monitor health status and limit care
- Report to child protective services
- Exclude parents from hospital
- Remove child from parents' care
- Terminate parental rights
- Prosecute parents in criminal justice system

### What is NOT Medical Child Abuse?

- Vulnerable Child Syndrome
  - Extreme parental anxiety about a true illness
  - Parental belief that a child has a serious illness
- School refusal by child
- Delusional or otherwise mentally ill caretaker
- Fabricated illness in a caretaker
- Munchausen Syndrome in teens

### How do you tell the difference??

- VCS tends to affect only one child, not a series of children
- VCS children have normal childhood illnesses that are over-exaggerated, but usually do not have unusual complaints like severe pain syndromes or life-threatening events
- VCS children do not have syndromes which are rare or difficult to diagnose
- Parents do not have exaggerated medical events of their own

## Management of VCS

- Identify staff members and physicians in your practice who deal most effectively with these patients
- Allow additional time for appointments
- Keep a list of positive issues with the patient and family in the chart and discuss at each visit
- Discuss normal exam findings throughout the child's medical examination

## Management

- Allow parents to communicate their concerns
- Pay attention to clues that signal excessive parental anxiety
- Consider this statement:
  - Many parents of children who have illnesses like Johnny's are very worried that their children may die. Are you worried about that?

## Management

- Avoid after-the-fact comments on the severity of an illness ("It was a good thing you came in when you did")
- Think carefully before ordering medical tests, and explain results clearly to avoid misunderstandings
- Provide reassurance to families at risk
  - Tell them (if appropriate) that the illness is over and will not recur

## Management

- Let the parents know when their child's behavior constitutes normal developmental events
- Help parents find social supports
- Advocate a normal life for the child
- Help parents set age appropriate limits that encourage autonomy and independence

## Prevention

- Early identification of families at risk
- Educating staff in NICUs and other high risk areas to help identify families
- Allow parents access to sick child
- Present diagnosis, prognosis, and treatment plan without overstating or understating the severity
- Carefully order any test, avoid unnecessary testing

## Outcomes of VCS

- Difficulty with age appropriate individuation from parents
- Difficulty adjusting to school
- Academic underachievement
- Lower adaptive development scores on standardized tests
- Behavior problems- hyperactivity, lack of self-control, insecurity, defiance
- Depression or anxiety in older children
- Vague somatic symptoms such as HA, abdominal pain and fatigue in older children

## A Ray of Hope?

- Parents of preemies show less perception of vulnerability at 3 years than at 1
- When the illnesses do not recur, the parents generally begin to view the child's health more positively
- By school age, much of this has resolved
- The further away the illness, the better the parent-child relationship
- Empathetic physicians offering realistic perspective can help prevent this

## Helpful References

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