Evidence Based Ethics and the Care of the Extremely Premature Infant

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For infants born at 22-25 wks gestational age: intensive care (IC) or comfort care?

What Outcomes Are Worse than Death Shortly after Birth?

- In opinion of virtually everyone: death after prolonged suffering. Mean age at death with IC ~ 25 d; survivors NICU stay ~ 100 d
- In opinion of great majority: survival with profound neurodevelopmental impairment (NDI). With current selective use of IC, ~10% of all infants, ~20% of survivors
- In opinion of some persons: survival with moderate or worse NDI. With current selective IC, ~20% all, ~40% survivors.

Suppose you are faced with a decision whether to give intensive care to your extremely premature baby.

What likelihood of a good outcome is too small?

What do you mean by a good outcome: -survival, -survival without moderate or worse NDI, or -survival without profound NDI?

Now suppose you are a health policy analyst advising how to allocate limited Medicaid/ Medicare budget.

In your opinion, what is the highest expense that could be justified for IC of extremely premature infants? (Express as dollars per survivor or per survivor without profound NDI.)

Ethical Principles

- Respect for persons (includes protection of autonomy of person or surrogate)
- Beneficence (maximizing benefits, minimizing harms)
- Justice (providing what is deserved, includes distributive justice)

For extremely premature infants—as with other complex ethical dilemmas—principles are often inadequate and conflicting.
Evidence-Based Ethics
Value judgments and disagreement are unavoidable. Yet, thorough and judicious consideration of best evidence relevant to the patient’s care and prognosis promotes Rx decisions that are progressively:
- less arbitrary
- better informed
- more individualized
- more transparent
- more broadly acceptable.

Current Guidelines
- ≤ 22 wks gestational age (postmenstrual age), give comfort care
- ≥ 25 wks gestational age, give intensive care (IC)
- 23-24 wks, parents and neonatologists make a joint decision

Simple, easily applied, & widely used. Yet from 21-25 wks, error of only 1-2 wks may dramatically change care.

What Is the Evidence?
- Mostly, small retrospective studies
- Limited data about % survival with NDI and profound NDI
- Problem of self fulfilling prophecy
- Evidence that gestational age not a reference standard that can be measured with adequate precision.

Variation in Cycle Length (and Presumably Ovulation) with Age in Healthy Women

<table>
<thead>
<tr>
<th>Age</th>
<th>SD</th>
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<tbody>
<tr>
<td>1st two years after menarche</td>
<td>20 d</td>
</tr>
<tr>
<td>2-3 years after menarche</td>
<td>10 d</td>
</tr>
<tr>
<td>Late adolescence</td>
<td>5 d</td>
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<tr>
<td>Adults</td>
<td>4 d</td>
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<tr>
<td>(increases at ≥35 y)</td>
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At all ages, 2 SD ≥ 8 d; Greater with illness. Some evidence that intercourse may stimulate ovulation. Pregnancy reported from single intercourse as early as d 2 to as late as d 30.

Width of Fertility Window Relative to Ovulation
In study of hormonal metabolites in healthy women (Wilcox et al), only 30% fertile only between 10-17 d; = 10% likelihood in fertility window each d from 6-21 d (2 wk span)

Supported by studies in women attempting pregnancy

Evidence that the GA recorded for many extremely premature infants is too low.
Accuracy of early sonograms?

Stated by ACOG to be $\pm 2$ wks*: 


Unfortunately, even 1 wk error important to prognosis & treatment decisions

Accuracy of sonograms in L&D likely to be less under “field conditions” and for deliveries at <26 wks.