Health Care Quality: A Consumer Perspective

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The "Well Child Health Care" Syndrome*

- Trust that children will turn out OK
- Lack of clear mechanisms for
  - Obtaining data
  - Making decisions - Taking responsibility

Private terminology, NS Green

The Story's Beginning

- Child born full term in 1995
- Uncomplicated delivery of a healthy newborn

Day 1 of Life

- 23 hours of age: nurse in newborn nursery noted jaundiced
- Jaundice not reported to the family or doctor
- Progression of jaundice not noticed
- No bilirubin or other tests

Day 2 of Life

- 33 hours of age: Jaundice continued but no bilirubin levels or other evaluation
- Normal physical exams and feeding
- 36 hours of age: Discharged home
- Pediatric follow up visit scheduled in 7 days

Parent Education

- The hospital's "parent education" consisted of:
  - a brochure
  - suggestion to put the baby in the window and
  - assurance that jaundice was normal and the baby was fine

1st Week of Life: Out-patient Problems

- Day 4 of life: began to breast feed with a weak suck and became lethargic.
- Mother called newborn nursery to tell them that he was "still yellow, lethargic and was feeding poorly"
- Mother reassured

More out-patient Problems

- Checked at visit to pediatrician's office
- Noted to look progressively jaundiced
- Bilirubin level not assayed

Re-hospitalized

- Hospitalized at 5 days of age
- Bilirubin was tested for the first time
- 35 mg/dcl = quite high
- Treatment limited to phototherapy
- Exchange transfusion was not done

More Problems

- Child's blood type never determined
- Admitting Pediatric resident incorrectly documented child's blood type - without typing done
- Blood incompatibility was "ruled out"

Signs of Neurologic Damage

- Day 6: developed respiratory distress
- Neurologic abnormalities (high pitched cry, increased tone and opisthotonos)
- Family not informed that this was typical Kernicterus.

False Reassurance

- Instead, reassured that Kernicterus "didn't happen any more in the United States"

More...

- Remained in the hospital for 5 days
- Several tests performed and family told that “none were significant”
- At discharge, child had:
  - multiple neurologic abnormalities
  - jaundice
  - poor feeding

Diagnosis

- 18 months of age - diagnosed with Kernicterus
- Age 2 years: child's blood type determined
- Retrospective diagnosis made of hyperbilirubinemia
  - caused by ABO incompatibility with isoimmunization

This is Kernicterus

- 7 years of age:
  - athetoid cerebral palsy
  - neurosensory hearing loss
  - dental dysplasia
  - ocular abnormalities
  - cannot walk independently or crawl
  - impaired speech
  - drooling

Sister – Lessons Learned

- Two and a half years later: child's sister born
- Parents had her cord blood sent for blood typing
- Confirmed that she was also a candidate for an ABO incompatibility

Correct Treatment

- 16 hours: she was noted to be jaundiced by the nursing staff
- Standing orders for a bilirubin test (per parental request)
- Bilirubin level was 13.5mg/dcl
  - (moderately high)
- Phototherapy initiated

A Normal Outcome

- Day 4: Sister discharged
- Discharged with home care nurse for 7 days to assess health and to follow blood bilirubin levels
- She is fine.

Fundamental Medical-Laboratory-Communication Problems

"*Well Child Health Care Syndrome*"

- Very common Pediatric problem
- Time-dependent
- Staff incredulity
- Inadequate or no Lab testing done

Multiple System Problems

- Inadequate staff observations
- Multiple lapses in follow-up of abnormalities
- Multiple medical staff involved
- In-patient and office lapses
- Insufficient use of laboratory to confirm clinical impressions

Interactions with Family

- Inadequate communication with family
- Inadequate parent education
- Inappropriate reassurance
- No corroborating laboratory and clinical data

Lessons Learned

- Multiple layers of error
- Lack of or inadequately enforced medical/nursing responsibilities
- Laboratory use: too late
- Unclear primary staff responsibility
- Family communication: too “rosy”

Prevention: Medical Needs

- Need routinized approach = Algorithm
  - e.g., possible mandatory Bilirubin screening in newborn nursery
- Mandatory provider participation
- Pediatric F/U = too late!

Prevention: Communication Needs

- Better parent educational materials
- Better attention to parental concerns
- Better use of laboratory data to address concerns