Cerebral Palsy: Perspectives on a Complex Condition

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 Again

- 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
A. J. at 5

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 improvements in Obstetric care – why?
- Because so many more premature infants are being resuscitated and have excellent neonatal care most of the children with CP in the USA today were born extremely prematurely

Making a Diagnosis

- The premature infant
- The child with motor delay
- Talking to parents
  - Diagnosis and Prognosis?
  - What to do?
- Therapies
- Family Support
- Available Resources
  - Babies Can’t Wait
  - Children’s Medical Services

Functional Implications

- 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

**Birth to Three**

- Early Intervention
- Feeding & growth
- Developmental expectations
- Medical complications
- Family dynamics
- Preparation for preschool
- Costs of care

**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
Medical Complications

- Neurology
  - Seizure Disorders
- Orthopedic
  - Contractures and Scoliosis
- Gastroenterology
  - Feeding and Nutrition Problems
  - Gastroesophageal Reflux
- Pulmonary
  - Aspiration Pneumonia
Neurological

- Seizures
- Neuromotor disorders
- Intellectual and learning disabilities
- Sensory
  - Vision
  - Hearing
- ADHD
- Autism Spectrum Disorders

Orthopedics

- Contractures
- 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”

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.

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
- Erosion and ulcerations
- Scarring and stricture
- Barrett’s metaplasia
- Gagging and vomiting
- Coughing or hoarse voice
- Aspiration pneumonia
- Anemia
Diagnosis and Treatment of Reflux

- Diagnosis
  - By history
  - Ph probe
  - Barium swallow
  - Endoscopy
- Treatment
  - Diet and eating habits
  - Medications
  - Surgery

Constipation

- Causes
  - Bowel motility
  - Diet
  - Muscle tone
  - Activity
  - Medication
- Treatment
  - Diet
  - Activity and routine
  - Laxatives
  - Enemas

Health Care Needs

- Multiple physicians
- Multiple medications
- Multiple hospitalizations
- Multiple emergency room visits
- Multiple surgeries
Speech, Language and Communication

- Factors affecting speech development
  - Oral motor
  - Cognitive
  - Dyspraxia
  - Social
- Therapeutic approaches
  - Speech therapy
  - Augmented communication
  - Social experiences

Emotional Factors in CP

- Anxiety
- Depression
- Social isolation
- Sexuality
- Independence
- Employment

Neurobehavioral Factors in CP

- Learning difficulties
- Intellectual Disabilities
- ADHD
- Autism
  - 7x more likely
Family Considerations in CP

• Parents
  – Emotional stress
  – Social stress
  – Fatigue
  – Work
  – Financial stress

• Siblings
  – Emotional stress
  – Social stress

Health Care Imperatives

• Nurturing & Loving
• Warm and Secure
• Good Nutrition
• Health Monitoring and Promotion
• Sensitivity to Change
• Sensitivity to Developmental Needs

Necessary Programmatic Elements

• Promoting Optimal Health
• Realizing Functional Potential
• Maximizing Social Opportunities
• Enhancing Skills for Application of Functional Potential
• Facilitating Activities of Daily Life
• Maintaining Infrastructure
Children's Healthcare of Atlanta

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

Hughes Spalding Cerebral Palsy Clinic

- 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
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
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

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

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
### TABLE 10-1 Risk of Adverse Child Outcomes and Environmental Conditions Associated with Poverty Status

<table>
<thead>
<tr>
<th>Child Outcomes</th>
<th>Risk for Poor Relative to Nonpoor Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead poisoning</td>
<td>3.5*</td>
</tr>
<tr>
<td>Birth to unmarried teenager</td>
<td>3.1*</td>
</tr>
<tr>
<td>Short-stay hospital episode</td>
<td>2.0*</td>
</tr>
<tr>
<td>Grade repetition and high school dropout</td>
<td></td>
</tr>
<tr>
<td>Low birthweight</td>
<td>1.7*</td>
</tr>
<tr>
<td>Mortality</td>
<td>1.7*</td>
</tr>
<tr>
<td>Learning disability</td>
<td>1.4*</td>
</tr>
<tr>
<td>Parent report of emotional or behavior problem that lasted 3 months or more</td>
<td>1.3*</td>
</tr>
<tr>
<td>SES Mediators</td>
<td></td>
</tr>
<tr>
<td>Child abuse and neglect</td>
<td>6.8/</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></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*

---

### Children: Poverty & Vulnerability

**Child Outcomes**

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

---

**Diagram: Cycle of Disadvantage and Disability**

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

- **Self Worth**
  - Guilt
  - Substance abuse
  - Pronoun

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

- **Newborn Infant**
  - Prematurity
  - Low birth weight
  - Fetal Alcohol Syndrome

---

**Potential Outcomes**

- Health concerns
- Neurodevelopmental disabilities
- Child neglect and abuse
- Violent crime arrest

---

**Risk Factors**

Dorothy with increased needs
- Medical needs
- Developmental needs
- Increased irritability
- Mother under stress
- Increased demands
- Lack of support
- Substance abuse
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.

Interdisciplinary CP Clinic at CHOA Hughes Spalding

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.

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.