Parents and Doctors View on Treatment of Babies Born at the Borderline of Viability

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Theme
• Parents and doctors think differently about decisions for tiny preemies.
• May be incompatible world views.
• Understanding the differences might help.

My perspectives
• General pediatrician with an interest in NICU follow-up and chronic disease.
• Bioethicist who has written about ethical issues in the NICU
• Grandfather of preemie twins.
General pediatrician at La Rabida Hospital

Now running a Bioethics Center at Children’s Mercy Hospital.

Grandfather of preemie twins

Will and Sam Johnson
Born at 23 2/7 weeks
550gms.
Sam died after just 24 hours.
Will is now five.
Some parents don’t want doctors to save their sick babies.

“The fact that an abnormal baby was born to me and my wife was a simple accident. Neither of us is responsible. All I can do is leave him at a university hospital and make certain that he’ll weaken and die naturally.”

Some parents want more treatment than doctors think is appropriate

“Before Annie was diagnosed, we had never heard of Trisomy 13. Once her chromosomes came back, the doctors discussed with us the possibility of terminating the pregnancy. We chose not to terminate. Instead, we decided that we would treasure the time that we had with her.”

Farlow B, Misgivings, Hastings Ctr Report, 2010

Some parents want more…

“Annie developed acute respiratory distress. She was admitted to the PICU. The intensivist seemed annoyed that we would not agree to a DNR order. We (later) learned that a DNR order had been entered without our knowledge or consent.”

Farlow, Hastings Ctr Report, 2010
Some parents change their minds about how much treatment they want.

On Day 1
Mother: “We want the twins to be DNR. I was against resuscitation at birth and I’m not in favor of prolonging life support. These babies were born too early.”

Doctor: “It is not typical for us to include this type of order in the chart.”

Two days later…
The day before, I stood outside of the NICU and cried and threatened to rip out every tube and line attached to my twins. But something had changed in the last 24 hours. While I was only 3 days into this ordeal, I had come to accept these compromised babies as mine.
“My milk had come in. I needed to decide if I would pump my milk or not, if there was a purpose to that act of motherhood. Everything was happening in the now and there was no standing back. I wished I could find words to describe how this whole mess felt oddly fated, that I was somehow meant to be Evan and Ellie’s mother.”

Some are scared and uncertain

- 42 year old teacher, labor at 24 weeks.
- 3 prior miscarriages, otherwise healthy
- Given antenatal steroids, delivered at 25 weeks. Apgars 1, 4, 7, BW - 830g
- Neonatal course, RDS, NEC, sepsis, jaundice

  — Richardson, JAMA 2001

Interview with Mom at 25 weeks

- “We decided that if the baby was a fighter to intervene and to help as much as possible. But if the baby wasn’t responding, quality of life for the baby wouldn’t be that good. So, obviously, we want a baby who is going to be healthy and also have a good quality of life.”

  — Richardson, JAMA 2001
Interview 4 days after birth

• A personal assessment of the baby:
• “It feels so good to have hope and to see her really fighting. I mean, she is a fighter.”

---Richardson, JAMA 2001

Interview 4 days after birth

• Fear:
• “She is so tiny and so fragile. I'll touch her—but I can't really touch her. I don't know why, but I'm scared, I'm very scared. I don't want to break her.”

---Richardson, JAMA 2001

Interview 4 days after birth

• A sense of personal parental duty:
• “If I didn't have the hope and the energy, I don't think she would have that much.”

---Richardson, JAMA 2001
Some parents just don’t want to be involved in decisions

- “In 2005, our daughter Violette was born at 24 weeks and 5 days. Violette had a stormy course. When she was sickest, so was I. I was better able to cope as she gradually became more stable; by the time she was on continuous positive airway pressure, I was fine.”


I’m only punching in

“I loathed visiting the NICU while she was unstable. I hated being encouraged to participate in her care. I visited because I felt I had to show the nurses and social workers that I was a normal parent who was bonding. I “had to” do kangaroo care and hold my 700-g baby as she became dusky.”


I’m only punching in

I held Violette and told nurses that I wanted to, even if I dreamt every night of dropping her and seeing her eyes roll on the floor and her brain gushing out.

Some parents feel ignored

“Our wishes, judgments, and thoughts were rarely of interest to the medical staff, who arrogated decisions to themselves as though we did not exist.”

Some feel misled

“The NICU staff members went out of their way to hide information from us about the likelihood that David would have neurologic damage. We weren’t given guidance about, for example, what a grade III brain bleed was. They said, “He may be a little behind.””

- Gary Horn, about his son David, born at 24 weeks in 1993,

Pessimistic assessments of Andrew’s condition and prognosis had been made by the Neurology Department, though they were never mentioned to us by anyone.”

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“If doctors and nurses knew what our life was going to be like, why shouldn’t we have known? They need to be more honest with parents.”

–Debby Barrett, mother of Michael, born at 1 lb, 15 oz and 24 5/7 wks

Some blog about it all

- www.caringbridge.com
- Parents “blog” on which they could post notices to family and friends and get letters back.
- A “virtual community” of NICU parents

Lessons from “Caring Bridge”

- Only other NICU parents can understand
- Doctors rarely appear
- Often isn’t really about the baby, either.
- Focus on how they will survive the heartache, grief, and stress.
Parental responses and ethics

- Parents feel strong, complex emotions
- Family pressures may be intense
- Basis for the decisions?
  - The baby’s interest?
  - Their desire to be a good parent?
  - A religious or philosophic commitment?
  - Fear? Love?

What is a doctor to do?

- How do deal with all this variation?
- When should we seek parents’ views?
- When should we override their requests for either treatment or non-treatment?

Conventional wisdom

- Three ethical/medical “zones”
  - Non-viable: <22 (or 23) weeks
  - The “grey zone”: 22-26 weeks
  - High survival: >26 weeks
- Doctors determine grey zone boundaries
- In the grey zone → treatment is optional
- Parents should be given choices.
Official statements reflect conventional wisdom

- “Decisions about non-initiation or withdrawal of intensive care should be made by the health care team and the parents of a high-risk infant working together.”
- “Parents should be active participants in the decision making process.”
  - American Academy of Pediatrics, Committee on Fetus and Newborn, Bell EF, Pediatrics, 2007

Who actually makes decisions?

- Every practicing neo in New England
  - to what extent is decision-making shared between neonatologists and parents?
  - what role do neonatologists see themselves as playing in these conversations?
  - Bastek et al, Pediatrics, Aug, 2005

Who Makes the Final Decision Regarding Resuscitation in the Delivery Room?

<table>
<thead>
<tr>
<th>Doctors views</th>
<th>Total</th>
<th>Neo</th>
<th>Parents</th>
<th>Neo and Parents</th>
<th>CB</th>
</tr>
</thead>
<tbody>
<tr>
<td>In your opinion, who should make the final decision to withhold resuscitation in the delivery room?</td>
<td>148</td>
<td>19 (13)</td>
<td>16 (11)</td>
<td>114 (77)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>In your opinion, who does make the final decision to withhold resuscitation in the delivery room?</td>
<td>146</td>
<td>74 (50)</td>
<td>13 (9)</td>
<td>59 (40)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Bastek et al, Peds, August 2005
What would you do?

• Surveys in 1996 and 2003.
• 500 U.S. neonatologists (from AAP)
• 4 potential scenarios, as follows:
  – (1) BW of <500g, GA of <23 weeks,
  – (2) BW of 500 to 600g, GA of 24 weeks,
  – (3) BW of 601 to 750g and GA of 25 weeks, and
  – (4) BW of >750g and GA of 26 weeks.
• Choices
  – (1) full resuscitation, (2) comfort care, or (3) deferral to the parents’ wishes.

Study subjects

• 18.2 years of neonatology experience
• 54% practiced in community settings
• 43 states and Puerto Rico
• No differences between 1996 and 2003

Delivery room responses as a function of GA
What do parents want?

- 587 subjects, 4/05-7/07, Hong Kong.
  - 135 health care workers,
  - 155 mothers of term infants,
  - 288 parents of preterm infants.
- Ranked two health states and death

> Lam et al, Pediatrics, June, 2009

Parent and professional agreement with the statement: "I believe an attempt should be made to save all infants regardless of birth weight."

Most parents say they want “everything.”
Two health states & Death

1. Death.
2. Severe global impairment – wheelchair, intelligence of 1y.o., unable to speak, read or write, incontinent, no independent ADLs.
3. Moderate global impairment – crutches, attends special school, cannot read or write, unable to live independently, continent.

What percentage think that severe disability is worse than death?

- Doctors and nurses - 55%
- Mothers of term babies – 40%
- Parents of preemies – 25%
Parents and professionals ratings of quality of life

- Interviews with:
  - 100 neonatologists
  - 103 neonatal nurses from 3 NICUs
  - 264 adolescents, including
    - 140 who were ELBW infants and
    - 124 sociodemographically matched term controls
  - 275 parents of the recruited adolescents.

- **Main Outcome Measure** Preferences (utilities) for 4 to 5 hypothetical health states of children.
  
  - Saigal et al JAMA 1999

“Best” and “Worst” children

- Jamie – can see, hear, talk, walk, bend, lift, jump, and run normally, does schoolwork more slowly than classmates.

- Pat – blind, deaf, unable to talk, needs equipment to walk, learns schoolwork very slowly and needs special help, needs help from another person to eat, bathe, dress or use the toilet.

Comparison of Preferences of Health Care Professionals and Parents for 4 Hypothetical Health States

Summary of empirical studies

• Parents more tolerant of disabilities than doctors or nurses
• They rate quality of life higher
• More likely to opt for treatment even if survival is likely to be with impairment.
• Parents who have had a preemie are more likely to favor treatment.

What have we learned about predicting outcomes?

Goal of prognostic studies

• To define “the grey zone” for policies about non-treatment.
• To provide empirical data for shared decisions about treatment or non-treatment. (“quantifying best interest.”)
Risk factors

• A simple Web-based tool allows clinicians to estimate the likelihood that intensive care will benefit individual infants.

• www.nichd.nih.gov/neonatalestimates


Five factors

Gestational Age
Birth Weight
Sex
Singleton Birth
Antenatal Corticosteroids (<7 Days Before Delivery)

Gestational Age: 23 weeks
Birth Weight: 450 grams
Sex: Female
Singleton Birth: Yes
Antenatal Corticosteroids: Yes

Outcomes | Outcomes for All Infants | Outcomes for Infants with MV
---|---|---
Survival | 22% | 32%
Survival Without Profound Impairment | 14% | 21%
Survival Without Moderate to Severe Impairment | 8% | 12%

http://www.nichd.nih.gov/about/org/cdbpm/pp/prog_epbo/
Gestational Age: 25 weeks  
Birth Weight: 575 grams  
Sex: Male  
Singleton Birth: No  
Antenatal Corticosteroids: Yes

<table>
<thead>
<tr>
<th>Survival</th>
<th>All infants</th>
<th>Infants given MV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survival</td>
<td>53%</td>
<td>54%</td>
</tr>
<tr>
<td>Survival Without Profound Impairment</td>
<td>34%</td>
<td>35%</td>
</tr>
<tr>
<td>Survival Without Moderate to Severe Impairment</td>
<td>17%</td>
<td>18%</td>
</tr>
</tbody>
</table>

How many 500g singletons survive unimpaired?

- 23 week boys 16%
- 24 week boys 24%
- 25 week boys 33%
- 25 week girls 47%

If “ok” means >50% survival without impairment, then none will be “ok.”

Among survivors, how many are unimpaired?

- 23 week boys 16% 57%
- 24 week boys 24% 61%
- 25 week boys 33% 64%
- 25 week girls 47% 76%

If “ok” means >50% or survivors are unimpaired, than all will be “ok.”
How many babies do well?

- 1992-1999: 32% No impairment, 60% Impaired, 11% Lost to follow-up, 5% Died
- 1999-2000: 40% No impairment, 30% Impaired, 41% Lost to follow-up, 6% Died
- 2000-2002: 50% No impairment, 117% Impaired, 14% Lost to follow-up, 3% Died

Outcomes for 24 weekers, Edmonton, 1974-2003

- 1992-1999: 32% No impairment, 72% Impaired, 28% Lost to follow-up, 11% Died
- 1999-2000: 40% No impairment, 36% Impaired, 41% Lost to follow-up, 4% Died
- 2000-2002: 50% No impairment, 117% Impaired, 16% Lost to follow-up, 2% Died

Robertson et al, Peds Neuro, March, 2009
Things you could honestly say

- Survival for these babies has improved.
- 80% of these babies survive (last 3 years)
- 60% of these babies survive (last 9 years)
- >30% survive unimpaired (10y avg)
- 90% survive unimpaired (last 3 years)
- Most survivors are unimpaired. (last 20 yrs)

The doctor question

- How likely is it that this newborn baby will survive and be unimpaired?

The parent question

- Will my baby be ok?
The key question

• Is it worse to have tried and failed than not to have tried at all?

So…

• Parents more likely to favor treatment even if survival associated with disability.
• Most survivors do not have disability.
• Predictions are not very good.
• But parents want decisions to be individualized…

Doctors alike, parent different

• Doctors want formulae.
• Parents want freedom.
Doctors alike, parent different

- Doctors: usually pessimistic paternalists.
- Parents: wider variation in response.

A thought experiment?

- Would more accurate predictions make neonatal ethics easier?
  - Prognosis for survival – probably yes.
    - Becomes a debate about futility
  - Prognosis for disability – probably not.
    - Think of Down syndrome or Trisomy 13

The only thing to learn from parents
The only thing to learn from parents
• Is to learn from parents.

Thank you!