Challenges in cerebral palsy surveillance: seeking harmony in inclusion and exclusion criteria

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Background

Common themes:
- Prevention
- Population surveillance
- Building a dataset for CP research
- Service planning

Collaboration

Inclusion criteria

Inclusion/exclusion criteria

Increase power for research
Monitor trends between and across regions
Evaluate new interventions
Simplifies the use of registers as sampling frames for multi-centre trials

Common inclusion/exclusion criteria
Harmonising criteria
Update the ‘What constitutes CP paper’
Current criteria used.
Criteria still debated?

Aims

Survey of CP registers, 2009


SCPE ‘decision tree’ & Badawi et al, 1998

Method

Age ascertainment considered complete
Exclusion of progressive conditions
Lower age limit for postneonatal brain damage

Agreement
What constitutes cerebral palsy?

Yulia Balatsi MSc MD FRAC, Fellow in Neurology, King Edward Memorial Hospital; Lipko Waterhouse Research Institute, Women’s and Children’s Health Research, Perth, WA, Australia

An update

1. Disorder of motor function


Mild, moderate & severe
Now GMFCS & MACS?
Activity limitation?
Does a disorder of movement and posture = activity limitation?
If no, is activity limitation necessary – and how severe an activity limitation?
No agreed severity criteria
Neurological signs +/- functional impairment?

1. Disorder of motor function

- Excluding cases who have died prior to age of final data collection excludes the most severe cases
- Problems with inclusion approach
- Changing landscape: Qualitative Assessment of General Movements

2. Minimum age of survival

Figure 1

Does the child have a disorder of motor function? Does the child have a disorder of movement or posture of central origin?

Yes
No

In the condition progressive cases of apparently arrested athetosis

Exclude

Does the child have a disorder of motor function?

Yes
No

Was the child at least 4 years old when assessed?

No
Yes

Does the child have a disorder of movement or posture of central origin?
Variable between CP registers (2-8 years)

Reflective of timing of:
- final data collection?
- regional definitions of brain injury?

Paediatric brain injury experts to assist in finding a consensus?

3. Maximum age for postneonatal injury

If clinical presentation meets the criteria for CP, then record the genetic abnormality as a co-occurring event.

Ensures greater consistency over time and allows for a broad sampling frame from which to select cases.

4. Chromosomal anomalies

<table>
<thead>
<tr>
<th>Syndromes/disorders</th>
<th>Badawi et al 1998 category</th>
<th>Consensus on inclusion/exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>18p- syndrome</td>
<td>A2</td>
<td>Included as a comorbidity if case meets clinical criteria for CP</td>
</tr>
<tr>
<td>3 methyl glutaric acid hydratase deficiency or 3-methylglutaryl-coA hydratase deficiency, 3MG-coA hydratase deficiency/IMGA type 1</td>
<td></td>
<td>Included as a comorbidity if case meets clinical criteria for CP</td>
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<tr>
<td>Aase Smith</td>
<td>B</td>
<td>Included as a comorbidity if case meets clinical criteria for CP</td>
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<tr>
<td>Absent septum pellucidum</td>
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<td>Included as a comorbidity if case meets clinical criteria for CP</td>
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<tr>
<td>Agammaglobulinaemia</td>
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<td>Included as a comorbidity if case meets clinical criteria for CP</td>
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<tr>
<td>Aicardi syndrome</td>
<td></td>
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</tbody>
</table>

Considerable agreement exists

Further discussion is warranted
- Severity of motor function or activity limitation
- Minimum age of survival for inclusion
- Maximum age for postneonatal injury

Publication of an updated ‘What constitutes CP’ article and on-line appendices

On-going dialogue

Conclusion
• Nadia Badawi
• Eve Blair
• Christine Cans
• Kate Himmelmann
• Meredith Wilson

• Ingeborg Krägeloh-Mann
• Sarah McIntyre
• Peter Uldall
• Linda Watson
• Jennie Slee

Acknowledgements