Medical Child Abuse and the Medically Complex Child

WI CAN Educational Series
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Disclosure Information for:
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Medical Child Abuse and the Medically Complex Child

Key Points

• Medical complexity and medical child abuse may be difficult to differentiate.

• Undiagnosed, rare diseases may raise concerns for medical child abuse when none is present and medical child abuse may be the cause of medical complexity.

• Both conditions require careful consideration to prevent harm to the child and family.
Children with Medical Complexity

- Children with multiple medical conditions
- <1-5% of the U.S. pediatric population
- Typically have:
  - Neurologic impairment
  - Functional limitations
  - Technology dependence
  - Multiple meds, specialists
  - High healthcare costs

Medical Child Abuse

- Child receives unnecessary and harmful/potentially harmful medical care at the instigation of a caregiver
  - Exaggeration
  - Fabrication
  - Induction

<table>
<thead>
<tr>
<th>Other names for MCA</th>
<th>First used by</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Munchausen Syndrome by Proxy (MSBP)</td>
<td>Sir Roy Meadow (1977)</td>
<td>Identified MSBP as a form of child abuse, focused on caregiver motive</td>
</tr>
<tr>
<td>Factitious disorder by proxy</td>
<td>DSM-IV (1994)</td>
<td>Psychiatric disorder in caregivers who falsely illness in a child for their own needs, focused on caregiver motive</td>
</tr>
<tr>
<td>Pediatric condition falsification (PCF)</td>
<td>APSAC (2002)</td>
<td>A child abused in this manner is a victim of PCF; focused on caregiver action</td>
</tr>
<tr>
<td>Child abuse in a medical setting</td>
<td>AAP SOCAN (2007)</td>
<td>Focused on the harm caused to the child</td>
</tr>
<tr>
<td>Medical child abuse</td>
<td>Rosellier and Jenny (2009)</td>
<td>Focused on the harm caused to the child</td>
</tr>
<tr>
<td>Caregiver-fabricated illness in a child</td>
<td>AAP SOCAN (2009)</td>
<td>Focused on caregiver action</td>
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</tbody>
</table>
- Practitioner = instrument of abuse
  - Blood draws
  - Exams
  - Admissions
  - Procedures
  - Surgeries
  - Medications
- Morbidity = 100%
  Mortality = 9%

- Delayed diagnosis = 21.8 mos
- Consequences for family and patient-provider relationship

- Avoid assumptions based on perceptions about caregiver/family
Caregiver Factors

- Communication challenges
  - Health literacy
  - Stressors
  - Unreliable information
- Requests for care
  - Lack of diagnosis
  - Second opinion
  - Fear/anxiety, secondary trauma
  - Vulnerable child syndrome
  - “Catastrophization”
  - Medical child abuse

Provider Factors

- Lack of familiarity with rare disease
- Defensive medicine
- Family-centered care
- Pursuit of “zebras”
- Availability of advanced testing
- Lack of diagnosis
- Lack of communication

Risk Factors

- Females > males
- Healthcare background
- Common presentations:
  - Bleeding
  - Seizures
  - CNS depression
  - Apnea
  - Feeding problems
  - Diarrhea
  - Vomiting
  - Fever
  - Rash
  - ?
**Red Flags (or when to consider MCA)**

| History does not match objective findings |
| Unexplained, unexpected symptoms, which may only be observed by a single caregiver |
| Atypical response of child’s illness to its standard treatments |
| Caregiver insistence that excessive/invasive interventions needed |
| Incongruent caregiver affect (e.g. parent not relieved when told child is improving or does not have an illness) |
| Caregiver or sibling(s) with history of unusual, unexplained illness |
| Disclosure of abuse by child |

**Red Flags**

- "Doctor shopping"
  - Multiple providers
  - Multiple institutions
- Resistance to release of records
- Previous provider concerns for MCA

**Clarification of Red Flags**

<table>
<thead>
<tr>
<th>Basis of Concern for MCA</th>
<th>Strategies</th>
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</table>
| Objective findings do not match the history | • Define clearly what was known and what was reported by the caregiver  
• Encourage verbatim documentation when caregiver discusses the history |
| Symptom only occurs when caregiver present | • Encourage respite time with close monitoring in caregiver absence (e.g. sitter)  
• Consider talking with the child alone if verbal |
Clarification of Red Flags

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| Caregiver request for procedures that appear incongruent with previously stated goals | • Assess whether goals have changed, caregiver understanding (e.g. teach back)  
• Consider social work consult to better understand psychosocial factors  
• Involve other caregiver supports (e.g. Health Psych) if struggling with grief or other issues  
• Consider ethics consult |
| Caregiver obstructs release of outside records | • Plan family meeting to explain rationale and to develop a ‘contract’ about expectations of the caregiver and healthcare team  
• Ask whether there are specific people at other institutions with whom one can speak |

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<td>Caregiver obtaining secondary gain from child’s condition</td>
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<td>Healthcare team is being triangulated by the caregiver</td>
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</table>
| Members of the team make negative assumptions about the caregiver’s behavior | • Consider social work consult to better understand psychosocial factors  
• Involve other caregiver supports (e.g. Health Psych) if struggling with grief or other issues |

Child Advocacy Involvement
Covert Video Surveillance

- Last resort
- Pre-established institutional protocol with appropriate safeguards
- May diagnose MCA or medical condition
- Caregiver will have to be told

Multi-disciplinary Response

- Re-evaluation of plan of care
- Reporting
  - Collaboration with medical providers
  - Request for records
    - Insurance/EDS reports
    - Social media review

Ongoing Management

- Monitoring for recurrence
- Monitoring for other types of maltreatment
Management
- Child > caregiver
- For therapy to be successful, caregiver must take responsibility for actions
- “Contract” with caregiver/family and medical providers to prevent further harm to the child
- Distribute the contract to all involved parties

Why?
- Caregiver motivation is not relevant to diagnosis.
- There are a number of possible motives in these cases.
- None of them excuse the harm done to the child.
Secondary gain

- Def: Interpersonal/social advantages gained indirectly from illness
  - Attention
  - Sympathy
  - Resources
  - Benefits
  - Status
  - Money
  - Donations
- ≠ MCA in isolation, but may constitute emotional harm

Take-Home Points

- It can be difficult to distinguish medical complexity and medical child abuse.
- Maintain a high index of suspicion and get more information.
- The child comes first!

References
