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

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I have nothing to disclose.

Presentation Overview

- Definition of public health surveillance
- Overview of CDC cerebral palsy (CP) surveillance
- Frequency and characteristics of CP
- Disparities in CP: birthweight/gestational age, sex, race, socioeconomic status and motor function
- How can we use these data to improve outcomes and quality of life for individuals with CP?

PUBLIC HEALTH MODEL FOR CEREBRAL PALSY
Public Health Model

What is Public Health Surveillance?

- The ongoing, systematic collection, analysis, and interpretation of data (e.g., regarding agent/hazard, risk factor, exposure, health event) essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control.

1979: How Many Children Have a Developmental Disability?

1968: Start of birth defects surveillance at CDC

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

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

1981-83: Pilot study of MR/ID in DeKalb County, GA
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.

CDC’s Cerebral Palsy Surveillance Method

Multisource, records-based surveillance methodology

Trained abstractors review and abstract selected records at multiple data sources in the community that educate, diagnose, treat, and provide services to children with developmental disabilities.

Trained clinicians review abstracted information from all data sources for a given child. These trained clinicians then determine if the child meets the case status for CP

Ongoing, Population-Based Surveillance

Strengths

• Active record review
• Multiple community sources
• Does not rely on previously documented CP diagnoses
• Can examine CP by subtype, race/ethnicity & co-occurring DDs
• Objective, reliable measures
• Ability to link to other datasets
• Minimal burden
• Ongoing program to monitor trends
• Extensive QC measures

Limitations

• More labor intensive and costly to operate than passive systems
• Timeliness
• May underestimate children with mild CP who have not come to the attention of service providers early in childhood
• Dependent on the availability/quality of records
Definition of CP for Surveillance

Defined as 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.*

- The motor disorders of CP are often accompanied by disturbances of sensation, perception, mental ability, communication, and behavior.*
- CP is also often accompanied by co-occurring epilepsy; and by secondary musculoskeletal problems.*
- The impairment of motor function may result in paresis, involuntary movement, or incoordination.
- CP does not include motor disorders that are transient, that result from progressive disease of the brain, or that are due to spinal cord abnormalities/injuries.
- CP acquired after birth (post-neonatal CP) are included as cases.


SURVEILLANCE FINDINGS: THE BASICS

Frequency of Cerebral Palsy ADDM Network, 2006-2010

SURVEILLANCE FINDINGS: CHARACTERISTICS OF THE POPULATION
**Percentage of Low Birth Weight children with CP ADDM Network, 2006-2010**

- 2006: 20%
- 2008: 25%
- 2010: 30%

Durkin et al., 2016

**Cerebral Palsy More Common among Boys ADDM Network, 2006-2010**

- 2006: Boys 2.5, Girls 1.5
- 2008: Boys 3.0, Girls 2.0
- 2010: Boys 3.5, Girls 2.5

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., 2014
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

SURVEILLANCE FINDINGS: DISPARITIES IN CEREBRAL PALSY

Cerebral Palsy More Common among Black Children than White Children, ADDM Network 2006-2010

Role of Socioeconomic Status and Perinatal Factors in Racial Disparities

- Tested three hypotheses:
  1. Risk of CP declines with increasing SES (maternal education)
  2. Observed racial/ethnic disparity in CP risk is due to confounding or is mediated by racial disparities in SES
  3. Perinatal factors (PTB & SGA) mediate the association between race as well as maternal education and CP risk

Durkin et al., 2016
Role of Socioeconomic Status and Perinatal Factors in Racial Disparities: Hypothesis 1

<table>
<thead>
<tr>
<th>SES Category</th>
<th>All CP Risk Ratio</th>
<th>Spastic CP Risk Ratio</th>
<th>Non-Spastic and Unspecified CP Risk Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>1.65</td>
<td>1.85</td>
<td>0.99</td>
</tr>
<tr>
<td>Middle</td>
<td>1.34</td>
<td>1.43</td>
<td>1.10</td>
</tr>
<tr>
<td>High</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
</tr>
</tbody>
</table>

Durkin et al., 2015

Role of Socioeconomic Status and Perinatal Factors in Racial Disparities: Hypothesis 2

<table>
<thead>
<tr>
<th>Race/Ethnicity Category</th>
<th>Spastic CP Risk Ratio</th>
<th>Spastic CP Odds Ratio (after adjusting for SES*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td>Black</td>
<td>1.52</td>
<td>1.35</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.89</td>
<td>0.72</td>
</tr>
<tr>
<td>Other/Undetermined</td>
<td>1.08</td>
<td>1.07</td>
</tr>
</tbody>
</table>

*SES in this analysis is based on maternal educational attainment

Durkin et al., 2015

Role of Socioeconomic Status and Perinatal Factors in Racial Disparities: Hypothesis 3

<table>
<thead>
<tr>
<th>Race/Ethnicity Category</th>
<th>All CP Odds Ratio</th>
<th>Spastic CP Odds Ratio</th>
<th>Non-Spastic and Unspecified CP Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td>Black</td>
<td>0.87</td>
<td>0.92</td>
<td>0.68</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.75</td>
<td>0.77</td>
<td>0.71</td>
</tr>
</tbody>
</table>

Odds ratios for each category are adjusted for: SES, sex, maternal age, gestational age at birth, small for gestational age, documented receipt of prenatal care, and multiple birth

Durkin et al., 2015

Role of Socioeconomic Status and Perinatal Factors in Racial/Ethnic Disparities

Tested three hypotheses and found:

1. Risk of CP declines with increasing SES

2. Observed racial/ethnic disparity in CP risk is due to confounding or is mediated by racial/ethnic disparities in SES

3. Perinatal factors (PTB & SGA) mediate the association between race as well as maternal education and CP risk

Durkin et al., 2015
Role of Socioeconomic Status and Perinatal Factors in Racial Disparities

- Further research needed:
  - Causal mechanisms underlying associations between low SES and spastic CP
  - Effects of other components of SES: income, occupation, insurance coverage, access to prenatal care
  - Longitudinal trajectories—evaluation of direction of association between CP and disparities in race/ethnicity and SES

- Public health goal: reduce risk of CP in the population overall to the level of risk experience by offspring of college-educated mothers
  - How might we achieve this goal?

Racial Disparities in Severity of Gross Motor Function

<table>
<thead>
<tr>
<th>Gross Motor Limitations</th>
<th>Black-White Prevalence Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>GMFCS Level I &amp; II</td>
<td>0.9</td>
</tr>
<tr>
<td>GMFCS Level III</td>
<td>1.6</td>
</tr>
<tr>
<td>GMFCS Level IV &amp; V</td>
<td>1.7</td>
</tr>
</tbody>
</table>

WHERE DO WE GO FROM HERE?
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A New Look at Trends in Cerebral Palsy over Time

Prevalence of Cerebral Palsy in Metropolitan Atlanta,

Van Naarden Braun et al., 2016

Where Do We Go From Here?
A New Look at Trends in Cerebral Palsy Birth Prevalence over Time

By Race/ethnicity and Birth weight

Van Naarden Braun, 2016 *p<0.05

Where Do We Go From Here?
A New Look at Trends in Cerebral Palsy Birth Prevalence over Time

- Racial disparities persisted over time
- No significant trends were observed by subtype, birth weight or gestational age overall
- BUT, different patterns did emerge for White non-Hispanic and Black non-Hispanic children by birth weight and gestational age

Van Naarden Braun et al., 2016
What's Impacting Trends in Cerebral Palsy Over Time?


Schwartz et al., 1994; O’Shea et al., 1997; Shinwell et al., 2000; Stark et al., 2014

Where Do We Go From Here?
A New Look at Trends in Cerebral Palsy over Time

Prevalence of Postneonatal Cerebral Palsy per 10,000 children aged 8 years, by etiology and race/ethnicity, MADDSP, 1991-2008

Infection Injury Cerebrovascular Accident Hypoxia/Encephalopathy

Where Do We Go From Here?
More research needed on the multitude of factors that could be impacting disparities in CP prevalence
More Than Just a Number...

Summary

- A public health model which includes prevention is used in understanding the epidemiology of CP
- CP occurs in about 1 in every 345 children in the US
- Most recent CDC data report that about 50% of children with CP were born low birthweight
- Boys and black children are more affected with CP than girls and white children and CP is more severe in black children
- Spastic CP is the most common CP subtype and children with CP have other disabilities
- CDC data show that there are racial disparities in the prevalence of cerebral palsy and those disparities have continued over time
- More studies are needed to explore how maternal education and other socioeconomic factors impact the risk of CP within racial/ethnic groups
- Findings from additional studies might inform the development of public health intervention/prevention of CP

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!
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Thank you!
You can contact me at mxy1@cdc.gov

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