



Ethical Dilemmas Involving Hospitalized Foster Care Children

Can we improve the quality of their
care?

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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

Fox, Myers, Pearlman. *Am J Bioeth* 2007;7(2):13-25.

Foglia, Pearlman. *Health Prog* 2006;87(2):31-5.



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

DuVal et al. *J Med Ethics* 2001;27:24-29.

LaPuma et al. *JAMA* 1998;260:808-11.

Orr, Perkin. *J Clin Ethics* 1994;5(4):323-8.



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?

DuVal et al. *J Med Ethics* 2001;27:24-29.

LaPuma et al. *JAMA* 1998;260:808-11.

Orr, Perkin. *J Clin Ethics* 1994;5(4):323-8.



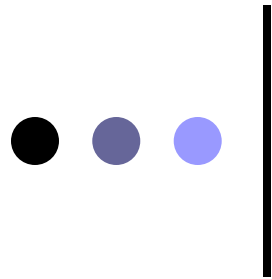
A New Model for Ethics Consultation

- o To address health care ethics issues on a systems level

Forrow et al. *J Clin Ethics* 1993;4(4):287-94.

Blake. *HEC Forum* 2000;12(1):8-32.

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

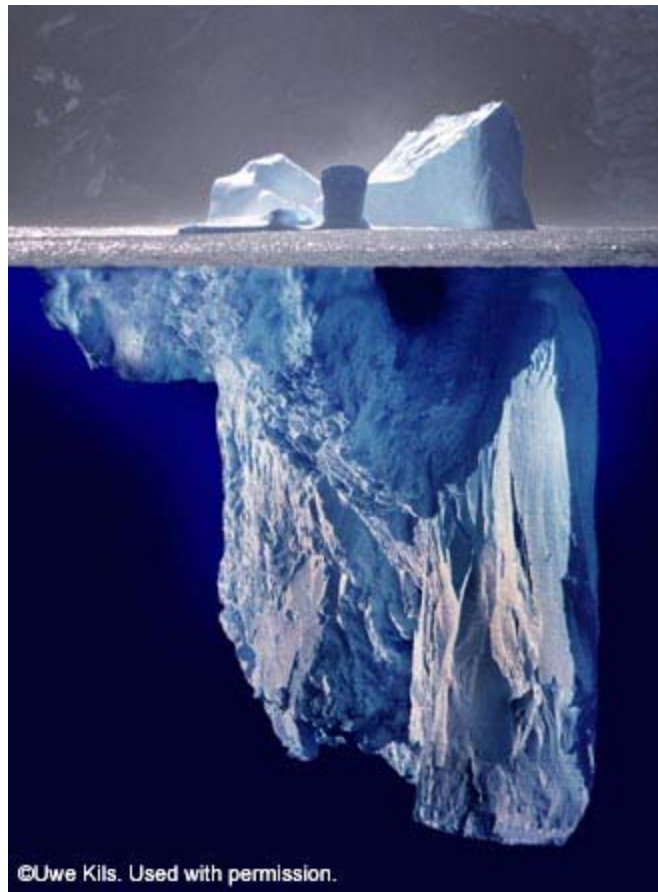
- Issue:

- 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



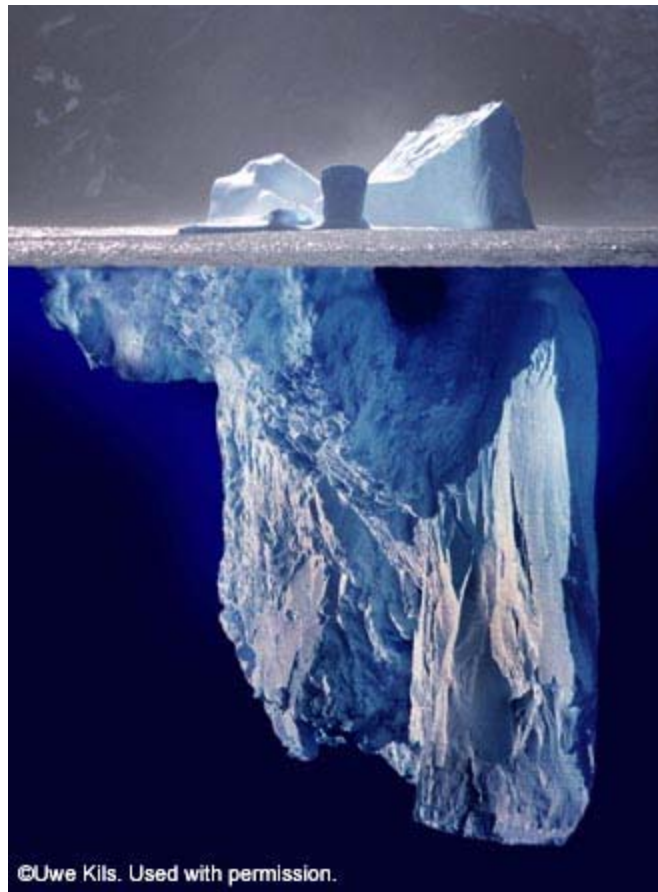
Systems *issues*
and processes

● ● ● | The Ethics Iceberg

Ethics Consultation



Decisions and actions
surrounding ethics cases



Systems *issues*
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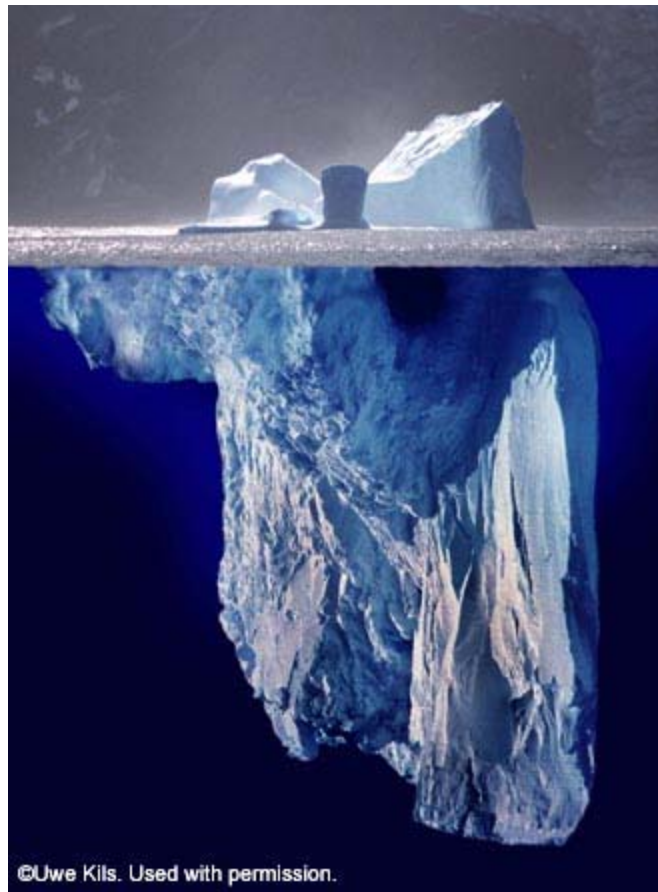
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● ● ● | The Ethics Iceberg

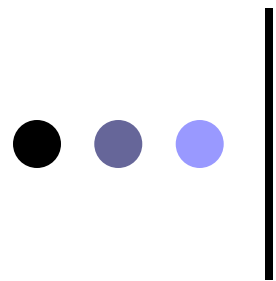
Ethics Consultation



Decisions and actions
surrounding ethics cases

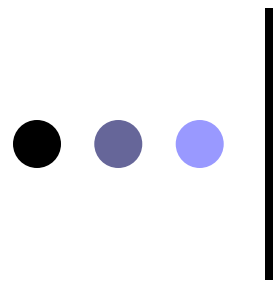


Systems *issues*
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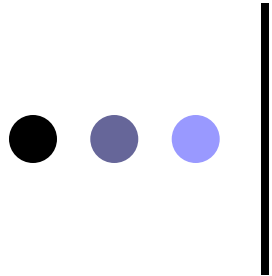
Approach to Ethics Consultation

	Case based	Systems based
Perspective	Reactive, case-based	Proactive, systems-based



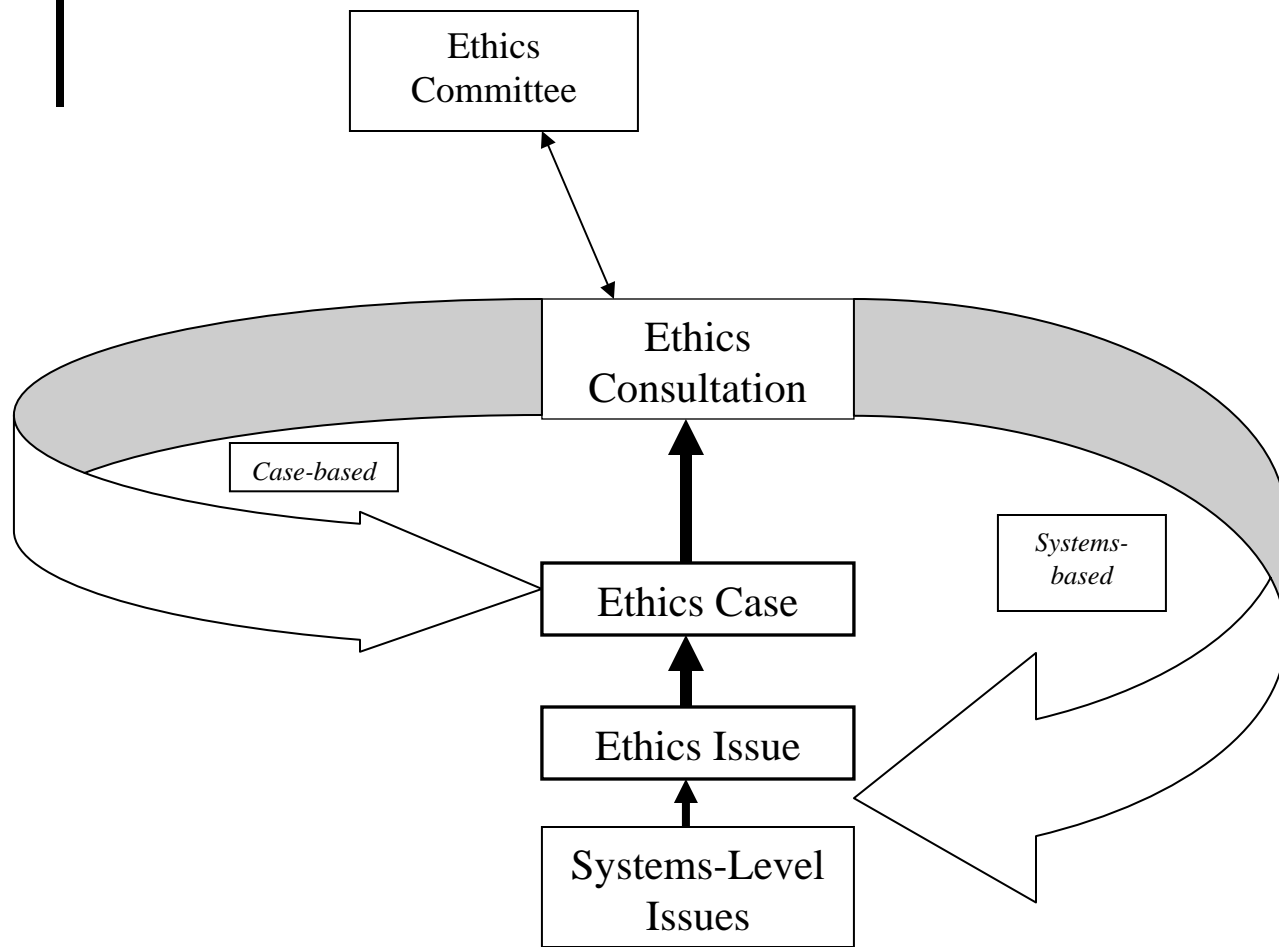
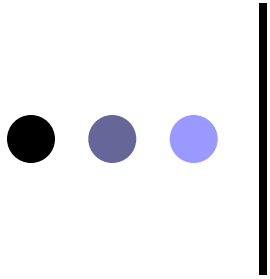
Approach to Ethics Consultation

	Case based	Systems based
Perspective	Reactive, case-based	Proactive, systems-based
Process		
Evaluation		



Approach to Ethics Consultation

	Case based	Systems based
Perspective	Reactive, case-based	Proactive, systems-based
Process	Ad hoc, variable processes	Systematic, consistent
Evaluation	Limited assessment of effectiveness	Improvement oriented





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 26th: 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



Limitation of Treatment

- 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 22nd: 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

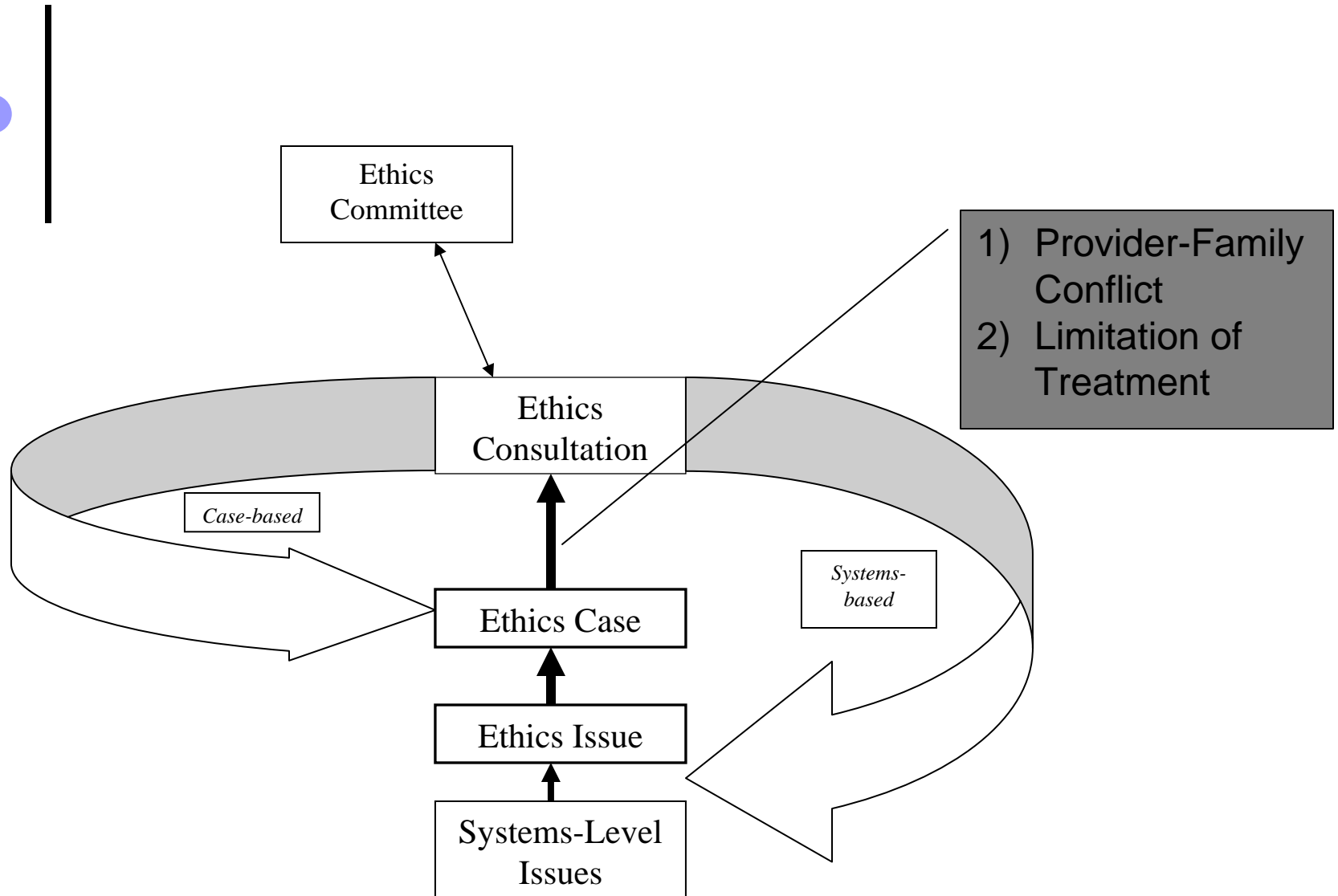
- o March 23rd:

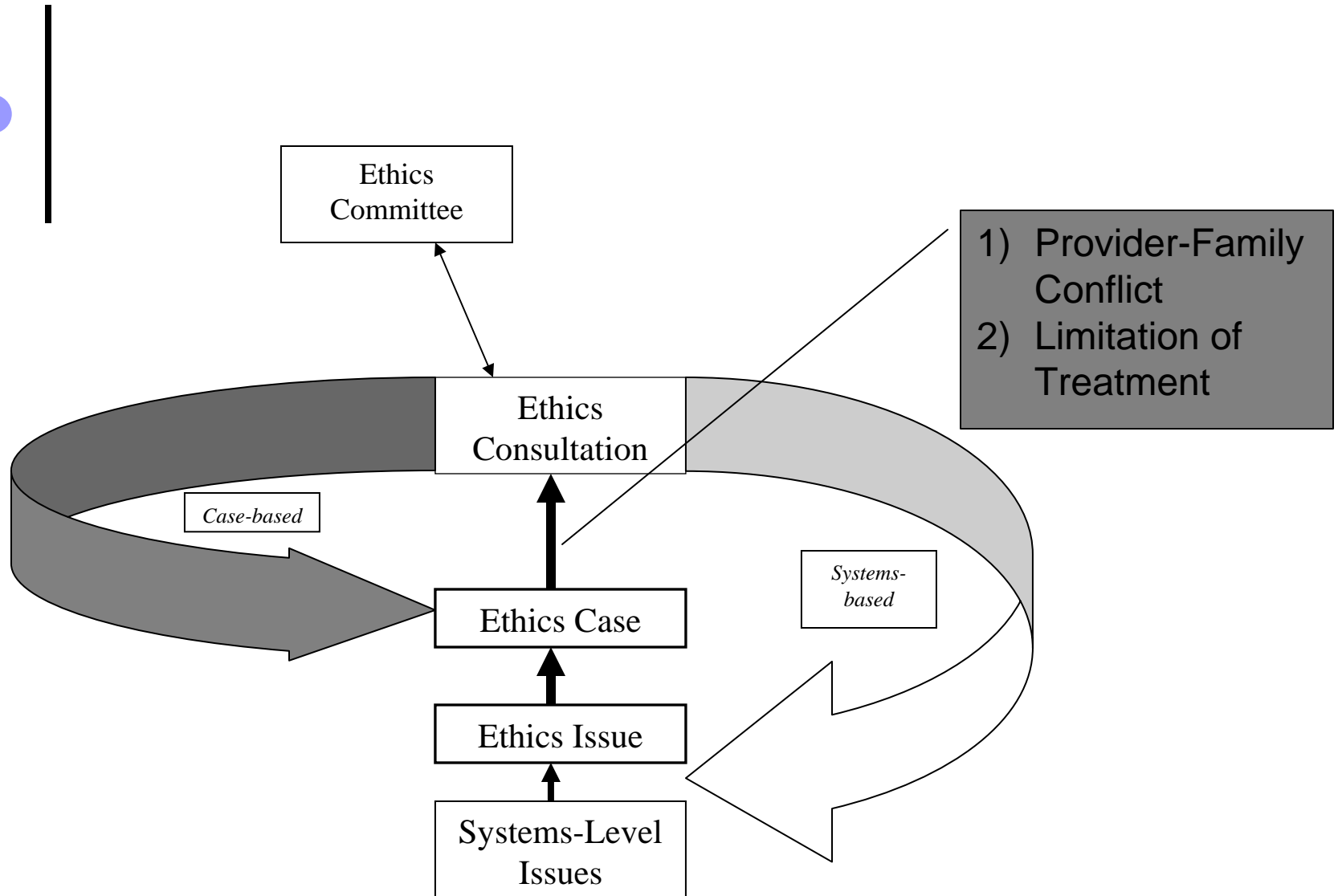
“Foster mom somnolent. Mom knows prognosis is grim, wants to continue blood product support.”



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”







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

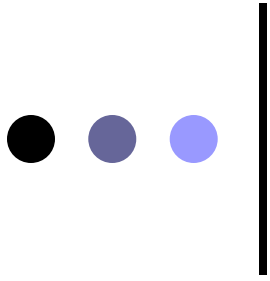
- March 24th: First care conference involving multiple providers and foster mother
- “Consistent recommendation’ from entire medical team presented
- L.N. died peacefully 3 days later



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

Boyle et al. *Crit Care Nurse Q* 2005; 28:302-316.



Systems issues

o Processes

● Time pressures

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

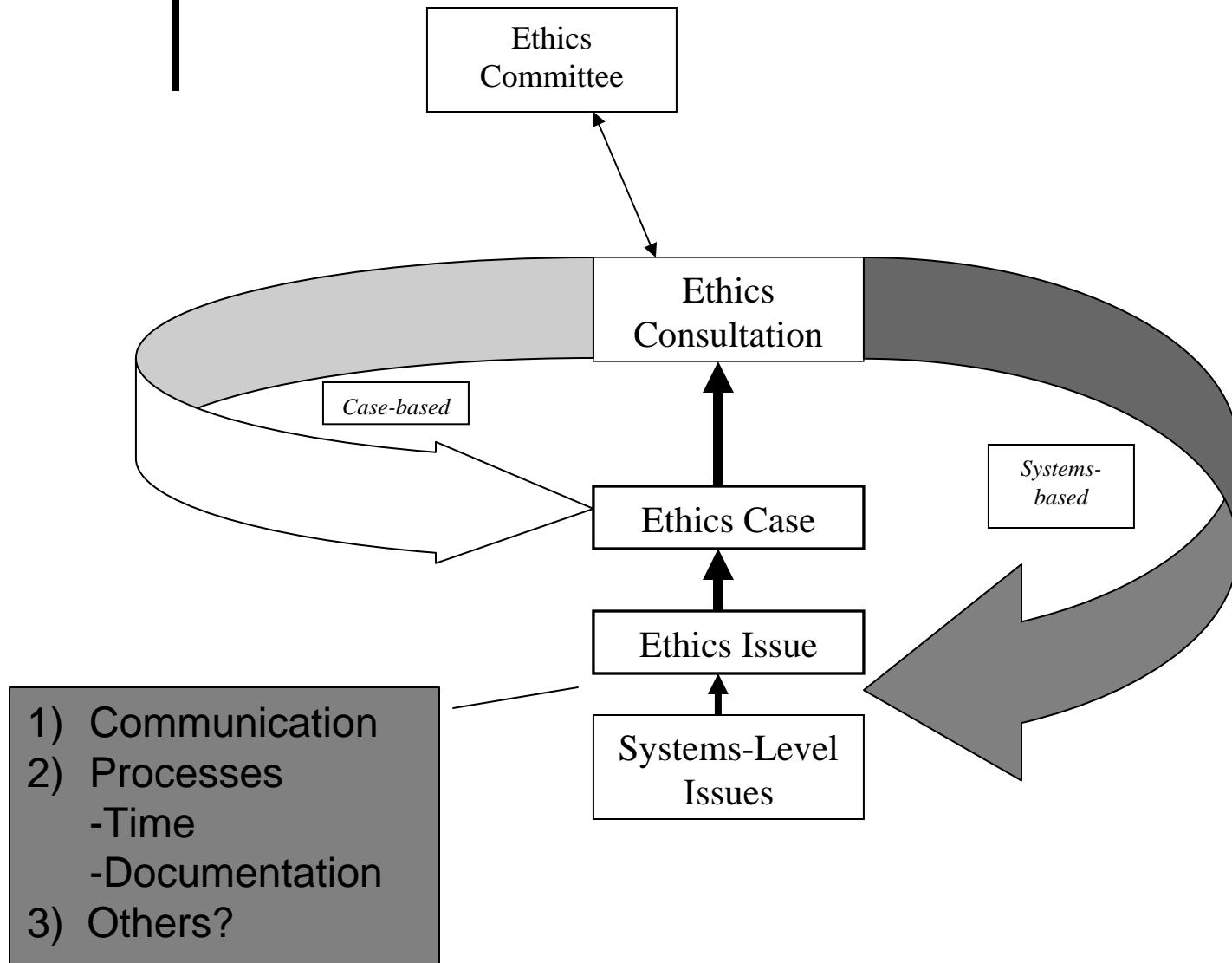
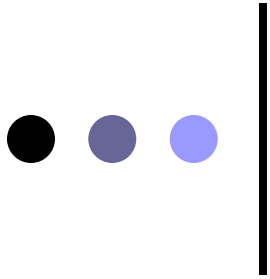
● Documentation

- 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





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



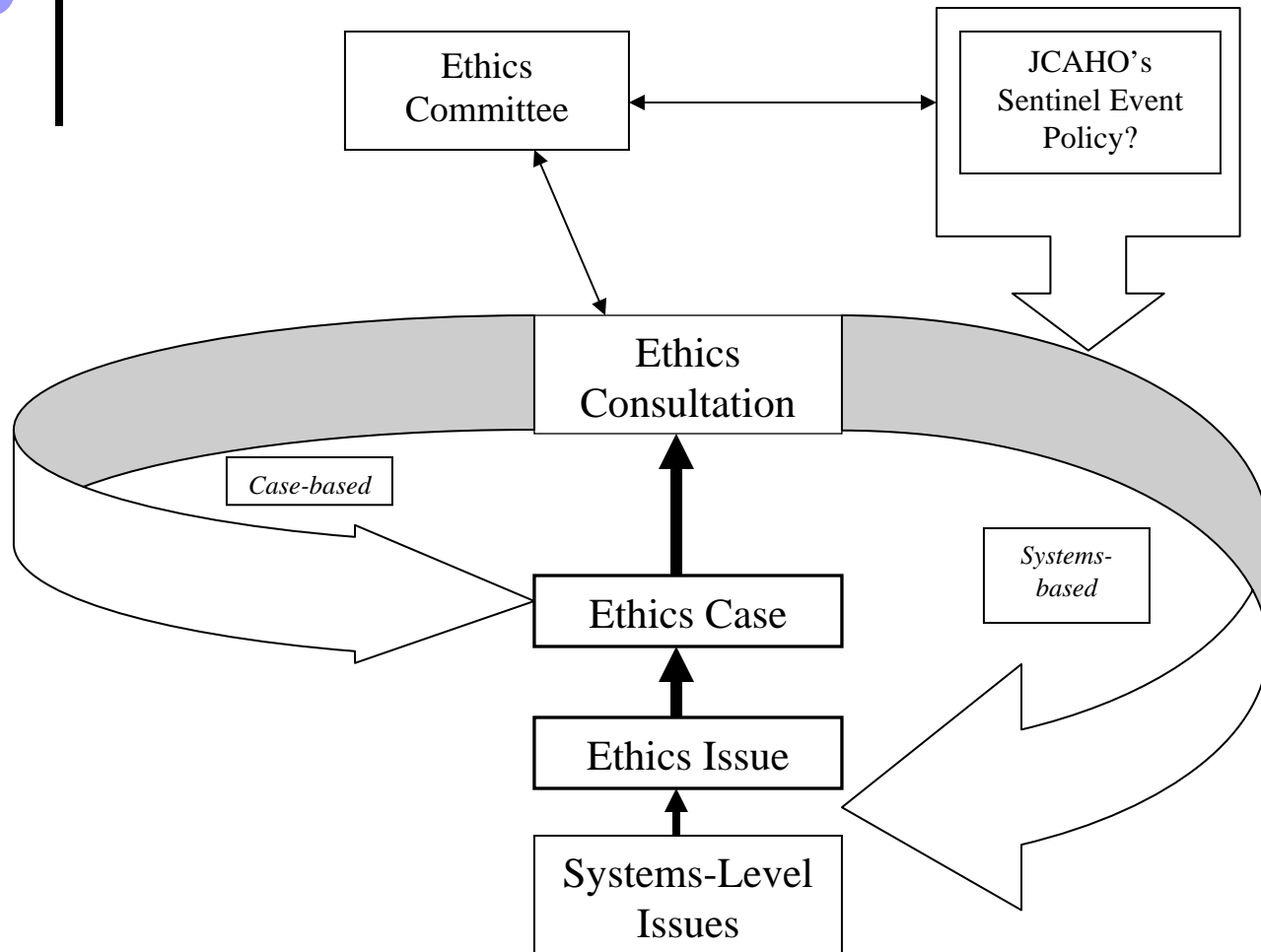
‘Psychological injury or risk thereof’

- 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

Winkenwerder. *JAMA* 1985;254:3454-7.

LaPuma et al. *JAMA* 1998;260:808-11.

Forrow et al. *J Clin Ethics* 1993;4(4):287-94.





Ethics and Quality

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