Challenges in estimating cerebral palsy prevalences and trends

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Aims of CP registers

Surveillance: determining prevalence and time trends.

World CP Congress Survey Report 2009

Prevalence

$$= \frac{\text{Number of cases}}{\text{Number at risk of condition}}$$

In a defined area at a defined point in time

$$N \text{ cases} = \frac{\text{registered number of cases}}{\text{ascertainment fraction}}$$

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In a defined area at a defined point in time

N =

N at census/birth x (in migration, out migration, mortality, neonatal survival)

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(a) Prevention: by clarifying the multiple aetiologies and evaluating preventive strategies.

(b) Improve quality of life of those with CP: by assisting with development and planning of services.

To assist with planning and development of services: want

- Number requiring services

What is Cerebral Palsy?

- An umbrella term for many disorders of movement and/or posture
- due to non-progressive cerebral lesions or anomalies
- arising in the immature brain
- may be accompanied by many other impairments

A clinical description rather than a diagnosis – it does not inform aetiology, pathology or prognosis

Why ‘Cerebral Palsy’?

- All require motor habilitation
- The means of motor habilitation very variable
- Dependent on type, location and severity of motor and other associated impairments

To assist with planning and development of services: want

Number requiring particular services

sub-classification should reflect the types of services from which they would benefit

Sub-classification by service requirements?

Numbers by GMFCS

x Upper limb function
x Oropharyngeal function
x Cognitive function
x Sensory function
x Communicative ability and Psychological and behavioural problems

Aims of CP registers

Surveillance: determining prevalence and time trends.

(a) Prevention: by clarifying the multiple aetiologies and evaluating preventive strategies

(b) Improve quality of life of those with CP: by assisting with development and planning of services

For clues to aetiology: want incidence=

$$\frac{\text{Number of new cases}}{\text{Number at risk of condition}}$$

What is Cerebral Palsy?

- An umbrella term for many **disorders of movement and/or posture**
- due to **non-progressive lesions or anomalies arising in the immature brain**

For early deaths should an incident case be defined as:

- Those with a relevant brain lesion/anomaly?
- Those in whom motor impairment is apparent
- OR can we only include those who survive to an age at which voluntary motor activity is clearly impaired and one can be reasonably sure that the cerebral lesion is not progressive?

“Birth” Prevalence =

$$\frac{\text{Number of cases (at age of recognition)}}{\text{Number at risk of condition (at birth)}}$$

In a defined area at “birth”

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Proximal factors
direct effectors of cerebral abnormality

- Malformation
- Ischaemia
- Toxins:
  - exogenous
  - endogenous
- Nutritional Deficits
- Direct microbial attack
- Stroke

Distal factors
(precusors of proximal factors)

- Conditions and events allowing proximal factors to occur

Overall prevalence

Not very useful for elucidating individual aetiology.

For clues to aetiology: want incidence in aetiologically relevant categories =

$$\frac{\text{N new cases with an aetiologically relevant factor}}{\text{Number at risk of condition}}$$

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Time trends

- Derived from a series of prevalence estimates over time.
- Reliable reflection of change in prevalence of condition ONLY if all prevalences are estimated under constant conditions.

Determinants of estimated prevalence

I : Likely to be under Register control

- Definition of CP
  - maximum age of acquisition
  - minimum age of survival
  - minimum severity

Determinants of estimated prevalence

II: Less likely to be under Register control

- Changes in diagnostic ability
- Changes in clinical practice in applying CP label
- Increasing clinical concerns about privacy
- Introduction of privacy legislation requiring consent for registration
- Changes in structure of service provision
- Changes in migration patterns or survival that differ between cases and controls

Are time trends useful?

- Valid clinically or aetiologically specific time trends are useful in a field where hypotheses are few and the means of testing them limited.

- The challenge is ensuring that the ARE valid.

Conclusions re challenges

- To maximise ascertainment fraction and reduce bias therein
- Address the effects of migration and mortality appropriately vis a vis service provision and aetiological research.
- Before accepting time trends, investigate changes over time in factors which determine prevalences as estimated by your register.

Suggestions re way forward

- Estimate clinically specific prevalences

  Requires clinically relevant, reliable and universally accepted classification systems for the many impairments

- Estimate prevalence specific to aetiologically relevant factors.

  These will change as we move closer to identifying discrete causal pathways

Thank you for your attention