MEDICALLY COMPLEX CHILDREN AND CARE IN NEW MEXICO

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Financial Disclosures

- None
Background Information

- Definition of children with medical complexity
- Components of care
- Current health trends
Children with Special Health Care Needs

- Have 1 or more chronic physical, developmental, behavioral or emotional conditions
- Require health and related services of a type or amount beyond that required by children generally
Children with Medical Complexity (CMC)

- Chronic conditions associated with
  - Medical fragility
  - Substantial financial limitations
  - Increased health and service needs
  - Increased health care costs/resource utilization
  - Functional limitations
  - Family-identified needs
Components of Care of CMC

- Account for 1/3 of all pediatric health care spending
- Families are typically primary providers of skilled and unskilled care
- Financial burdens
  - Equipment not covered, adaptive clothing, etc.
- State dependent waiver and Medicaid coverage
- Require intensive coordination
  - Typically not reimbursed
Prevalence of CMC

- Number increased >400% since 1960
- 23% of US households have at least 1 child with special needs
- Children with life threatening diseases live longer
Case Studies

- Premature infant
- Congenital heart condition
- Developmental delay/Failure to Thrive
- Cerebral palsy
- Trisomy 21
Case #1

- JB was born at 24 weeks.
- Birth weight 600 grams.
- Sent home at 5 months of age
  - Corrected gestational age 42 weeks

https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Health-Issues-of-Premature-Babies.aspx
Case #1

- Concerns
  - Bronchopulmonary dysplasia
  - Feeding difficulty
  - Retinopathy of prematurity
  - Osteopenia of prematurity
BPD/Chronic Lung Disease of Prematurity

• Disruption of lung development
  – Decreased septation and alveolar hypoplasia
    ▪ Larger alveoli
    ▪ Decreased surface for gas exchange

• Dysregulation of pulmonary vascular resistance
  – Risk of pulmonary HTN
Case #1 - Bronchopulmonary dysplasia (BPD)

- Received 3 doses of surfactant/Curosurf
- Intubated for 30 days
- Sent home on ¼ liter of oxygen
- On exam – tachypneic with subcostal retractions
**BPD – weaning oxygen**

- Growth is important factor in weaning oxygen
  - Do not wean if not growing well
- Decrease oxygen by half
  - Give at least 2 weeks on each amount before next wean
- Can wean to room air awake by saturations if growing well, good activity and good behavior
- Overnight pulse oximeter when feel ready to discontinue oxygen with sleep
- If has pulmonary hypertension, cannot wean by oxygen saturations and have to wean by ECHO/BNP
BPD

- Reduce risk of infection
  - Synagis
  - Influenza vaccination
- Limited benefit seen for other medications
  - Diuretics
  - Albuterol
  - Inhaled corticosteroids
- Can have reactive airway disease symptoms with exacerbations
Case #1 - Feeding Difficulties

- JB is taking bottle feedings but struggles with that
- Mom describes symptoms of reflux
  - Fussiness with feedings
  - Back arching
  - Occasionally vomiting
- Can take over 30 minutes to eat
  - Mom feeding every 2-3 hours
- Growth has been optimal overall
Feeding Difficulties

• GERD
  – In infants at risk, consider treating
  – Can lead to worsening feeding issues/oral aversion
  – Optimal dosing:
    ▪ Ranitidine: 10 mg/kg/day divided twice a day
    ▪ PPI: 2 mg/kg/day divided twice a day

• Feeding therapy if available
  – Positive feeding experiences

• Transition to baby foods
  – Developmental cues, not age based
Retinopathy of Prematurity

• Due to incomplete retinal vascularization at time of birth
  - Vessels can grow abnormally out from the retina into the vitreous
  - Can lead to retinal hemorrhage and edema

• At discharge JB had mature vascularization
  - Should continue outpatient follow up
Osteopenia of Prematurity

- Premature infants at increased risk for rickets
- Fetus acquire highest amounts of calcium/phosphorus at 32-36 weeks
- Rapid growth
  - Require higher amounts of Ca and Phos
- Formula choice
  - Term versus preterm
- Breastfeeding
  - May need fortifier
## Neonatal Bone Health

<table>
<thead>
<tr>
<th>Nutrient</th>
<th>Recomm. intake (mg/kg)</th>
<th>Unfortified human milk (20 cal/oz)</th>
<th>Fortified human milk (24 cal/oz)</th>
<th>Preterm formula (24 cal/oz)</th>
<th>Transitional formula (22 cal/oz)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calcium</td>
<td>150 to 220</td>
<td>37</td>
<td>184 to 218</td>
<td>210 to 234</td>
<td>125 to 144</td>
</tr>
<tr>
<td>Phosphorus</td>
<td>75 to 140</td>
<td>21</td>
<td>102 to 125</td>
<td>107 to 130</td>
<td>74 to 80</td>
</tr>
<tr>
<td>Vitamin D</td>
<td>200 to 400</td>
<td>2.4</td>
<td>283 to 379</td>
<td>290 to 468</td>
<td>125 to 127</td>
</tr>
</tbody>
</table>

Recommendations for preterm infants weighing 1000 to 1500 grams
Osteopenia of Prematurity

- Goal vitamin D level > 20
  - Supplement 400-1000 IU daily
- If requires calcium/phosphorus supplementation, consider endocrine follow up
- Alkaline phosphatase good marker for bone health
  - Need to look at norms for age
  - Pediatric levels higher than adult levels
Case #2

- SG was born with a large VSD
- PA band placed to allow her to gain more weight until cardiac surgery
- Sent home on diuretics – furosemide
VSD

PA Band

Prevents overcirculation and increased blood flow in the pulmonary vessels

If overcirculation not treated, can lead to pulmonary hypertension and hypertrophy of pulmonary blood vessels
**Goals of Care/Warning Signs**

- **Heart failure/over circulation**
  - Diaphoresis with feeds
  - Tachypnea
- **Diuretic use**
  - May need to increase as baby gains weight
- **Have to monitor volume of feedings**
  - Higher volumes can lead to overcirculation
  - Typically like to keep at 120-130 cc/kg/day
- **Goal for surgery – typically weight**
  - May need higher calorie formulas
Case #3

• CK is a 7 month old coming in for first visit
• Born at term, IUGR
• No significant complications intrauterine or at delivery
• Growth has been a struggle since birth
• Developmentally: not sitting up well, poor truncal tone, smiles and laughs
• Fussy with feedings, no change in symptoms with using reflux medications
Reasons for Poor Weight Gain

• Not taking in enough calories
  – Feeding difficulties/oral aversion
  – Neurological abnormalities affecting feedings
    ▪ Discoordination of suck/swallow
  – Social factors

• High expenditure of calories
  – Hypertonia
  – Congenital Heart Disease
  – BPD
  – Hyperthyroid
Reasons for Poor Weight Gain

• Inadequate absorption
  – Malabsorption
  – Inborn errors of metabolism
  – Food intolerance

• Genetic disorders
  – Associated with different patterns of growth
  – Need to plot on appropriate growth chart
Growth Failure

Degrees of protein/calorie malnutrition

Weight loss initially

Length decreases after

Head preserved above all else
Growth Failure

Social Factors
Increased caloric needs
Decreased caloric intake

Growth Failure

Chronic conditions – mismatch of caloric intake and needs

Genetic syndromes

In born error of metabolism
Growth Failure

Weight preserved
Length decreasing

Concern for underlying endocrine abnormality
Thyroid
Growth Hormone
General Goals – Nutrition

- Infants:
  - 0-4 months: 25-30 grams/day weight gain
  - 4-8 months: 10-16 grams/day

- Caloric needs:
  - Minimum 100 kcal/kg/day
  - May need up to 120-130 kcal/kg/day

- Volume
  - Minimum 100 cc/kg/day
Infant Formulas

• 19-20 cal/oz
  – Most can concentrate up to 26 cal/oz as needed

• Do not need additional water

• Standard formulas
  – Similac, Enfamil, Gerber

• Milk Protein Allergy
  – Nutramigen, Alimentum

• Hypoallergenic formulas
  – Elecare, Neocate, Puramino
Developmental Delays

- Recommend at least quick screening at all visits
  - Ages and Stages through AAP can guide
- Poor nutrition can be contributing factor
- If concerns, ask for early intervention evaluation if 0-3 years of age
  - NM FIT program
    - On line list of providers by county
    - 1-877-696-1472
Case #4

- NB is a 14 year old with cerebral palsy
- Seizure disorder
- Non-ambulatory
- G tube dependent
- Global delays
Nutrition

• Toddler/Adult formulas
  – Depends on weight and not age when decide to transition
  – Usually 40 kg is a good goal for transition to adult formulas

• Usually need additional free water to meet minimum fluid needs

• Goal BMI 10-25%
Constipation

- Try to meet minimum fluid requirement needs
- Most require medications
  - Miralax
  - Senna
  - Suppositories
- Formulas with fiber/giving additional fiber
  - Patient response individual
Bone Health

• At risk for osteopenia, fractures
  – Non ambulatory
  – Seizure medications
  – PPI use

• Optimize calcium and vitamin D supplementation
  – Calcium goal 1000-1500 mg/day
    • Calculate amount from formula along with any supplementation
  – Vitamin D level goal > 40
    • Can give higher supplementation if needed to reach goal
Bone Health

• Bisphosphonates Controversial
  – Can help with bone pain
  – Unclear if significantly reduces fractures risk
  – Concern for jaw necrosis and increased femur fracture risk
  – Usually requires consultation with endocrinology and inpatient admission to dose
Musculoskeletal

- Risk for scoliosis
- Can worsen during puberty
- Benefits from early screening/referral
- Hip dislocation
Spasticity

- Modified Ashworth Scale
  - 1-5 scale
    - Normal muscle tone to difficulties with passive movement

- Treatment options
  - Therapy
  - Splinting/orthotics
  - Stretching
  - Medications
    - Baclofen
    - Botox
  - Surgery
SOCIAL CONSIDERATIONS

• DD waiver
• Discussion about guardianship when turns 18
• Goals of Care
• School and services
  – Parents Reaching Out
    ▪ (505) 247-0192
Case #5

- LH is a 15 month old with Trisomy 21
- Seeing you for WCC
- Growth is good
- No concerns per family
- Delays but receiving therapy
Surveillance for Trisomy 21

• Hearing screen at 6 months, 1 year and then annually
• Ophthalmology exam annually
• Thyroid at 6 months, 1 year and then annually
• CBC annually
• At risk for seizures
• At risk for obstructive sleep apnea
Surveillance as Get Older

- At risk for celiac disease
- At risk for axial-atlanto (C1-C2) instability
- Growth
  - Use appropriate growth chart
- Development
- Behaviors
Children with Chronic Medical Conditions

- Complicated care that involves multiple medical systems – limited resources in New Mexico
- Intensive care coordination
- Multiple specialists
- Family centered care
- Goals of Care
- Time intensive
- Very rewarding
References

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ANY QUESTIONS?