Developmental, Medical, Educational, Social and Emotional Aspects of Cerebral Palsy

Leslie Rubin MD
Morehouse School of Medicine
Developmental Pediatric Specialists
Southeast Pediatric Environmental Health Specialty Unit at Emory University
Faculty Disclosure

In compliance with ACCME Guidelines, I hereby declare:

• I do not have financial or other relationships with the manufacturer(s) of any commercial services(s) discussed in this educational activity.
Learning Objectives

• Recognize the complexity of CP as it affects the individual, the family and the community
• Appreciate the complexity in caring for children with CP and their families
• Consider the concept of health disparities as it applies to CP
William John Little 1810-1894

- On the influence of abnormal parturition, difficult labours, premature births, and asphyxia neonatorum, on the mental and physical condition of the child, especially in relation to deformities.

- Trans Obstet Soc Lond 1862;3: 293-344
Little’s 1861 paper also discussed the value of treatment and early intervention.

“Many of the most helpless have been restored to considerable activity and enjoyment of life,” he wrote.
Definition

• A non-progressive disorder of movement and posture as a result of a fixed insult to the developing brain
Expanded Definition

• Cerebral Palsy (CP) is a neurological condition that can result in multiple medical problems with major implications on the child’s health, on the child’s functioning ability and on the function of the family.

• In large part this is also a challenge to society not only to meet the health care needs of the child, but to achieve functioning potential and to assure full integration of the child with CP into society.
Definition of Health

• Not merely freedom from disease but.....

• The promotion of Physical Emotional & Social Well Being
Prevalence of Cerebral Palsy

• Approximately 2/1,000 live births
• Prevalence has not changed much over the past few decades despite dramatic improvements in Obstetric care – why?
• Because more premature infants survive because of excellent care so many of the children with CP in the USA today were born extremely prematurely
• There remain many children with unknown reasons for their CP
Making a Diagnosis

• Presentation:
  – Birth related, e.g. prematurity
  – The child with motor delay or other indicator

• Evaluation:
  – Medical evaluation
  – Functional assessment

• Talking to parents:
  – Diagnosis and Prognosis
  – Therapeutic Plan
Functional Assessment

- Motor
  - Ambulation
  - Manipulation

- Cognitive
  - Development
  - Learning

- Social
  - Communication
  - Behavior
Therapeutic Approaches

• Motor
  – Ambulation – Physical Therapy
  – Manipulation – Occupational Therapy

• Cognitive
  – Development – Early Intervention
  – Learning – Special Education

• Social
  – Communication – Speech Therapy
  – Behavior – Play Therapy/Counseling
State Programs

• Babies Can’t Wait
  – Birth to Three

• Children’s Medical Services
  – Children with CP
  – Children with other conditions

• Public Schools
  – Special Needs Preschool – from age 3 years
  – Special Education – from Kindergarten
Management Approach: Birth to Three

- Early Intervention
- Feeding & growth
- Developmental expectations
- Medical complications
- Family dynamics
- Preparation for preschool
- Costs of care
Management Approach: School Age

- Special Needs Preschool
- Ongoing therapies
- Ongoing medical conditions
- Individual Education Plan – IEP
- Child’s social life
- Family’s social life
- Graduations
  - Elementary to Middle School
  - Middle to High School
  - Transition from High School to Independence
Transition in Care

Dependence
- Health
  - Pediatric
- Education
  - School
- Living
  - Home with Parents

Independence
- Health
- Family Practice
- Vocation
  - Employment
- Living
  - Home of One's Own

Transition
CP Classifications

• By muscle tone and movement
  – Tone – hypotonic, spastic or mixed
  – Movement – extrapyramidal, ataxic, etc

• By topography
  – Hemiplegia
  – Diplegia
  – Quadriplegia

• By degree
  – GMFCS
GMFCS Level I
Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

GMFCS Level II
Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

GMFCS Level III
Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

GMFCS Level IV
Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

GMFCS Level V
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

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Medical Complications

• Neurology
  — Seizure Disorders

• Orthopedic
  — Contractures and Scoliosis

• Gastroenterology
  — Feeding and Nutrition Problems
  — Gastroesophageal Reflux and Constipation

• Pulmonary
  — Aspiration Pneumonia
Neurological

- Seizures
  - Anticonvulsants
- Neuromotor disorders
  - Spasticity
  - Movement disorders
- Sensory
  - Vision
  - hearing
Orthopedics

- Contractures
  - Hips & Legs
  - Arms & Hands
- Joint disorders
- Scoliosis
Gastroenterology

- Feeding Disorders
- Gastroesophageal Reflux
- Constipation
Gastrointestinal Motility

• “Gastrointestinal motility problems represent an important cause of morbidity and sometimes mortality in patients affected by developmental disorders”

Martinelli & Staiano Gastroenterol Clin North Am 2011 4:765-75
Feeding Disorders in Children With CP

- Children with CP are at increased risk for feeding difficulties and secondary nutritional deficiencies.
- Problems such as
  - poor oral-motor coordination,
  - swallowing dysfunction,
  - gastroesophageal reflux, and
  - aversive feeding behaviors
- comprise significant obstacles to growth, prevent the achievement of developmental potential, and threaten clinical stability.

Schwarz, Infants & Young Children: 2003 - Volume 16 - Issue 4 - p 317-330
Dysphagia
Esophageal Dysmotility

a. Classical achalasia
b. Vigorous achalasia
c. Esophageal spasm
d. Diverticulum
e. Normal peristalsis
f. Slow transit
g. GE reflux
h. Hiatal hernia
Presenting Features of Gastroesophageal Reflux

• Pain and discomfort
• Gagging and vomiting
• Coughing or hoarse voice
• Asthma
• Aspiration pneumonia
• Scarring and stricture
• Erosion and ulcerations
• Anemia
• Barrett's metaplasia
Diagnosis and Treatment of Reflux

• **Diagnosis**
  - By history
  - Barium swallow
  - Ph probe
  - Endoscopy

• **Treatment**
  - Dietary modifications
  - Medications
  - Surgery
Constipation

• Causes
  – Bowel motility
  – Diet
  – Muscle tone
  – Activity
  – Medication

• Treatment
  – Diet
  – Activity and routine
  – Laxatives
  – Enemas
Other Medical Conditions

- **Eyes**
  - Refractory errors
  - Strabismus
- **Dental**
  - Gums and teeth
- **Bones**
  - Osteoporosis and risk of pathological fractures
- **Skin**
  - Pressure sores
Neurodevelopmental Factors

- Learning difficulties
- Intellectual Disabilities
- ADHD
- Autism
  - 7x more likely
Speech, Language and Communication

• Factors affecting speech development
  – Oral motor
  – Cognitive
  – Social
• Therapeutic approaches
  – Speech therapy
  – Augmented communication
  – Social experiences
Emotional Factors in CP

- Anxiety
- Depression
- Social isolation
- Sexuality
- Independence
- Employment
Family Considerations in CP

- Parents
  - Emotional stress
  - Social stress
  - Fatigue
  - Work
  - Financial stress

- Siblings
  - Emotional stress
  - Social stress
Necessary Programmatic Elements

• Assuring Optimal Health
• Realizing Functional Potential
• Facilitating Activities of Daily Life
• Enhancing Skills for Application of Functional Potential
• Maximizing Educational and Social Opportunities
• Coordinating Care
Health Care Infrastructure

- Intensive Care
- Hospitalizations and Surgery
- Emergency Services
- Specialty Health Care
- Routine/Primary Health Care
- Wellness and Prevention
Hughes Spalding
Cerebral Palsy Clinic

• The Inner City Population of Atlanta in the 1990’s was low income, predominantly minority and decidedly underserved

• In 1998 we started an interdisciplinary clinic for children with Cerebral Palsy
In 2002 we surveyed the records of 260 children who had attended the clinic since its inception.

We found a complex set of medical, developmental and social complications.
Percentage of Patients Whose Mothers Used Substances during Pregnancy, per Gestational Age Group

<table>
<thead>
<tr>
<th>Gestational Age in Weeks</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;28</td>
<td>25.58%</td>
</tr>
<tr>
<td>28-32</td>
<td>19.64%</td>
</tr>
<tr>
<td>33-35</td>
<td>18.18%</td>
</tr>
<tr>
<td>36-40</td>
<td>14.29%</td>
</tr>
<tr>
<td>41+</td>
<td>8.89%</td>
</tr>
</tbody>
</table>
The Child lives with...

- Mother: <28-35 weeks - 64, 36-41+ weeks - 58
- Grandparent(s): <28-35 weeks - 41, 36-41+ weeks - 18
- Foster/Adopt: <28-35 weeks - 9, 36-41+ weeks - 21
- Both biologic: <28-35 weeks - 13, 36-41+ weeks - 17
- Father: <28-35 weeks - 3, 36-41+ weeks - 2
Demographic and Etiological Findings

• A high rate of mothers using substances during pregnancy particularly in the lower birth weights and gestational age

• More than 50% children live in single parent families with mother but and about 20% live with their grandparents
Risk Factors for Prematurity

- A mother's age, race, and poverty level,
  - African-American women,
  - poor women are at greater risk of having early birth.

- Mother’s Health
  - Chronic health problems such as high blood pressure, diabetes, and clotting disorders
  - Certain infections during pregnancy
  - Cigarette smoking, alcohol use, or illegal drug use during pregnancy
Poverty Disparities

- **Race:**
  - 12.3% of white children
  - 31.9% of Hispanic children
  - 37.1% of black children

- **Education:**
  - some college education, 13% are poor
  - less than a high school degree, 57% are poor

- **Employment:**
  - 1 parent works full-time, 9% are poor
  - no parent works full-time, 48% are poor

Mediators of Child Poverty Pascoe et al Pediatrics April 2016
Poverty Disparities

• The absence of fathers in the home is associated with a fourfold risk of poverty.
  – 42% of single female-headed families are poor
  – 12% for 2-parent families

• Children of single mothers are at greater risk for:
  – infant mortality
  – child maltreatment
  – failure to graduate from high school
  – incarceration

Mediators of Child Poverty Pascoe et al Pediatrics April 2016
## Children: Poverty & Vulnerability

<table>
<thead>
<tr>
<th>Child Outcomes</th>
<th>Risk for poor children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child abuse and neglect</td>
<td>6.8</td>
</tr>
<tr>
<td>Lead Poisoning</td>
<td>3.5</td>
</tr>
<tr>
<td>Birth to unmarried teenager</td>
<td>3.1</td>
</tr>
<tr>
<td>Depression</td>
<td>2.3</td>
</tr>
<tr>
<td>Experiencing violent crimes</td>
<td>2.2</td>
</tr>
<tr>
<td>Short-stay hospital episode</td>
<td>2.0</td>
</tr>
<tr>
<td>Grade repetition and high school dropout</td>
<td>2.0</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>1.9</td>
</tr>
<tr>
<td>Low birth weight</td>
<td>1.7</td>
</tr>
</tbody>
</table>

*From Neurons to Neighborhoods IOM 2000*
Sociodemographic factors and environmental influences in early childhood have been demonstrated to have significant impact on development, mental health, and overall health throughout the lifespan.
**Cycle of Disadvantage and Disability**

**Environment**
- Poverty
- Poor community support
- Poor health services
- Poor education

**Self Worth**
- Despair
- Substance abuse
- Promiscuity

**Risk Factors**
- Infant with increased needs
  - Medical needs
  - Developmental needs
  - Increased irritability
- Mother under stress
  - Increased demands
  - Lack of supports
  - Substance abuse

**Potential Outcomes**
- Health concerns
- Neurodevelopmental disabilities
- Child neglect and abuse
- Foster care placement

**Pregnancy**
- Limited prenatal care
- Tobacco, alcohol & drug use
- Risk of STD's/HIV

**Newborn Infant**
- Prematurity
- Low birth weight
- Fetal Alcohol Syndrome
Health Care Imperatives

• Nurturing & Loving
• Good Nutrition
• Health Monitoring and Promotion
• Sensitivity to Changes
• Sensitivity to Developmental Needs
• Sensitivity to Educational Needs
Promoting Health: medical perspective

• Vaccines
• Screening for at-risk conditions
• Management of existing chronic medical conditions
• Monitoring of medications
Promoting Health: Physical and Physiological Perspective

- Diet and eating patterns
- Exercise patterns
- Sleep patterns
- Bowel patterns
Promoting Health: Psychosocial, Cultural and Spiritual Perspective

- Daily activities
- Preferred activities
- Personal relationships
- Social activities
- Personal time
A medical home is **not** a building, house, or hospital, but rather an **approach** to providing comprehensive primary care.

A medical home is defined as primary care that is:
- accessible,
- continuous,
- comprehensive,
- family centered,
- coordinated,
- compassionate, and
- culturally effective.
Interdisciplinary CP Clinic
at Children’s Hughes Spalding
Conclusion

• Children with Cerebral Palsy are likely to have complex physical, medical, emotional and social challenges
• They need a lot of care from a lot of people in a systematic, interdisciplinary and coordinated manner
• It can be costly to do this well
• We must continue to strive to do the best we can for each individual and family
• .....in the most thoughtful & efficient way
Ultimately the practices and values of a society are judged by how they treat their most vulnerable citizens.