Ethical Dilemmas Involving Hospitalized Foster Care Children

Can we improve the quality of their care?

Doug Opel, MD
Ethical Decision-Making

- Health Care Providers
  - Physicians, Nurses, Social Workers...

- Ethics Consultants
- Ethics Committee
Ethics Consultation

- Recent Survey of 600 US general hospitals:
  - 81% have ethics consultation services
  - 95% if include those in development
  - 68% of consult services were small team of individuals
  - 23% by full ethics committee
  - 9% by single consultant
  - Many use combination

Ethics Consultation

- Few standards...
  - Consultation practices varied widely both within and between ethics consultation services
    - 65% always made recommendations
    - 6% never did

- Yet...
  - Rely on case based approach

Case based approach

Results in recurrence of ethics cases

- Adults:
  - End-of-life decision-making
  - Patient autonomy

- Children:
  - Limitation of treatment
  - Treatment conflict
  - Surrogacy issues

Case based approach

- Results in recurrence of ethics cases
  - Adults:
    - End-of-life decision-making
    - Patient autonomy
  - Children:
    - Limitation of treatment
    - Treatment conflict
    - Surrogacy issues
  - Are we missing an opportunity?

A New Model for Ethics Consultation

- To address health care ethics issues on a systems level


Singer et al. *BMC Med Ethics* 2001;2(1).
Ethics Cases vs. Ethics Issues

- **Case:**
  - Active patient cases in which there is uncertainty or conflict
    - e.g. withdrawal of ventilatory support from post-op neurosurgical patient

- **Issue:**
  - Ongoing situation involving organizational systems and processes that give rise to uncertainty or conflict
    - e.g. not the first case of its type, but typical of many cases involving neurosurgical patients
The Ethics Iceberg

Decisions and actions surrounding ethics cases

Systems issues and processes

The Ethics Iceberg

Ethics Consultation

↓

Decisions and actions surrounding ethics cases

Systems issues and processes

The Ethics Iceberg

Ethics Consultation

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Decisions and actions surrounding ethics cases

Systems issues and processes

Fox et al. *Integrated Ethics* 2005.
### Approach to Ethics Consultation

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<tr>
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*Table showing a comparison between case-based and systems-based perspectives.*
## Approach to Ethics Consultation

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<td><strong>Evaluation</strong></td>
<td>Limited assessment of effectiveness</td>
<td>Improvement oriented</td>
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Ethics Committee

Ethics Consultation

Ethics Case

Ethics Issue

Systems-Level Issues

Case-based

Systems-based
Example: L.N.

- 8 y.o. with endstage AIDS
  - Numerous complications, including cirrhosis of liver
- Primary medical team was Infectious Disease (ID)
- Foster child
  - Same placement for >1 year
  - Experienced foster mother
Hospital Admission

- February 26\textsuperscript{th}: admitted to ICU in liver failure
  - Internal bleeding
  - Pain
  - Changes in mental status

- ICU team, ID team
Prognosis

- Gastrointestinal (GI) consult:
  - “Prognosis is grim. Likelihood of survival is in days, not weeks or months.”

- GI consultant, ID physician, and ICU team discuss prognosis with foster mom
Foster mom agrees to limit treatment:
- “...would not like to prolong L.N.’s life unnecessarily...”
- Would forgo blood products

L.N. developed pancreatitis, diffuse abdominal pain
Stabilized

- Condition deteriorated
- Pain medication, IV fluids given
- Slow decrease in blood clotting factors, rise in risk for internal bleeding
- But...stabilize, transferred out of ICU
Change in Plans

- March 12th: foster mom’s stance changed
  - “wants to give L.N. the opportunity to survive an acute decompensation”
- March 13th: Splenectomy and blood products
- March 19th: Hematology consulted; more blood products
Limitation of Treatment #2

- March 22\textsuperscript{nd}: Now 4 weeks since grim prognosis of ‘days to live’
- Same ID attending again discusses limitation of treatment
  - Foster mom “would like to continue blood support in spite of knowing L.N.’s likelihood for long term survival is minimal”
GI bleed

- March 23rd:

  “Foster mom somnolent. Mom knows prognosis is grim, wants to continue blood product support.”
Ethics consult

- Prolonging death
- Putting child at risk of suffering
- “Foster mom agreed to limitation of care, but each time L.N. begins to deteriorate, she insists on treatment.”
- “The entire medical team believed that patient would be best served by limiting aggressive medical therapies”
1) Provider-Family Conflict
2) Limitation of Treatment
1) Provider-Family Conflict
2) Limitation of Treatment
Case based approach

- Foster mother had developed some distrust of ID attending’s recommendations since prediction of death within a week.
- Since L.N. alive 4 weeks later, “foster mom not convinced medical team is accurate in their prognosis”
Case Resolution

- March 24\textsuperscript{th}: First care conference involving multiple providers and foster mother
- “Consistent recommendation’ from entire medical team presented
- L.N. died peacefully 3 days later
Systems Issues

- Communication
  - In context of:
    - Large number of providers
      - ID team
      - PICU team
      - Medical ward team
      - GI consultant
      - Surgical team
      - Heme-Onc consultant
    - Transfer of care from PICU → ward
Patient and family well-being are directly linked to the quality of communication from a medical care team.

Systems issues

Processes

- Time pressures
  - Do staff have the appropriate amount of time to perform duties effectively?

- Documentation
  - Are families wishes documented thoroughly and clearly so anyone caring for the patient can do so correctly?
Foster Care-Specific Systems Level Issues?

- System of relationships
  - Biologic parents
  - Legal guardianship
  - CPS

- Interface of health care system, social services system, and judicial system
1) Communication
2) Processes
   - Time
   - Documentation
3) Others?

- Time-Documentation

- Ethics Committee

- Ethics Consultation

- Ethics Case

- Ethics Issue

- Systems-Level Issues

- Case-based

- Systems-based
1) Communication
2) Processes
   - Time
   - Documentation
3) Others?

- Time-Documentation

Ethics Committee

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Case-based

Systems-based
Ethical Cases as Sentinel Events?

- “an unexpected occurrence involving death or serious physical or psychological injury, or risk thereof”
- Root cause analysis:
  - Understand cause(s), including systems issues
  - Design and implement processes to prevent recurrence

‘Psychological injury or risk thereof’

- Polarized opinions, emotional exhaustion by the time ethics case reaches consultant
- High costs for families involved
  - Collaborative relationships between family and providers eroded
  - Successful resolution less likely


Ethics Committee

JCAHO’s Sentinel Event Policy?

Ethics Consultation

Case-based

Ethics Case

Systems-based

Ethics Issue

Systems-Level Issues
Ethics and Quality

- Ethical dilemmas in clinical care
  - Can impact quality of care
- Addressing systems level issues when faced with a case can potentially can reduce the likelihood of a similar case recurring
  - Increase patient/family satisfaction
  - Improve quality of care