Ethical Dilemmas in the NICU: Strategies for Response

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18th Annual Ethics Symposium
March 7, 2009

Classic Neonatal Ethics Concerns

What/How Much Should We Do?
Who Gets To Decide?
How Ought Conflicts Be Resolved?

Situating Neonatal Decision Making in a Broader Framework
FRAMEWORK FOR DECISIONMAKING

<table>
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<tr>
<th>PATIENT CATEGORY</th>
<th>STANDARD</th>
<th>PRINCIPLE</th>
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<tbody>
<tr>
<td>COMPETENT WITH CAPACITY</td>
<td>INFORMED CONSENT/INFORMED REFUSAL</td>
<td>AUTONOMY</td>
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<td>FORMERLY HAD CAPACITY</td>
<td>SUBSTITUTED JUDGMENT</td>
<td>AUTONOMY</td>
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<tr>
<td>NOT YET/NEVER HAD</td>
<td>BEST INTEREST</td>
<td>BENEFICENCE/NONMALEFICENCE</td>
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<td>CAPACITY; NO CAPACITY OR SURROGATES</td>
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Taking a Closer Look at the Best Interest Standard

What Do We Mean By “Best?”

What Do We Mean By “Interest?”

Factors Traditionally Considered

Risk/Harm
Benefit
Quality of Life
Two Different Approaches

Procedural vs. Substantive

Arguments in Favor of Deferring to Parental Authority

They will live with the outcomes, not the team
They presumably love their child the best and are guided by the bonds of affection
We accord parents latitude in other arenas
We can’t know for sure what will happen

Arguments Against Deferring to Parental Authority

They may not fully understand
They may make poor choices
Babies need special protection
Babies are not their parents’ possessions
### Arguments in Favor of Medical Team Acting As Decision Makers
- Have the requisite knowledge/experience
- Can be trusted more than parents to make the right decisions
- Don’t have the same conflicts of interest
- Can evaluate the baby’s best interest more objectively
- Will be guided by their fiduciary obligations

### Arguments Against Medical Team Acting as Decision Makers
- It’s not their baby
- It’s overstepping their bounds
- It’s an overgeneralization of expertise
- Parents have the right to make their own decisions
- The values of the medical team should not be imposed on parents
- The team won’t have long term responsibility for the baby

### Tracing the Evolution of a Collaborative Model of Decision Making in Neonatology
- Straight Paternalism
- Duff and Campbell
- Baby Doe Controversy
- Futility Debate
Guiding Questions to Ask in Specific Cases

What opinions are we hearing about the child’s best interest?
Whose opinions are they?
What values/perspectives are influencing their opinion?
What definitions are they assuming of “best” and “interest?”

Who is in the best position to make a decision in this case?
Whose and what other interests might be relevant?
How have similar cases been handled in the past?

Assuming a Posture of Curiosity: Preserving a Role for Genuine Dialogue

Kleinman’s Classic Questions:

Techniques For Cultural Engagement
What do you call “the problem?”

What do you think caused “the problem?”

Why do you think “it” happened?

What do you think the “sickness/defect/condition” does?

How does it work?

How does it affect the baby’s body?

How severe is the “sickness/defect/condition?”

Will it always affect the baby?

What problems will it cause your baby?

What treatment do you desire for your baby?

What do you hope the treatment will do?

What do you think will happen to your baby without the treatment?
Is there any message or lesson in your baby’s illness?

What would be signs to you that the baby is “getting better?”

What would be signs to you that the baby is “getting worse?”

When if ever do you think it would be time to stop the treatments?

How do you know what the right thing to do is?

Who or what do you seek guidance from in making decisions?

Remembering the Promise of the Ethics Contribution

A safe forum for discussion

A chance to hear and come to understand the sometimes conflicting perspectives of the involved stakeholders

An opportunity to develop a consensually agreed upon plan