Child Medical Neglect: What the MDT Needs to Know
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Medical neglect
- Child is harmed or is at risk of harm due to lack of health care
- Recommended health care offers significant net benefit to the child
- The anticipated benefit of the treatment is significantly greater than its morbidity so that a reasonable caregiver would choose treatment over nontreatment
- It can be demonstrated that access to health care is available and not used
- The caregiver understands the medical advice given

I have no financial disclosures.
Medical neglect

Examples
- Delay of seeking care for known medical issue
- Refusal of recommended medical care
- No mental health care or lack of means restriction in a child with a history of suicide attempts
- Failure to provide adequate dental care or treatment (e.g. no treatment of cavities)

Assess the Situation

- What is the medical concern?
- Who manages the medical problem?
  - Primary care physician
  - Subspecialist: Cardiology, Endocrine, Gastroenterology, Pulmonology etc.
- Where is the best place to get information about the medical problem or to get medical records?
What is the condition of the child?

- Does the child need immediate medical care?
- Does the child have all of the necessary medications?
- Does the child have the medical supplies/equipment needed?

What interventions have been attempted?

- Help with insurance
- Help with transportation
- Financial resources
- Various communication attempts: phone, mail, texts, portal
- Previous CPS report

How has the family responded to the attempts?

- Appointment attendance
- Compliance with medications
What are the medical recommendations for the child?
- Medication needs
- Appointments with medical providers
- Medical equipment; in home nursing
- What are the risks to the child if these recommendations/goals are not met?

Failure to thrive
- Failure to thrive
- What is current weight? Has the child been gaining or losing weight? What is cause for poor growth?
- How much weight gain is expected at this age?
- What and how is child being fed?
- What is recommended nutrition plan?
- Where is child going for weight checks/medical follow up?
- Risks of on-going poor growth: developmental delay, poor brain growth, electrolyte imbalance, nutritional deficiency, impaired immune function, permanent cognitive deficits, death

Diabetes
- What medication: injection or oral?
- Have they been admitted to the hospital? ICU?
- Hemoglobin A1C? Normal 4-5.5%
- Have they had any complications of diabetes?
- How many appointments have they missed?
- Are they checking blood sugar as directed?
- Risks: multiple organ involvement (kidney, heart, eyes, brain), strokes, death
Multifactorial, Multidimensional

- Some neglect may be worrisome only when it occurs repeatedly
- Some single acts that pose serious risk can constitute neglect
- Most neglect is likely unintentional
  - Other problems impair their abilities to meet needs
  - A child can still be at significant risk of harm regardless of intent

Context

- Cultural context
- Parental characteristics
- Child characteristics
- Family characteristics
  - A practice being “normal” within a culture or family does not preclude possible harm
  - Understanding culture, family, child characteristics should influence intervention strategies

Parental and Family Contributors

- Maternal mental health
- Parental substance abuse
- Intellectual abilities
- Parenting skills
- Knowledge of developmental stages
- Problem-solving skills
- Social isolation
- Estrangement from kin
- Poverty
- Stress
Case Examples

12-month-old female
- Born extremely premature, at 23 weeks
- Medical problems
  - Chronic lung disease, required oxygen
  - Gastroesophageal reflux
  - On multiple medications
  - In NICU x 4 months
- Made it to appointments for first month after discharge

12-month-old female
- Poor weight gain noted at first appointment
  - About 20% of goal weight gain
  - Doctor recommended a new, higher calorie formula
- Next appointment, had not made changes
- Then lost to follow up…
- …For 5 months
12-month-old female
- Admitted to hospital
- Weight LOSS over prior 5 months
- Not on medications
- Not on oxygen
- And now requires more than before
- SEVERE developmental delays
- Skull fracture

Are the Basic Needs Met?
- Health
  - Not gaining weight (LOSING weight)
  - Not following recommended treatment plan
  - Not seeking care for new problems
- Safety
  - Unexplained injury
  - Health status increases risk of injury in general
- Development
  - Extreme delays
  - Substantial risk of long-term psychological effects

12-month-old female
- Placed in foster care
- Great catch-up growth
- Gaining developmental milestones
- Receiving recommended care
3-year-old female

- Presents to the pcp office for a well-child check
- During the exam, the doctor sees burns.

Family states burns occurred “months ago”
- Never sought care, applied aloe vera at home

Medical neglect due to:
- Depth of burns
- Large area of burns
- Pain
- Scarring
- Risk of infection
- Risk of other complications (inability to walk!)

Are the Basic Needs Met?

- Health
  - Severe injury, no care sought
  - Risk of burn complications (pain, fluid loss)
  - Risk of infection
  - Risk of long term complications (scarring)
- Safety
  - How did injury occur?
  - Concern for supervisory neglect, abuse
- Development
  - Long term complications could cause problems
8-month-old female

- Diagnosed with PKU at birth via abnormal newborn screening
- Followed by Genetics since birth
- Phenylketonuria (PKU) arises from the absence of a single enzyme called phenylalanine hydroxylase. This enzyme normally converts the essential amino acid, phenylalanine, to another amino acid, tyrosine. Failure of the conversion to take place results in a buildup of phenylalanine. The excess phenylalanine is toxic to the central nervous system.

PKU requires a strict diet and adherence to the diet to maintain Phe levels within treatment range (2-6mg/dl). Pt's with PKU should submit a Phe level at least weekly to monitor Phe levels are within treatment range to ensure appropriate brain development. Some PKU Pt's require specialty formula to supplement breast milk or newborn formula. WIC is a resource often used to provide the newborn formula and a DME company to provide the specialty PKU formula.

Since birth, pt has submitted 18 Phe levels ranging from >0.5-11.9. Frequent fluctuations in Phe levels can cause damage to the developing brain. The last level received on pt was >0.5. This is indicative of parents not following the “batch” recipe of PKU formula which is crucial to maintaining treatable levels.

Pt has no showed 15 times and rescheduled 16 times

Genetics determined a hotline was needed

She is doing well, her Phe levels are in the acceptable range and weight gain is good!!
How do I make a report/hotline?

- Kansas
  - Department for Children and Families (DCF):
    - M-F 8a-5p
    - 1-800-922-5330

How do I know who is assigned to the case?

- Department for Children and Families
  - 1-800-922-5330
  - Kansas City Office – 913-279-7000
  - Overland Park Office – 913-826-7300
  - Leavenworth Office – 913-367-5345
  - Douglas Office – 785-832-3700
  - Atchison Office – 913-367-5345

Interventions

- ENSURE THE CHILD’S SAFETY
- Child and/or Caregiver treatment
  - Trauma-focused, Parent-Child Interaction Therapy, Caregiver therapy for depression, anxiety, substance abuse treatment
- Domestic Violence Resources
- Parenting classes, home visitation programs
- Establish networks of support (family, community...)

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Collaboration

- Medical cases are complex and require good communication and explanations to non-medical team members.
- I recommend a case conference (collaborative) with the medical team, CD investigator/supervisor, family court, and occasionally LE.
- Family preservation can be useful in medical neglect cases.
- If there is an infant in the home, a referral to a home visiting agency might be beneficial to the caregiver.

In summary:

- An effective response by a healthcare provider to medical neglect requires a comprehensive assessment of:
  - The child’s needs
  - The parents' resources
  - The parents' efforts to provide for the needs of the child
  - Options for ensuring optimal health for the child

References
