Child Medical Neglect: What Every APRN Needs to Know

Amy Terreros, DNP, RN, APRN
Division of Child Adversity and Resilience
SCAN Clinic
I have no financial disclosures.
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
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)
Epidemiology

- 2017 Child Maltreatment Report

- Nationally:
  - 74.9% of referrals to CPS were for neglect
  - 1720 child fatalities for abuse or neglect
  - 75.4% of those who died suffered from neglect

# Child Fatalities 2017

<table>
<thead>
<tr>
<th>Maltreatment type</th>
<th>Child Fatalities</th>
<th>Number</th>
<th>Percent</th>
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<tbody>
<tr>
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<td></td>
<td>101</td>
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<tr>
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<td>8</td>
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<td>1368</td>
<td>143.5</td>
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</table>

Hotlines from CMH

- Neglect
- Medical Neglect
- Other abuse
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

- 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
The problem with Neglect

• How do we clarify whether a certain situation or pattern of circumstances jeopardizes a child’s well-being?
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 x4 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..
3-year-old female

- 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.
8-month-old female

• 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 breastmilk 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 on 3/25/19 which was >0.5. This is indicative of parents not following the "batch" recipe of PKU formula which is crucial to maintaining treatable levels.
8-month-old female

• Pt has no showed 15 times and rescheduled 16 times
• Genetics determined a hotline was needed
<table>
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<th>Duration</th>
<th>State</th>
<th>Appointment Type</th>
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</table>

Collaborative meeting held 8/1/19
Hotline made on 7/23/19
8-month-old female

- 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

• Missouri
  • Children’s Division (CD);
    • 24/7
    • 1-800-392-3738
    • [https://apps.dss.mo.gov/OnlineCanReporting/default.aspx](https://apps.dss.mo.gov/OnlineCanReporting/default.aspx)
How do I know who is assigned to the case?

• Children’s Division (MO)
  • 816-929-7800

• 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…)

LOVE WILL.
Collaboration

• Medical cases are complex and require good communication and explanations to CD/DCF.

• I recommend a case conference (collaborative) with the medical team, the CD/DCF investigator/supervisor, and sometimes family court.

• IIS/FCS/Family preservation are 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


Amy Terreros
816-983-6820
anterreros@cmh.edu