After the NICU – Following Fragile Infants

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Multi-system Approach

• Brain and Central Nervous System
• Cardiopulmonary
• GI/Nutrition
• Endocrinology
• Ophthalmology
• Growth and Development
Dakota

25 weeks gestation with intrauterine growth retardation
370 grams
PDA ligation
Necrotizing enterocolitis, bowel resection
Rickets
Retinopathy of prematurity
Hypothyroidism
Bronchopulmonary dysplasia – discharged on supplemental oxygen and aldactazide
Central Nervous System

- Intraventricular Hemorrhage
- Periventricular Leukomalacia (PVL)
Intraventricular Hemorrhage
IVH

- Grade 1: Germinal matrix
- Grade 2: Into the ventricles
- Grade 3: Dilating the ventricles
- Grade 4: Into the parenchyma
IVH
Periventricular Leukomalacia (PVL) – an independent risk factor for CP

• The result of hypoxia/ischemia
• Edema and necrosis
• Macrophage response forms cysts
• Areas of cystic necrosis collapse to form scars and gliosis
CNS Surveillance after Premature Birth

• Monitor head circumference
  • Too little or too much growth
• Look out for seizures
• Pituitary dysfunction – monitor growth
• Cortical visual impairment is associated with PVL
• Developmental surveillance
Measuring head circumference

Right way and wrong way
Microcephaly
Hydrocephaly
Bronchopulmonary Dysplasia

- Needs supplemental oxygen after 28 post-natal days or after 36 weeks post-menstrual age.

- Impaired alveolar development

- Dysmorphic pulmonary vasculature
Why BPD?

- Damage from ventilators – stretch injury and high O2 concentration
- Inflammation
- Infection
- Genetics
- Nutrition
- Early extra-uterine alveolar development – fewer but larger alveoli
BPD Management and Surveillance

• As many as two thirds will have growth failure
• Synagis, influenza vaccine
• Oxygen and Diuretics
• Most improve. Some progress.
Pulmonary Hypertension
Pulmonary Hypertension

- Increased arterial pressure in the pulmonary bed – triggered by V/Q mismatch

- Caution in weaning oxygen
Patent Ductus Arteriosus
Chronic Lung Disease and Pulmonary Hypertension

• Increased pulmonary pressure makes the right heart work harder.
• Babies with pulmonary hypertension are more easily fatigued, dyspneic, often dependent on supplemental oxygen
• Exercise caution when weaning the oxygen
• Follow the ECHO
Normal Growth Velocity

• Less than 3 months – 25 to 30 grams per day
• 3 to 6 months – 15 to 21 grams per day
• 6 to 12 months – 10 to 13 grams per day
Obstacles to Feeding and Growing

• Disorganized suck, swallow, breathe

• Energy inefficient feeds with high caloric expenditure

• Volume intolerance

• Esophageal reflux
Strategies

• Increase the calories and decrease the volume by concentrating the formula

• Standard formula is 20cal/oz. This can be concentrated up to 28cal/oz by adjusting the amount of water to powder. Formula can also be added to breast milk to increase calories

• Alternates to oral feeds conserve energy – nasogastric, oral gastric, or gastric tube
Aspiration Pneumonia
Managing Disorganized Feeders

- Suck
- Swallow
- Breathe

- Thickened formula may improve aspiration risk, but it takes more energy to suck it out of the bottle.
- No longer using powdered thickener because of risk for NEC
- Consider a faster flow nipple for thickened feeds, or a slower flow nipple for thin liquid
Esophageal Reflux

• Not always a problem!

• Can be a big problem!
• Decreased lower esophageal sphincter tone
• Liquid diet
• Smaller stomach volume
• Gravity
Managing esophageal reflux

- Medications
- Thickened formula (additives, Similac Spit Up)
- Positioning
- Smaller more frequent feeds
- Surgical interventions
- Anticipatory observation (most)
Nissen Fundoplication
Endocrine

- Osteopenia of Prematurity (aka Nutritional Rickets)
  - Inadequate mineral intake
  - Prolonged parenteral nutrition
  - Chronic diuretic therapy
    (increased urinary calcium loss)
  - Ostomy output
Endocrine

- Hypothyroidism
- Immature hypothalamic-pituitary axis
- Immature thyroid gland
- Nutritional problems
- Decreased production of thyroid binding globulin
Retinopathy of Prematurity (ROP)

500+ children blinded annually
Abnormal blood vessels grow in the retina
Vessels leak and cause scarring
When the scars shrink, they pull on the retina and cause detachment.
Retinopathy of Prematurity

Highest risk: <1250 gm or <31 weeks gestation

• Zone - location

• Stage - severity

• Plus Disease – tortuous vessels and poor visual prognosis
Development

Greatest Risk Factors:

- BPD
- Grade 3-4 IVH or PVL
- Severe ROP
Prematurity

• Preterm birth: before 37 weeks gestation
• Late preterm birth: 34 through 36 weeks gestation

• Birth Weight categories:
  • Low Birth Weight (LBW) under 2500 grams (5 ½ lbs)
  • Very Low Birth Weight (ELBW) under 1500 grams (3 ½ lbs)
  • Extremely Low Birth Weight (ELBW) under 1000 grams (2 ¾ lbs)
Premature Birth Rates\(^1\)

In 2013, 1 in 9 babies (11.4\% of live births) was born preterm in the United States.
Preterm is less than 37 completed weeks gestation. Very preterm is less than 32 completed weeks gestation. Moderately preterm is 32–36 completed weeks of gestation.

Late preterm is between 34 and 36 weeks gestation.
Preterm is less than 37 completed weeks gestation. Very preterm is less than 32 completed weeks gestation. Late preterm is between 34 and 36 weeks gestation.


Distribution of all preterm births

US, 2013  Percent of preterm births

- <28 weeks: 13%
- 28-31 weeks: 10.5%
- 32-33 weeks: 6.4%
- 34-36 weeks: 70.2%

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Preterm is less than 37 completed weeks gestation. Very preterm is less than 32 completed weeks gestation. Late preterm is between 34 and 36 weeks gestation.

Preterm is less than 37 completed weeks gestation.

Average medical costs among preterm and term births
US, 2005

- Preterm: $32,325
- Term: $3,325
Distribution of $26 billion societal economic costs of preterm birth
US, 2005

Preterm is less than 37 completed weeks gestation.

Late preterm is between 34 and 36 weeks gestation.

Preterm Birth Rate in Tennessee

In 2014, the preterm birth rate declined to 10.8%.\textsuperscript{2}
Mortality

International survival rates (Western countries):

• 5-10% at 22 weeks
• 40% at 23 weeks
• 40-60% at 24 weeks
• 60-80% at 25 weeks
• 70-80% at 26 weeks
National Institute of Child Health and Human Development (NICHHD) Neonatal Research Network

- 18 clinical centers
- Mission is to facilitate advancement of neonatal care, with focus on ELBW infants
- Cohort of 4,446 infants
- Neurodevelopmental Outcomes using Bayley Scales of Infant Development II
National Institute of Child Health and Human Development (NICHHD) Neonatal Research Network

<table>
<thead>
<tr>
<th>Gestational Age</th>
<th>Death before NICU discharge</th>
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</thead>
<tbody>
<tr>
<td>22 weeks</td>
<td>95%</td>
</tr>
<tr>
<td>23 weeks</td>
<td>74%</td>
</tr>
<tr>
<td>24 weeks</td>
<td>44%</td>
</tr>
<tr>
<td>25 weeks</td>
<td>24%</td>
</tr>
</tbody>
</table>
Mortality

Best chance for survival includes variables such as

• Female

• No growth restriction

• Birth in hospital with NICU$^3$
Neurodevelopmental Outcomes of Prematurity

• Survival rates of preterm infants have dramatically improved

• In general, risk for long-term morbidities increases as gestational age and birth weight decrease\(^3,4\)
## Outcomes at 18 to 22 Months Corrected Age

<table>
<thead>
<tr>
<th>Gestational Age</th>
<th>Death</th>
<th>Death/Profound ND Impairment</th>
<th>Death/Moderate ND Impairment</th>
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</thead>
<tbody>
<tr>
<td>22 Weeks</td>
<td>95%</td>
<td>98%</td>
<td>99%</td>
</tr>
<tr>
<td>23 Weeks</td>
<td>74%</td>
<td>84%</td>
<td>91%</td>
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<tr>
<td>24 Weeks</td>
<td>44%</td>
<td>57%</td>
<td>72%</td>
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<tr>
<td>25 Weeks</td>
<td>25%</td>
<td>38%</td>
<td>54%</td>
</tr>
</tbody>
</table>
Outcomes only for Mechanically Ventilated Infants in the Sample\(^4\): 3,702 cohort infants

<table>
<thead>
<tr>
<th>Gestational Age</th>
<th>Death Before NICU Discharge</th>
<th>Death</th>
<th>Death/Profound ND Impairment</th>
<th>Death/Moderate ND Impairment</th>
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<tr>
<td>22 Weeks</td>
<td>79%</td>
<td>80%</td>
<td>90%</td>
<td>95%</td>
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<tr>
<td>23 Weeks</td>
<td>63%</td>
<td>63%</td>
<td>76%</td>
<td>87%</td>
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<tr>
<td>24 Weeks</td>
<td>40%</td>
<td>41%</td>
<td>55%</td>
<td>70%</td>
</tr>
<tr>
<td>25 Weeks</td>
<td>23%</td>
<td>24%</td>
<td>37%</td>
<td>54%</td>
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</tbody>
</table>
Neurodevelopmental Outcomes in Sweden (Serenius et al, 2013)\(^5\)

- National population-based prospective study of all infants born alive or stillborn before 27 weeks of gestation between 2004 – 2007
- Examined outcome of infants born before 27 weeks gestation
- Cohort was 707 live-born infants; 491 (69%) survived to 2.5 years
- Each preterm infant was matched with 2 children in control group (term birth matched by sex, ethnicity, and municipality)
Neurodevelopmental Outcomes in Sweden

• Cognitive, language, and motor development was assessed with Bayley Scales of Infant and Toddler Development (3rd edition; Bayley-III)

• Outcomes:
  • 42% had no disability
  • 58% had disability
    • 31% mild
    • 16% moderate
    • 11% severe
Neurodevelopmental Outcomes in Sweden

- Neurodevelopmental outcome improved with each week of gestational age
- Moderate or severe disability

<table>
<thead>
<tr>
<th>Gestational Age in Weeks</th>
<th>Disability</th>
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<tr>
<td>22</td>
<td>60%</td>
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<td>23</td>
<td>51%</td>
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<tr>
<td>24</td>
<td>34%</td>
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<tr>
<td>25</td>
<td>27%</td>
</tr>
<tr>
<td>26</td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>Preterm Group</td>
</tr>
<tr>
<td>-------------------</td>
<td>---------------</td>
</tr>
<tr>
<td><strong>Cognitive</strong></td>
<td></td>
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<tr>
<td>Moderate Delay</td>
<td>5%</td>
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<tr>
<td>Severe Delay</td>
<td>6.3%</td>
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<tr>
<td><strong>Language</strong></td>
<td></td>
</tr>
<tr>
<td>Moderate Delay</td>
<td>9.4%</td>
</tr>
<tr>
<td>Severe Delay</td>
<td>6.6%</td>
</tr>
</tbody>
</table>
Long-term Outcomes of Very Preterm or Tiny Infants

- L. Doyle and S. Saigal (2009) reviewed data on infants born <30 weeks gestation or VLBW (<1,500 grams) or ELBW (<1000 grams) at various ages from infancy to adulthood

- Update from original review in 2008
Neurodevelopmental Outcomes in Early Childhood

- 25% of very preterm survivors have substantial neurologic morbidity compared with 4% of term infants

- Neurodevelopmental impairments include cerebral palsy (CP), developmental delay, intellectual disability, and visual and auditory deficits
Neurodevelopmental Outcomes in Early Childhood

• In general, rates of CP increase as gestational age decreases, with 10% for very preterm or tiny infants vs. 0.1-0.2% for term infants\textsuperscript{3}

• Extremely preterm infants who do not have CP and have normal intelligence, have higher rates of coordination problems (gross motor and fine motor) in childhood\textsuperscript{7}
School Difficulties and Higher Cognitive Function

• Very preterm survivors have much higher rates of cognitive and school difficulties
  • Meta-analysis of studies of children born before 1990 showing that preterm children had IQ that was two thirds of a standard deviation below controls

• Overall, see school difficulties in 3 of 4 children compared with 1 of 8 in controls
School Difficulties and Higher Cognitive Function

- Very preterm survivors have much higher rates of problems in other cognitive areas:  
  - Visual processing
  - Academic progress (including academic testing)
  - Executive function (includes planning, cognitive flexibility, abstract thinking, and behavior change)
- In general, see adult intellectual disability in 1 in 22 compared with 1 in 250³
Behavioral and Psychological Problems

• Very preterm infants are at higher risk for attention-deficit/hyperactivity disorder, with rates of 60-70%\(^3\)

• This increased risk persists into teenage years, although these teens don’t consider themselves different from controls\(^11\)

• Increased reports of shyness, anxious/withdrawn, unassertiveness into adulthood\(^3\)

• In general, see behavioral or psychological problems in 1 in 40 compared with 1 in 500\(^3\)
Outcomes in Early Adulthood

• Reports vary:
  • ELBW and VLBW survivors had lower rates of educational achievement, employment, and independent living\textsuperscript{3,12}

  • In general, very preterm survivors have lower rates of post-secondary education, especially males\textsuperscript{12,13,14}

  • Unemployment rates did not vary with gestational age in Ontario cohort that was relatively advantaged\textsuperscript{6}; other studies in Sweden and Norway show higher rates of disability with subsequent financial assistance\textsuperscript{12,13,14}
Other Health Outcomes

• Children born ELBW had 2 to 3 times more hospital readmissions in early years$^3$

• In adulthood, ELBW survivors had few differences in acute health problems but had more chronic health problems$^3$
Other Health Outcomes of Young Adults Born Preterm

• In general, very preterm survivors weigh less into adulthood but reach genetic height potential$^{3,12}$

• Many studies show higher blood pressure$^{3,12}$

• Frequency of asthma is significantly higher than controls in some but not all studies$^{12}$

• Vision or hearing problems and epilepsy rates were 1 in 25 compared with 1 in 500$^3$
Functional Limitations and Health-related Quality of Life

• Teenagers born ELBW reported more restriction in activities of daily living and self-care abilities\(^3\)

• Several studies report that adults show no differences in self-reported quality of life despite recognition of their disabilities\(^3,12\)
Late Preterm Births

• Growing body of evidence of increased risk for medical and neurodevelopmental sequelae of late-preterm deliveries

• Once called “near-term,” this group of infants delivered between 34 and 36 weeks gestation has increased risk for medical complications, impaired neurological development, and neuropsychological problems\textsuperscript{15,16}
Late Preterm Births

“Fetal development occurs along a dynamic maturational continuum from conception to birth, with each successive gestational day likely to improve overall outcome.”\textsuperscript{15}
Late Preterm Births

• Review by Baron, et al\textsuperscript{15}, showed increased risk of medical complications both as newborn and throughout first year of life, higher mortality risk and more frequent and prolonged hospitalizations both as a newborn and into childhood and young adulthood.

• Also showed subtle intellectual and neuropsychological deficits in late pre-term children as compared with healthy children born full term.

• Risk increases as gestational age decreases (greater for births at 34 weeks gestation and decreasing at 35 weeks and again at 36 weeks).
Late Preterm Births

• In a study of 140,000 children born in California between 2000 and 2004, Petrini et al\textsuperscript{16} found that late preterm infants had significantly higher risk of developmental delays than infants born full term

  • Late preterm infants (34 – 36 weeks) have 3 times the risk of CP as full term infants

  • Infants born between 30 to 33 weeks gestation had 8 times the risk of CP
Late Preterm Birth’s Effects on Brain Development

• Period of rapid brain growth

• Characterized by prominent gyral and sulcal infolding, increasing synaptic density, dendritic arborization, axonal sprouting, glial cell proliferation, and neural networking$^{15}$
A baby’s brain at 35 weeks weighs only two-thirds of what it will weigh at 39 to 40 weeks.
If your pregnancy is healthy, it’s best if your baby is born at 40 weeks.

A baby’s brain at 35 weeks weighs only two-thirds of what it will weigh at 40 weeks.

- In the last 6 weeks of pregnancy, your baby’s brain adds connections needed for balance, coordination, learning and social functioning. During this time, the size of your baby’s brain almost doubles.

- Babies born early have more learning and behavior problems in childhood than babies born at 40 weeks.

- Babies born early are more likely to have feeding problems because they can’t coordinate sucking, swallowing and breathing as well as full-term babies.

- Babies born early are likely to have breathing problems, like apnea. Apnea is when a baby stops breathing.

- Babies born early are more likely to die of sudden infant death syndrome (SIDS). SIDS is when a baby dies suddenly and unexpectedly, often during sleep.

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#37-2229-07 Late-preterm Brain Development Card 2/08

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Neonatal Follow-up Program at JMCGH

- Neonatal Follow-up Clinic began in March, 2005
  - High-risk, short-term clinic providing specialized pediatric care
  - Professional Staff: pediatrician, nurse, physical therapists (or PT and OT), dietician
  - Typical clients were highest risk graduates of Neonatal ICU
  - Provided close monitoring of medical, nutritional, and developmental needs
Neurodevelopmental Clinic

• Began in April, 2012
• Goal is to provide medical and neurodevelopmental surveillance to highest risk graduates of Neonatal ICU
• Began with entry criteria of birth weight <1,500 grams (3 ½ lbs)
• Accept referrals from regional providers and hospitals
• Assess medical, neurological, nutritional, and developmental status of infants in first 3 years through 5 evaluations
Data analysis

• Preliminary analysis of 4 years of data

• Comparison of 2 groups of children with birthweight <1,500 grams
  • Follow-up Clinic group also eligible for Neurodevelopmental Clinic
  • Neurodevelopmental Clinic group
Summary: Strategies to Support Infants/Children Born Preterm

Early neuroprotection to support developing brain

- Close medical surveillance with referrals and/or follow-up with specialists as indicated
- Common areas of concern
  - Weight gain: consider nutrition as well as sufficient oral motor skills
  - Infant stress: infants have lower threshold for sensory input and are easily over-stimulated
  - Thermoregulation: energy consumptive
- Parent education and support
Summary: Strategies to Support Infants/Children Born Preterm

• Consider risk
  • Increases as gestational and birth weight decreases
  • Don’t forget about infants born late preterm

• Developmental Services
  • Tennessee’s Early Intervention System (TEIS): service coordination and early intervention services
  • Healthier Beginnings: early intervention for first-time or at-risk mothers
  • Pediatric therapies: PT, OT, SP (feeding)
  • Special education: ages 3 through 21 years
References


References


