IN CHILDREN WITH EPILEPSY

HOW DOES IT COMPARE TO CHILDREN IN THE GENERAL POPULATION & TO CHILDREN WITH CEREBRAL PALSY?

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McMaster University Hamilton On
FINANCIAL DISCLOSURE

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• The funding agency had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data
BACKGROUND

- Epilepsy (10.2/1000) & CP (3.6/1000) are the most common neurological conditions in childhood
- Both have profound social and public health impacts worldwide, as children and as adults
RESEARCH QUESTION

How does the quality of life (QoL) of children with epilepsy compare to that of children in the general population and children with CP?
WHAT IS QUALITY OF LIFE?

QoL often means different things to different people

Our operational definition is consistent with that of the WHO: ‘an individual’s perception of [his/her] position in life… in relation to their goals, expectations, standards and concerns’ WHOQOL 1993
DANCERS WITH IMPAIRMENTS
THE ‘DISABILITY PARADOX’

There is an increasing body of evidence that suggests that it is difficult to attribute better or poorer QoL solely to the biological aspects of a disease and its medical treatment

Albrecht & Devliger 1999
HOW TO MEASURE QOL IN CHILDREN?

• Optimal way is for children to self-report on their life experience…

• …but a more complete understanding of QoL involves both child- and proxy-reported QoL to capture multiple perspectives
OBJECTIVES

(i) To compare the self- and proxy-reported QoL of children with epilepsy to that of children in the general population

(ii) To compare the self- and proxy-reported QoL of children with epilepsy to that of children with CP
HYPOTHESIS

• Children’s self-reports will be similar to those from children from the general population

• Parental assessments might identify condition-specific observations and concerns
STUDY OVERVIEW

• We measured self- and proxy-reported QoL of children with epilepsy

• Contrasted it with data from:
  • the general population (European KIDSCREEN 2005-6)
  • children with CP (SPARCLE study 2006-8)
EPILEPSY DATA OVERVIEW

Baseline data from the QUALITÉ longitudinal study of patient-reported outcomes (PROs) in children with epilepsy

Six tertiary care study sites across Canada

Broad inclusion criteria:

- 8-12 years old at baseline
- Ability to self-report (estimated verbal IQ>70)
- Active epilepsy or medication-managed
- Understand English or French
QOL MEASUREMENT

- The KIDSCREEN is a transcultural generic QoL measure developed across 13 European countries, for individuals 8-18 years old
- Validated on 22,827 children and adolescents
- Shown to be a reliable, valid, sensitive and conceptually appropriate QoL measure in many countries Ravens-Sieberer 2005
## THE KIDSCREEN-52 MEASURE

<table>
<thead>
<tr>
<th>Domain</th>
<th>Number of Items</th>
<th>Domain Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Wellbeing</td>
<td>5</td>
<td>Physical activity level, energy and fitness</td>
</tr>
<tr>
<td>Psychological Wellbeing</td>
<td>6</td>
<td>Positive emotions and satisfaction with life</td>
</tr>
<tr>
<td>Moods &amp; Emotions</td>
<td>6</td>
<td>Depressive moods and stressful feelings</td>
</tr>
<tr>
<td>Self-Perception</td>
<td>5</td>
<td>Satisfaction with looks and clothes</td>
</tr>
<tr>
<td>Autonomy</td>
<td>5</td>
<td>Control over social and leisure time</td>
</tr>
<tr>
<td>Parent Relation &amp; Home Life</td>
<td>6</td>
<td>Relationship with parents and the atmosphere at home</td>
</tr>
<tr>
<td>Social Support &amp; Peers</td>
<td>6</td>
<td>Relationship with other children</td>
</tr>
<tr>
<td>Financial Resources</td>
<td>3</td>
<td>Availability of monetary funds</td>
</tr>
<tr>
<td>School Environment</td>
<td>6</td>
<td>Feelings about school</td>
</tr>
<tr>
<td>Bullying</td>
<td>3</td>
<td>Rejection by peers (social acceptance)</td>
</tr>
</tbody>
</table>
WHY THE P VALUE IS NOT ENOUGH

- ‘The $p$ value was never meant to be used the way it’s used today’ Goodman
- ‘It is hard to drag authors away from their $p$ value, & the more zeroes after the decimal point the harder people cling to them’ Campbell
- We should be asking: ‘How much of an effect is there?’ not ‘Is there an effect?’ Cohen, Cummings
MORE ABOUT THE $P$ VALUE (Nature 2014)

STATISTICAL ERRORS

'values, the 'gold standard' of statistical validity, are not as reliable as many scientists assume.
STATISTICAL ANALYSIS

- For each set of analyses, we used both the self- and proxy-reported scores
- Sum scores of each domain were converted to a value out of 100 (= SPARCLE Study)
- Clinical importance was set at 0.5 SD [effect size of 0.5] Norman et al. 2004
## RESULTS: DEMOGRAPHICS

<table>
<thead>
<tr>
<th></th>
<th>Epilepsy</th>
<th>Cerebral Palsy</th>
<th>General Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (min-max)</td>
<td>9.9 (8-12)</td>
<td>10.2 (8-12)</td>
<td>9.7 (8-11)</td>
</tr>
<tr>
<td>Sample Size</td>
<td>345</td>
<td>489</td>
<td>5950</td>
</tr>
<tr>
<td>Sex (% female)</td>
<td>47.8%</td>
<td>43%</td>
<td>51.3%</td>
</tr>
<tr>
<td>Countries (language)</td>
<td>Canada (281 English, 64 French)</td>
<td>UK, France, Denmark, Ireland, Germany, Sweden, Italy</td>
<td>Hungary, UK, Netherlands, Germany, Switzerland, Poland, Czech Republic, Austria, France, Ireland, Spain</td>
</tr>
<tr>
<td>Overlap</td>
<td>10(3%)</td>
<td>44(9%)</td>
<td></td>
</tr>
</tbody>
</table>
CHILD REPORTED DATA

NONE OF THE DIFFERENCES AMONG THE GROUPS REACHED THE LEVEL OF CLINICAL IMPORTANCE (COHEN’S $d$)

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<td></td>
<td>Epilepsy</td>
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</tr>
<tr>
<td>Physical Wellbeing</td>
<td>79.2</td>
<td>76.7</td>
</tr>
<tr>
<td>Psychological Wellbeing</td>
<td>86.0</td>
<td>83.5</td>
</tr>
<tr>
<td>Moods &amp; Emotions</td>
<td>81.4</td>
<td>85.5</td>
</tr>
<tr>
<td>Self- Perception</td>
<td>86.4</td>
<td>84.0</td>
</tr>
<tr>
<td>Autonomy</td>
<td>81.0</td>
<td>78.1</td>
</tr>
<tr>
<td>Home Life</td>
<td>86.9</td>
<td>86.2</td>
</tr>
<tr>
<td>Social Support</td>
<td>82.4</td>
<td>76.4</td>
</tr>
<tr>
<td>Financial Resources</td>
<td>69.6</td>
<td>73.2</td>
</tr>
<tr>
<td>School Environment</td>
<td>79.8</td>
<td>81.0</td>
</tr>
<tr>
<td>Bullying</td>
<td>84.7</td>
<td>89.2</td>
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CHILD REPORTED $P$ VALUES

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<th>$p$</th>
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</tr>
<tr>
<td>Physical Wellbeing</td>
<td>79.2</td>
<td>76.7</td>
<td>76.4</td>
<td>0.015</td>
</tr>
<tr>
<td>Psychological Wellbeing</td>
<td>86.0</td>
<td>83.5</td>
<td>82.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Moods &amp; Emotions</td>
<td>81.4</td>
<td>85.5</td>
<td>82.1</td>
<td>&lt;0.001</td>
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<tr>
<td>Self- Perception</td>
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<tr>
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<tr>
<td>School Environment</td>
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</tr>
<tr>
<td>Bullying</td>
<td>84.7</td>
<td>89.2</td>
<td>85.2</td>
<td>&lt;0.001</td>
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</tbody>
</table>
# PROXY-REPORTED DATA

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<tbody>
<tr>
<td></td>
<td>Epilepsy</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>Physical</td>
<td>77.3</td>
<td>64.8</td>
</tr>
<tr>
<td>Wellbeing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td>79.8</td>
<td>70.0</td>
</tr>
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<td>Social Support</td>
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CONCLUSIONS

• Children with epilepsy tend to perceive their QoL to be similar to that of their typical peers, despite any level of impairment.

• Parents of children with epilepsy report a clinically important difference in the QoL domains of:
  (i) mood and emotion in comparison to that of children with CP and those in the general population
  (ii) bullying compared to the CP group
WHAT THESE FINDINGS MEAN...

• Families should be reassured that most children with epilepsy do not perceive differences in QoL compared to their peers.
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• Clinicians routinely need to address the potential parental concerns of mental health and bullying in their daily practice.
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• Clinicians routinely need to address the potential parental concerns of mental health and bullying in their daily practice

• Epilepsy programs need to provide psychosocial as well as medical services to the families we serve