The Frequency of Cerebral Palsy in the Population: Results from Population-Based Surveillance

Waisman Center Cerebral Palsy Day with the Experts

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Presentation Overview

- Overview of cerebral palsy (CP) surveillance
- Frequency and characteristics of CP
- CP and low birth weight
- CP and motor function
- How can we use these data to improve outcomes and quality of life for individuals with CP?
Public Health Model

Surveillance

Partnerships

Epidemiologic Research

Prevention
What is Public Health Surveillance?

- Ongoing, systematic collection, analysis, and interpretation of data (e.g., regarding agent/hazard, risk factor, exposure, health event)

- Also referred to as “tracking” or “monitoring”
1979: How Many Children Have a Developmental Disability?
The Impetus for Cerebral Palsy Surveillance at CDC

1968: Start of birth defects surveillance at CDC

1979-80: Request for presentation of data on intellectual disability and cerebral palsy

1981: EIS Officer assigned to Birth Defects Branch to study developmental disabilities

1981-83: Pilot study in DeKalb County, GA
Multi-source, records-based surveillance methodology
CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network CP Sites

- Georgia
- Missouri
- Wisconsin
The Goals of the ADDM CP Network

• Obtain a complete count of the number of children with CP in each project area.

• Provide comparable, population-based CP prevalence estimates in different sites.

• Study if CP is more common in some groups of children than in others, and if rates are changing over time.
What can we learn from ADDM CP network surveillance?
Frequency of Cerebral Palsy ADDM Network, 2006-2010

Prevalence per 1,000 children aged 8 years

Year

Durkin et al., 2016
Percentage of Low Birth Weight children with CP ADDM Network, 2006-2010

Durkin et al., 2016
Cerebral Palsy More Common among Boys
ADDM Network, 2006-2010

Durkin et al., 2016
Majority of Children Have Spastic Cerebral Palsy

- Non-Spastic includes dyskinetic, ataxic, hypotonic, and dyskinetic-ataxic
- Other includes spastic-ataxic, spastic-dyskinetic, and cerebral palsy not otherwise specified

Durkin et al., 2016
Many Children with Cerebral Palsy Have Co-Occurring Epilepsy and/or Autism

- **41%** with co-occurring epilepsy

- **6.9%** with co-occurring autism
  - Overall prevalence of autism among US children is about 1-2% → Prevalence of autism among children with CP seems to be higher than among their peers without CP

Christensen et al., 2016
Over Half of Children with Cerebral Palsy Walk Independently

- Walking ability data available on 74.7% of children identified with CP by ADDM CP Network

Christensen et al., 2016
Cerebral Palsy More Common among Black Children than White Children, ADDM Network 2006-2010

Durkin et al., 2016
To investigate racial/ethnic disparities, we analyzed the data and found the following:

1. CP frequency decreases with higher SES.

2. Racial/ethnic disparity in CP risk is only partially explained by racial/ethnic disparities in SES.

3. Perinatal factors (including preterm birth and low birth weight) help explain the association between race and CP risk.
# Racial/Ethnic Disparities in Severity of Gross Motor Function

<table>
<thead>
<tr>
<th>Gross Motor Function Classification Scale (GMFCS)</th>
<th>Black-White Prevalence Odds Ratio</th>
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<tbody>
<tr>
<td>GMFCS Level I &amp; II</td>
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<tr>
<td>GMFCS Level III</td>
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<tr>
<td>GMFCS Level IV &amp; V</td>
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</tbody>
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Maenner et al., 2016
Racial/Ethnic Disparities in Severity of Gross Motor Function

Potential mechanisms?
- Racial differences in risk factors
- Access to interventions
- Under-identification of mild CP in black children

Maenner et al 2016
More Than Just a Number...

- Increase awareness of CP
- CDC’s CP Surveillance Data
- Help communities to coordinate service delivery
- Guide research of other scientists
- Provide a more complete picture of children with CP
Summary

• The frequency of CP in the ADDM CP Network declined between 2006 and 2010.

• Racial/ethnic disparities exist among children with CP
  – Black children were more likely to have CP, and this may be due to perinatal risk factors.
  – Black children with CP were more likely to have limited or no walking ability.

• Further studies of the population characteristics of CP, including disparities, can help ensure that all children reach their full potential.
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!