A neonate with NEC and 10 cm of bowel remaining: Do nothing

Cindy Tai, MD
Surgery Grand Rounds Debate
March 19, 2012
Causes of SBS in children

- Necrotizing enterocolitis
- Intestinal atresias
- Midgut volvulus
- Gastroschisis
Do nothing?!

- Best interest of the child
- Cost of comprehensive care
- Impact on family
- Outcome and quality of life
Objectives:
- To determine the total cost of care for pediatric patients with SBS
- To analyze their utilization of home and hospital-based health care services

- **Design:**
  - Retrospective review of the total charges incurred by 41 children with SBS over the past decade
  - SBS: defined as the loss of ≥70% of SB from resection or congenital defect or ≥2 mo of TPN
Results:

- The mean (± SD) total costs of care for pediatric SBS was $505,250 ± $248,398 (corrected for inflation to the year 2005) for the first year of care alone.
- Inpatient hospitalization accounted for most of these expenses.
Results (cont’d):

- Home-care services increased every year for the first 5 years, reaching $184,520 ± $111,075 for the fifth year.
- Mean total cost per child over a 5-year period was $1,619,851 ± $1,028,985.
- Strong correlation between higher charges and infants with <10% of predicted small-bowel length.
Conclusions:

- The comprehensive care of pediatric SBS patients costs significantly more than has previously been estimated.
- Contrary to previous views, home care significantly increases each year after diagnosis.
Impact on family

- Financial costs
- Interruption of normal family life
- Increased time devoted to help children cope
- Feelings of guilt
- Strain on marriage
- Effect on siblings

- Psychosocial impact of pediatric liver and/or intestine transplantation on parents were assessed in a cross-sectional sample of 41 mothers and 20 fathers
- Parental mental health, parenting stress, and quality of life assessed
Over half reported elevated psychological symptoms on the Brief Symptom Inventory (BSI), with fathers showing greater distress than mothers (p < .05)

Parents reported lower vitality ratings (SF-36)

Family conflict associated with higher psychological distress on the BSI
Medical management of SBS

- TPN
  - Cost
  - Catheter-related infections and thrombosis
  - Liver failure
  - Lipid reduction
- Omegaven
  - Short-term data
  - Not FDA-approved
- Growth factors and gut adaptation
  - Experimental
Surgical management of SBS

- Bowel lengthening procedures
  - After STEP procedure, only about half of patients were successfully converted to full enteral tolerance (International STEP Registry)

- Intestinal transplantation
  - Availability
  - Outcome
# Intestine transplants in US by recipient age 1/1/1988-12/31/2011

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Graft half-life, conditional on 1-year survival, has remained relatively low and has not increased substantially over the past decade.
Cumulative incidence of first acute rejection was 43.1% by 12 months post-tx
Intense immunosuppression regimen

**Slide 5.1:**
Initial immunosuppression regimen in intestinal transplant recipients, 2009 (steroids not considered)

**Slide 5.2:**
Induction agents used at time of intestinal transplant, 2009

**Slide 5.3:**
Immunosuppression regimen at one year in intestinal transplant recipients, 2008 (steroids not considered)
## Graft and patient survival at 3 months, 1 year, 3 years, 5 years, and 10 years

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<th>3 Months</th>
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<td><strong>Patient</strong></td>
<td>93.5%</td>
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Summary

- Our responsibility to provide family with education and support
- Discussion with multi-disciplinary team focusing on the best interest of the child
- Provide compassionate care even if you cannot cure
Summary (cont’d)

- Caring for a child with SBS is extremely expensive, costing about half a million per child the first year and 1.6 million per child over a 5-yr period
- Significant financial, emotional and time strain on patient’s family
Summary (cont’d)

- Quality of life affected by disease process and complications
- Despite recent medical and surgical innovations, outcome is still poor
- 10-year graft survival 24%
- 10-year patient survival 47.8%