Yin and Yang in Palliative Care: When East and West Collide

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Case One: Corey

- Healthy pregnancy, 36 week gestation, healthy male
- Parents from Taiwan, no family support in USA
- Parents married, own a home in the suburbs
- Parents very educated, both work in computer and information technology sector

- DOL 2: Jaundiced. Phototherapy for 7 days.
- DOL 11: referred to ED from a local pediatric acute care clinic with one day history of fussiness and fever 101, hypoglycemia, neutropenia.
- In ED: Sepsis work-up done. Began to have apnea, was given fluid bolus and abx started
- Admitted to PICU.

- Condition worsens, transferred to Children’s main campus’ NICU.
- Brain scans show worsening edema, diffuse inflammatory exudates, laminar necrosis, bilateral temporal and anterior frontal empyemas.
- Dx: E. Coli sepsis and meningitis. Prognosis is very poor.

- Hospital day 15 Palliative Care consulted, discussion includes withdrawal of non-beneficial life-sustaining treatment.
- Parents ask to postpone decision until after IV abx therapy and follow up brain scan are completed.
- At this time he is on day 15/21 of abx.

- Infant is slowly weaned from ventilator and successfully extubated to NC oxygen on hospital day 17.
- Tolerating NGT feeding. Vigorous suck. Begins to take oral feedings over next days but not consistently able to tolerate full po feeding.
- MRI on hospital day 21: brain atrophy, encephalomalacia, continued large subdural empyemas...

Care Conference

- Hospital day 24
- Poor prognosis, likely moderate-to-severe global developmental delays.
- Continues to take almost all feedings by mouth.
- On room air.
- ID recommended 21 more days of abx

Baby Doe Regulations

- As a precondition for receipt of federal funds for CPS, Texas certifies that it has policies and procedures in place to ensure that "medically indicated treatment" is provided to infants (up to 12 months)
- "Medically indicated treatment": treatment needed to maintain life

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- Exceptions:
  - When infant is permanently unconscious
  - When treatment would be futile in terms of survival
  - When treatment would be “virtually futile” (in terms of survival) and the treatment itself would be inhumane (in terms of pain)

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- Exceptions to exceptions (*i.e.*, these treatments are always "medically indicated" (required to be provided)):
  - "appropriate nutrition [and] hydration"
  - "appropriate . . . medication"

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More information from the care conference….

Questions

- Can his parents take him home and not feed him?
- If he required a GT for feeding, could his parents successfully refuse?
- Can his parents refuse another 21 day course of antibiotics?
- Is he a candidate for hospice and OOH DNR?
- Should parents be allowed to refuse recommendations for medical treatment?

Outcome

- Discharged home on DOL 44, hospital day 33.
- And …

Case Two: Loretta

- Thirteen y/o female, S/P heart transplant 2006 for complex CHD
- Dx summer 2010 with osteosarcoma in right mastoid
- Underwent treatment at Children's and sought treatment at two other facilities
- Elected to stop treatment in 2011

- Parents are married, educated and both employed in communications industry
- From China, both patient and her younger brother were born in China

- Elected to follow up with eastern medicine and herbal treatments.
- Loretta was admitted late 2013 in septic shock
- Pancreatitis
- Noted to have blasts on peripheral smear, mother declined oncology work-up

- Mother contacted eastern medicine practitioner to come to Dallas
- Requested that he be allowed to assess and treat Loretta in PICU
- Specific treatments to include acupuncture and herbal tea infusions
- Chi

Care Conference

- Parents
- Eastern medicine practitioner
- PICU attending
- Transplant team
- Palliative Care
- Support services
- Pharmacist

Ethics Conference

- Palliative Care
- Ethics committee representing PICU, Oncology, Pastoral Care, community legal genius
- Hospital legal representative
- PICU nursing
- Pastoral Care

Questions

- Should mother be allowed to opt out of heme/onc dx?
- Should the non-credentialed provider be allowed to
  - Examine the patient?
  - Perform acupuncture?
  - Prescribe herbal supplements?

- If you were Loretta’s nurse or resident, would you be willing to participate in the alternative treatment plan?
- Should parents be allowed to direct care?

Here's what happened ….

Current status

Case Three: Sara

- Twelve yo female with Gorham's disease, dx approximately six years ago
- Recurrent pleural effusions, very fragile
- Transfusion dependent
- Pleurovenous shunt placed a year ago
- Admitted with respiratory distress

- Parents from China, divorced
- One older brother
- Both parents engineers
- PTA Sara was attending school

- At least one parent at bedside continuously
- Problems with hygiene, pain management
- Parents often declined physical exam, sometimes declined blood products and IVF
- Sara rarely spoke, looking to parents to coach answers

- Worsening respiratory distress
- Continued disease modifying tx despite medical communication that she was nearing the EOL
- Parents wanted radiation therapy, medical team declined. Parents called radiologist and arranged on their own for treatment.

- Started pain medication continuous plus PCA, mother would move PCA button out of Sara’s reach.
- Other disruptive behavior, but no one wanted to separate parents and child when she was clearly nearing the EOL.

Questions

- How should pain be managed when parents deny their child's pain?
- Is it acceptable for parents to demand treatments that the medical team do not believe are indicated?
- What steps should the care team take when disruptive behaviors have the potential for harm?

What happened to Sara?