A Population Perspective on Cerebral Palsy: Findings from Current Surveillance and Research

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Department of Epidemiology, Spring 2012 Seminar Series
Presentation Overview

• Why is cerebral palsy (CP) an important public health issue?
• History and definitions
• Epidemiologic terminology
• Public health model for CP
• CP surveillance and epidemiology
• Summary
Why is Cerebral Palsy an Important Public Health Issue?

- 15% of children in the United States have a developmental disability
  - 1 in 303 children has cerebral palsy

- Children with developmental disabilities, including cerebral palsy, require increased pediatric health and specialist services -- both to treat their developmental disability and any concurrent medical conditions

- Medical costs for Medicaid-enrolled children with cerebral palsy were **10 times higher** than for Medicaid-enrolled children without cerebral palsy

- Per-person lifetime costs associated with cerebral palsy estimated to be almost $1 million (2003 dollars)

Boyle et al., 2011; Schieve et al., 2012; Kancherla et al., 2012; CDC, 2004
History

1862: William John Little described 47 children with spastic rigidity: 1) hemiplegic rigidity (one side only); 2) paraplegia (legs more than arms); 3) generalized rigidity.

1992: Mutch et al. in DMCN “an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development.”

Classification of CP

CP Definition for Surveillance

- A group of permanent disorders of the development of movement and posture that are attributed to non-progressive disturbances that occurred in the developing brain.*
- Often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy; and by secondary musculoskeletal problems.*
- Includes postnatally acquired CP (MADDSP modification)
- Impairment may result in paresis, involuntary movement, or incoordination.
- Does not include motor disorders that:
  - are transient
  - result from progressive disease of the brain
  - are due to spinal cord abnormalities/injuries

EPIDEMIOLOGIC ISSUES IN CP PREVALENCE STUDIES
## Prevalence of CP (per 1000) Found in Population Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Denominator Population</th>
<th>Rate/1000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hagberg; Sweden, 2001</td>
<td>Cross-sectional; live births</td>
<td>2.1</td>
</tr>
<tr>
<td>Johnson (SCPE); Europe, 2002</td>
<td>Birth cohorts; live births</td>
<td>2.1</td>
</tr>
<tr>
<td>Winter; US, 2002</td>
<td>MADDSP Birth cohorts; live births</td>
<td>2.0</td>
</tr>
<tr>
<td>Sundrum; UK, 2005</td>
<td>Retrospective cohort; live births</td>
<td>2.8</td>
</tr>
<tr>
<td>Serdarogulu; Turkey, 2006</td>
<td>Cross-sectional; all children ages 2-16</td>
<td>4.4</td>
</tr>
<tr>
<td>Ozturk; Turkey, 2006</td>
<td>Cross-sectional; live births</td>
<td>1.1</td>
</tr>
<tr>
<td>Bhasin; US, 2006</td>
<td>MADDSP; Cross-sectional, 8-year-olds</td>
<td>3.1</td>
</tr>
<tr>
<td>Yeargin-Allsopp; US, 2008</td>
<td>ADDM; Cross-sectional, 8-year-olds</td>
<td>3.6</td>
</tr>
<tr>
<td>Boulet; US, 2009</td>
<td>NHIS; Children ages 3-17</td>
<td>3.9</td>
</tr>
<tr>
<td>Kirby, US, 2011</td>
<td>ADDM; Cross-sectional, 8-year-olds</td>
<td>3.3</td>
</tr>
</tbody>
</table>
Choice of Denominator

Birth prevalence:

Number of CP cases who resided in the geographic area at birth
Number of live-births or 1-year survivors in the geographic area.

Period prevalence:

Number of CP cases who resided in the geographic area during a specified time period regardless of residence at time of birth
Number of children residing in the geographic area during a specified time period.
Issues To Consider When Comparing Birth and Period Prevalence

• Case ascertainment for birth and period prevalence is in childhood, not at birth.

• Period prevalence numerator and denominator are subject to the same survival and migration effects; not true for birth prevalence.

• Follow-up of entire underlying live-birth cohort is crucial to comparing birth and period prevalence.

• MORTALITY AND MIGRATION ARE KEY FACTORS
Public Health Model for Prevention of CP

Surveillance Systems
- prevalence
- registry of cases
- monitor prevention

Epidemiological Studies
- risk factors
- protective factors
- public concerns

Prevention Programs
- prevention strategies
- public policy
- education
Methods for Conducting CP Surveillance

- Notification (Reportable Disease Surveillance)
- Periodic Population-Based Surveys
- Aggregate Data
- Disease Registries
- Ongoing Population-Based Surveillance
CDC’s Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

- Ongoing, population-based administrative prevalence program based in five counties of metro Atlanta (Clayton, Cobb, DeKalb, Fulton, Gwinnett)
- Autism, cerebral palsy, hearing loss, intellectual disability, vision impairment
- Children 8 years old
- Multiple health and education sources
  - 9 school systems (2 with decentralized records)
  - 24 clinical sources
**MADDSP Surveillance Case Definitions**

**Cerebral Palsy (CP)**
A group of permanent disorders of the development of movement and posture that are attributed to non-progressive disturbances that occurred in the developing brain.

**Intellectual Disability (ID)**
I.Q. $\leq 70$ on most recently administered psychometric test
*Formerly referred to as Mental Retardation (MR)

**Hearing Loss (HL)**
Measured bilateral pure tone hearing loss averaging 40 decibels or higher (unaided) in the better ear

**Vision Impairment (VI)**
Measured visual acuity of 20/70 or worse in the better eye with correction

**Autism spectrum disorder (ASD)**
A constellation of behaviors indicating social, communicative, and behavioral impairment or abnormalities-essential features are (a) impaired reciprocal social interactions, (b) delayed or unusual communication styles, and (c) restricted or repetitive behavior patterns.
MADDSP: Types of Data Collected

• Demographics: child and parent names, race, ethnicity, gender, residence, DOB
• School service data: school, spec ed eligibility category
• Psychometric test results: intelligence, adaptive, autism
• Hearing and vision test results
• Physical findings (CP)
  – Including gross motor function
• Verbatim descriptions of behaviors (ASDs)
• Associated medical conditions
• Other developmental disabilities monitored by MADDSP

Prevalence per 1,000 Surveillance Year

- Non-Migrant Prevalence
- Period Prevalence

CDC’s Autism and Developmental Disabilities Monitoring (ADDM) CP Network

Current ADDM Network Sites, Surveillance Years 2010 and 2012

- Monitoring 8 year olds
- Monitoring 4 and 8 year olds

Legend:
- Autism
- Autism, Cerebral Palsy
- Autism, Intellectual Disability
- Autism, Cerebral Palsy, Intellectual Disability, Vision Impairment, and Hearing Loss
# Overall Prevalence*, SY2006

<table>
<thead>
<tr>
<th>Study Area</th>
<th>AL</th>
<th>GA</th>
<th>MO</th>
<th>WI</th>
<th>All Sites</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Northern AL</td>
<td>Metropolitan Atlanta</td>
<td>Metropolitan St. Louis</td>
<td>Southeastern Wisconsin</td>
<td>All Sites</td>
</tr>
<tr>
<td>Total number of CP cases</td>
<td>117</td>
<td>178</td>
<td>84</td>
<td>97</td>
<td>476</td>
</tr>
<tr>
<td>Total 8-year-olds in study area</td>
<td>35,126</td>
<td>46,621</td>
<td>26,533</td>
<td>34,058</td>
<td>142,338</td>
</tr>
<tr>
<td>Total prevalence per 1,000</td>
<td><strong>3.3</strong></td>
<td><strong>3.8</strong></td>
<td><strong>3.2</strong></td>
<td><strong>2.9</strong></td>
<td><strong>3.3</strong></td>
</tr>
</tbody>
</table>

## Gender-Specific Prevalence, SY 2006

<table>
<thead>
<tr>
<th>State</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>3.2</td>
<td>2.4</td>
</tr>
<tr>
<td>Georgia</td>
<td>4.1</td>
<td>3.5</td>
</tr>
<tr>
<td>Missouri</td>
<td>3.6</td>
<td>2.8</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>3.5</td>
<td>2.2</td>
</tr>
<tr>
<td>Average</td>
<td>3.6</td>
<td>3.0</td>
</tr>
</tbody>
</table>

Boys: shown as yellow bars, Girls: shown as green bars. Prevalence per 1,000 8-year-olds.

Source: Kirby et al., 2011
# Race-Specific Prevalence, SY2006

<table>
<thead>
<tr>
<th></th>
<th>AL</th>
<th>GA</th>
<th>MO</th>
<th>WI</th>
<th>All Sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>White NH</td>
<td>3.1</td>
<td>3.8</td>
<td>2.8</td>
<td>3.0</td>
<td>3.2</td>
</tr>
<tr>
<td>Black NH</td>
<td>4.3</td>
<td>3.9</td>
<td>3.4</td>
<td>2.8</td>
<td>3.7</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.2</td>
<td>3.3</td>
<td>1.3</td>
<td>1.0</td>
<td>1.8</td>
</tr>
<tr>
<td>Asian/Pacific Islander NH</td>
<td>-</td>
<td>2.6</td>
<td>1.3</td>
<td>3.3</td>
<td>2.4</td>
</tr>
</tbody>
</table>

Kirby et al., 2011
**CP Subtypes, SY 2006**

- Spastic subtype = 81%
  - Bilateral Spastic includes diplegia, quadriplegia, tetraplegia, and triplegia
  - Unilateral Spastic includes hemiplegia and monoplegia
  - Other includes ataxic, dyskinetic, hypotonic, mixed CP subtypes, and CP NOS

Kirby et al., 2011
Gross Motor Function Classification System (GFMCS)

- **LEVEL I** - Walks without limitations
- **LEVEL II** - Walks with limitations
- **LEVEL III** - Walks using a hand-held mobility device (crutches, cane, walker)
- **LEVEL IV** - Self-mobility with limitations; may use powered mobility
- **LEVEL V** - transported in a manual wheelchair

GMFCS by Palisano et al., 1997
Defining Walking Ability

• In several ADDM CP Network studies, walking ability for children with an assigned GMFCS* level was categorized as follows:
  – Level I or II: “walks independently”
  – Level III: “walks with a handheld mobility device”
  – Level IV or V: “limited or no walking ability”

*Some children did not have sufficient information to assign a level of walking ability using the GMFCS. In those cases, walking ability is assigned using the methodology of the Surveillance of Cerebral Palsy in Europe group.

Kirby et al., 2011; Christensen et al., unpublished
Walking Ability Among 8-Year-Old Children with CP, ADDM CP Network, 2006

- 56% Walks Independently
- 33% Limited or No Walking Ability
- 11% Walks with Hand-held Mobility Device
The Association between Cerebral Palsy or Intellectual Disability and Prenatal Magnesium Sulfate Exposure in Atlanta Infant Survivors

<table>
<thead>
<tr>
<th>Prenatal Magnesium Sulfate Exposure</th>
<th>Yes</th>
<th>No</th>
<th>OR</th>
<th>95% CL</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP</td>
<td>1 (0.9%)</td>
<td>30 (7.7%)</td>
<td>0.11</td>
<td>0.02, 0.81</td>
</tr>
<tr>
<td>MR/ID</td>
<td>2 (1.8%)</td>
<td>22 (5.8%)</td>
<td>0.30</td>
<td>0.07, 1.29</td>
</tr>
</tbody>
</table>

Magnesium Sulfate Reduces CP Risk after Preterm Birth

- 2,241 women at "imminent risk" of preterm birth
  - 24 through 31 weeks gestation
- Cases randomized to intravenous magnesium sulfate or placebo
- Results:
  - Overall prevalence of CP was lower in the mag sulfate treated group (1.9% versus 3.5%).
  - The risk of death did not differ significantly between groups and no woman had a life-threatening event.

### Medical Costs Associated with CP

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Medical costs (2005 dollars)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neither CP or Intellectual Disability</td>
<td>$1,674</td>
</tr>
<tr>
<td>CP Alone</td>
<td>$16,721</td>
</tr>
<tr>
<td>Both CP and Intellectual Disability</td>
<td>$43,338</td>
</tr>
</tbody>
</table>

- Among Medicaid-enrolled children, medical costs...
  - For children with CP alone were **10 times higher** than for children without CP or intellectual disability.
  - For children with both CP and intellectual disability were **26 times higher** than for children without either.
  - For children with both CP and intellectual disability were almost **3 times higher** than for children with CP alone.

Racial Disparities in Severity of Gross Motor Limitations

• Overall prevalence by race
  – 3.7 per 1,000 Black children
  – 3.2 per 1,000 White children

• Among children with cerebral palsy, Black children had higher rates of limited or no walking ability

<table>
<thead>
<tr>
<th>Gross Motor Limitations</th>
<th>Black-White Prevalence OR (95% CI)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>GMFCS Level I &amp; II</td>
<td>0.9 (0.7- 1.3)</td>
</tr>
<tr>
<td>GMFCS Level III</td>
<td>1.6 (0.8- 3.3)</td>
</tr>
<tr>
<td>GMFCS Level IV &amp; V</td>
<td>1.7 (1.1- 2.4)</td>
</tr>
</tbody>
</table>

*Imputed Analysis

## Frequency of Autism Spectrum Disorder, MADDSP, SY 2000-2006

<table>
<thead>
<tr>
<th>Year</th>
<th>Among children with CP</th>
<th>Among all children</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>8.9 (12)</td>
<td>0.65</td>
</tr>
<tr>
<td>2002</td>
<td>8.9 (15)</td>
<td>0.76</td>
</tr>
<tr>
<td>2004</td>
<td>9.8 (14)</td>
<td>0.89</td>
</tr>
<tr>
<td>2006</td>
<td>9.0 (16)</td>
<td>1.0</td>
</tr>
</tbody>
</table>
CP in the CDC–Denmark Collaboration

- Established agreement with the Danish Medical Research Council to collaborate on research
- Use Denmark’s unique data infrastructure to address questions for which:
  - Data are not currently available in the US, or
  - Much more costly to replicate

- Partners include:
  - University of Aarhus
    - Department of Epidemiology
    - Department of Biostatistics
    - University Hospital of Child and Adolescent
    - University Hospital, Skejby
  - Staten Serum Institute
    - Department of Clinical Biochemistry
      - Newborn Screening Biobank
  - Collaborations with several other Danish institutions in a network
Why A Collaboration with Denmark?

• National network of database systems
  – Nearly 200 disease and administrative databases
  – Unique personal identifier for each citizen links to data systems
  – Permits assembly of cohorts with unaggregated, individual level data on thousands or millions of people

• National Biobank of PKU Samples
  – Established in 1982

• “Better Health for Mother and Child”
  – Danish National Birth Cohort of over 100,000 pregnant women and their offspring
    • Includes blood samples, pre- and postnatal interviews, etc.
Examples of CDC-Denmark Analyses In Progress

- Prenatal exposure to self-reported maternal infections, smoking, and congenital cerebral palsy
- Maternal infections during pregnancy and the risk of cerebral palsy in singleton births: Results from a large population-based cohort study
- Association between early motor milestones and cerebral palsy among CP cases in the Danish National Birth Cohort
Summary

• Epidemiology is the science that provides the information upon which public health decisions can be responsibly made.

• The epidemiology of cerebral palsy is a rapidly evolving field.

• CDC is involved in understanding more about CP using the public health model in order to ultimately guide prevention programs and public policy.
Acknowledgements

“It Takes A Village”

• It takes many individuals at each ADDM Network site to run our monitoring programs, including:
  – Primary investigators, project coordinators, abstractors, data managers, programmers, clinician reviewers, epidemiologists and other project staff

• They are dedicated, creative, hard-working, and resourceful and we are thankful for each and every one of them!
How Can I Get Public Health Training?

• Student Internships and Fellowships
• Post-doctoral Research Fellowships
• Career Training Fellowships
  – Epidemic Intelligence Service
  – ASPH/CDC Public Health Fellowship Program
  – Presidential Management Fellows
• CDC Training Resources
  – Minority Health Workforce Internship Opportunities
  – Training and Continuing Education Online

For more information about these and many more opportunities, please visit http://www.cdc.gov/Fellowships/
Thank you!
You can contact me at mxy1@cdc.gov

For more information, please visit www.cdc.gov/cp

For more information please contact Centers for Disease Control and Prevention

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