Cultural Context and Medical Neglect

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Incidence of Neglect

- Neglect reports have the most mixed trend picture of all types of maltreatment
- Variability among states

- For the purpose of our discussion

NEGLECT HAPPENS

Delay or failure in obtaining health care.

- Current practice typically considers neglect when a child has a significant health problem that a parent (or “average layperson”) can reasonably be expected to recognize and respond but fails to do so in a timely manner. AAP, 2007

Etiology

- There is no single cause of child neglect
- Developmental and social-ecological theory posits that multiple and interactive factors at the individual, family, community, and social factors contribute. (Belsky, 1984;Cicchetti & Carlson,1989)

CULTURE And Child Maltreatment: Considerations for Research

How do certain collectives (not necessarily defined by race or other types of stratification) value children, adopt harsh parenting or execute certain more codes/beliefs in the contexts in which they reside.

IOM, 2014

Challenge to look at other factors: Social Isolation (reasons why women are socially isolated; domestic violence; substance use; separation from informal support networks;

Non-adherence (noncompliance) with health care recommendations

- Non-adherence is preferred term
- It is important to ascertain that the child's condition is clearly attributable to the lack of care.
- What is the diagnosis? On what is it based? How confident in the dx is the Medical team?
- Identifying and addressing the barriers to care including careful consideration of the provider-family relationship and communication.

AAP, 2007

- Child is harmed or at risk because of lack of health care (hc)
- Recommended hc offers significant net benefit to the child
- Anticipated benefit of treatment is significantly greater than it's morbidity
- It can be demonstrated that access to hc is available and not used
- The caregiver understands the medical advise given

AAP recommendations

- Translation
- Understand family's concerns
- Counsel family about need for hc
- Expand the circle of caregivers
- Involve family in medical plan
  - Written contract by physician and family
- Enlist community
- Directly observed therapy
- Partial hospital or day-hospital (Availability?)
- Refer to CPS

Jenny, C., 2007

Multiple and interacting blocks to care

- Maternal and family factors; ie depression, lack of transportation
- Community factors; ie, limited access to health care.
- Health care provider factors; ie, explanations that are rushed or in “medicalese” contribute to lack of understanding, errors, and omissions in care. Bias.

GOT PEOPLE?

Assessing the social supports available and the context of the family as a preventative strategy.

Who in the office, clinic practice gets to know families and during case reviews always can tell the “real story”?

Building relationship for hearing the story of the family.

Cultural and communication*

- 1. What do you call the problem?
- 2. What do you think caused the problem?
- 3. Why do you think it started when it did?
- 4. What do you think the sickness does? How does it work?

Culture and communication

- 5. How severe is the sickness? Will it have a short or long course?
- 6. What kind of treatment do you think the child should receive? What are the most important results you hope he/she receives from this treatment?
- 7. What are the chief problems this sickness has caused?
- 8. What do you fear most about the sickness?

Culture and communication

- 9. Who makes the medical decisions in your household?
- 10. What (if any) other sources of information are you relying on?
- 11. What (if any) other modalities of therapy or investigation have you tried for this problem?
- 12. Do you have concerns regarding your or your families ability to assist in treating this condition?

Dental Neglect: AAPD

- Defined as: “a willful failure on the part of the child’s parent or caregiver to seek and follow through with treatment necessary to ensure a level of oral health essential for adequate function and freedom from pain or infection.”
- AAPD definition serves as neither law nor a standard of practice, but a guideline. “it is up to the health care practitioner to weigh the guidelines and legal definitions against such issues as money and access to care.”

Obvious pain and carries

Dental neglect

- Baby bottle tooth decay: a severe form or rampant carries resulting from the habit of putting a child to bed with a nursing bottle or letting a child fall asleep at the breast. It is completely preventable and recurrence could be considered a form of neglect.

VARIETY OF SOURCES

- Pediatric Healthcare Providers
- Families, Divorce/Custody Issues
- Community: Schools, Daycare
- Internally Generated: Discovered in the course of investigating other alleged maltreatment

All vary in dimensions such as severity, actual risk of harm to the child and other important considerations

Good and bad fit to MN definition

- Good fit:
  - IDDM, other endocrine disorder, Seizure disorder, Leukemia, HIV, Asthma, acute infection (pneumonia, osteomyelitis, menningitis, etc), Congenital heart disease, fracture,
- Not so great fit:
  - ADHD, refusal to vaccinate, autism, migraine, pain syndromes
- Poor fit:
  - obesity, physical inactivity,

MN: disease specific indicators

- Insulin Dependent Diabetes Mellitus
  - Encourage investigator to review logs, have child spot check blood sugar
    - If >300, check urine ketones
    - If positive, to emergency dept.
  - Positive ketones relates to lack of insulin
  - Longer term indicators of non-adherance
    - Hemoglobin A1C: 3m
    - Glycosylated prealbumin: 2-4 weeks

Seizure disorder

- Who is the treating neurologist?
- What anticonvulsant are they prescribed?
- Are serum anticonvulsant levels measured?
- When was the prescription filled?
- How many pills are still in the bottle?
- Who gives the medication?
- Do they watch the child swallow it?
- Can a liquid form be used?

Human Immunodeficiency Virus

- Primary prevention of pediatric HIV is an obstetrical issue.
- Women are screened as a routine part of prenatal care and positive are offered antiretroviral therapy. Infants are put on AZT for some period (6weeks) after birth and the vertical transmission rate drops from 1/3 to close to zero.

Pediatric HIV

- Infection is confirmed by p24 antigen or other reliable methods (rna, viral load) not just by antibody tests because they reflect maternal antibody for about 6 months.
- Antiviral therapy is specific for the sensitivities of the virus. Some viral resistance will develop, worsened by non-adherence to therapy.
- Unfortunately, some financial incentive for worse disease in foster care.

HIV cont

- Check prescription filling, clinic appointment follow-up, serial viral load, viral sensitivities.
- If non-adherence, strong case should be made for alternative placement.

Cystic Fibrosis

- Defect in sodium, chloride cell membrane pump,
- variable in it's effects from mild to severe,
- GI, nutrition, and respiratory organ failure.
- Treated with replacement digestive enzymes, vitamin supplements, pulmonary treatments, frequent hospitalizations for tune ups
- It is not as easy to spot non-adherence

Congenital Heart Disease

- Lots of different forms with variable needs for management
- Some variation in recommended optimal management may exist among experts, but there are areas of complete agreement
  - Unchecked chronic increased pressure and blood flow to the lungs will result in pulmonary hypertension and be irreversible (eisenmenger syndrome)
  - Prosthetic valves require anticoagulant

Case Studies

What Else Do You Want To Know???

Case One

- K. M. is a 11 y/o female
- Hx of type I diabetes.
- Diagnosed in November 2010 at age 8.
- Long hx of noncompliance with multiple admissions
- Admitted over 11 times in 3 years with 3 PICU admissions
- 4 admissions of DKA in 5 months prior to referral to CPT
- Patient was removed from home after 4th admission in 5 months.
- While in foster care continued to have high blood sugars but was never admitted for DKA
- Patient reporting she is not controlled in foster care, which means her unstable blood sugars were not due to mother.
- Patient was found to be hoarding food and sneaking candy.

Case One Revelation

- K.M. hoarding food to get back to mother.
- After being in foster care for 6 months no further admissions and DKA under control

Case Two

- Z.S. 10 month old female hx of HIV.
- Mother was diagnosed with HIV late in pregnancy and did not get regular prenatal care or take her antiviral medication that would protect both her and her baby.
- Child was born at 29 weeks and diagnosed with HIV.
- History of failure to thrive and needs to use an apnea monitor during sleep.
- The mother frequently missed appointments and did not follow through with recommendations.
- Only consistently used the machine at daycare.
- In order to discontinue the apnea monitor need enough data from consistent use as prescribed.
- Child's viral load has never been at an undetectable level (under 20).
- Mother not administering the medication as instructed.
- Mixes the medication with her milk and the child doesn't take all the medication
- Missed the medical daycare for 8 days; missed 8 doses of her Neupogen
- Child now has "full blown AIDS," she is immunosuppressed, and is at risk for a fatal infection. In her current state, the child's life expectancy is 2-3 years.

Case Two Revelation

The mother is now pregnant again and not taking her medication as prescribed.

The patient was removed and placed in foster care.

The mother has since lost the 2nd pregnancy due to a domestic violence incident where the father caused severe trauma to the abdomen causing a miscarriage.

Case Three

Angel is 8 week old discovered unresponsive and not breathing while sleeping with mother.

Mother called father at work and he returned home .

911 then called after father arrived home.

Angel was unable to be resuscitated.

Revelation in Case Three

Marijuana was found in the baby blanket at the hospital and a lot of marijuana was found in the home.

Parents tested positive for cocaine.

The family had several older children.

The next youngest was 2 years of age.

Previous infant demise at 9 months under similar circumstances (daytime, sleeping alone with mother)

Other children were removed for some period of time due to parents drug use.

Case Four

Star is a 9 month old Korean infant with Down's Syndrome and endocardial cushion defect.

Mother dropped out of prenatal care after her first trimester.

Seen by cardiologist at birth and diagnosed at that time.

Each visit with pediatrician reminded to follow-up with cardiologist which they did not do.

The pediatrician made follow-up appts for the infant with the specialist, arranged transportation, discussed the severity of the condition, had mother listen to the baby's heart.

Eventually and reluctantly reported the family for medical neglect.

Case Four Revelation

The mother was not the medical decision maker.

Office nurse discovered that the family attends her church and have contributed to a tele-evangelist who reassured that he had cured the infant.

Suspect that she dropped prenatal care when discussion re: down syndrome.

Summary: MN

- There is a complex intersection of culture, society, families, science, resources, and the medical profession that often may result in a bad fit between the medical needs of the child and the abilities of the family and the profession to meet those needs. This is an ongoing challenge.
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