The quality of life of children with cerebral palsy: the SPARCLE study

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on behalf of the SPARCLE group

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Quality of life

• Child’s **level of functioning** in each of the core areas defined by the ICF has direct impact on the way s/he lives his/her life.

• Essential to go beyond **objective** measures to try and capture the child’s **subjective** appreciation of his/her life.

• **Definition** (WHOQOL, 1993):
  “An individual’s perception of their position in life in the context of the cultural and values systems in which they live, and in relation to their goals, expectations, standards and concerns.”

• **Multi-dimensional** construct

• Increasingly recognised as **important determinant of health**
Quality of life (2)

In children
- 90% studies used proxies to assess child QoL (Bullinger, 1995)
- Children should self-report where possible (WHO, 1993)
- A few studies compare child and parents reports of QoL (Eiser & Morse, 2001)

In children with cerebral palsy (CP)
- Small or clinic-based studies relying on parental proxy-reports of child QoL
- Conflicting evidence concerning relationship between QoL and severity of motor impairment → domains related to physical symptoms more affected than other domains
Quality of life (3)

Research is lacking

- on self-reported QoL (subjective perceptions) in large population-based samples of disabled children
- on multi-informant proxy-reported QoL in children with severe disabilities

Underlying conceptual bases

- QoL of children with CP should be assessed using same standards as for all children
- Every effort should be made to obtain children’s own opinion on their QoL
- Disagreement between respondents should not be considered as bias but reflects different perspectives
Aims of the SPARCLE Study

• Assess QoL of all children with CP
  – regardless of the severity of impairment
  – using self-report wherever possible

• Study child, parent and professional reports

• Examine determinants of disagreement between respondents
Quality of life measure

- **KIDSCREEN-52** (Ravens-Sieberer et al, 2001)
- **Generic** QoL questionnaire (child and proxy versions)
- Based on **focus groups with children** and parents from several European countries
- 52 items grouped into **10 domains**
  - Physical well-being
  - Autonomy
  - Psychological well-being
  - Moods and emotions
  - Self-perception
  - Parent relations/home life
  - Peers and social support
  - School life
  - Bullying (social acceptance)
  - Financial resources
- Domain scores from **0 to 100** (0=worst QoL, 100=best QoL)
<table>
<thead>
<tr>
<th>Physical well-being</th>
<th>Explores the level of the child’s physical activity, energy and fitness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological well-being</td>
<td>Examines the psychological well-being of the child, including positive emotions and satisfaction with life</td>
</tr>
<tr>
<td>Moods and emotions</td>
<td>Covers how much the child experiences depressive moods and emotions, and stressful feelings</td>
</tr>
<tr>
<td>Self-perception</td>
<td>Explores whether the child perceives his/her bodily appearance positively or negatively; body image is explored by questions concerning satisfaction with looks as well with clothes and other accessories</td>
</tr>
<tr>
<td>Autonomy</td>
<td>Looks at the child’s opportunities to create leisure and social time</td>
</tr>
</tbody>
</table>
Parental relations
Examines relationships with parents and atmosphere at home

Social support and peers
Examines the nature of the child’s relationships with other children

School environment
Explores the child’s perceptions of their cognitive capacity, learning and concentration and their feelings about school

Social acceptance (bullying)
Covers the aspect of feeling rejected by peers

Financial resources
Assesses the child’s perceptions of their financial resources
QoL reports in SPARCLE

- Child self-reports as often as possible (formal competency assessment)
- Parent reports should be obtained for all children
- Obtain reports from another informant for non self-reporting children → professionals (teachers, carers, therapists)

- Child self-report study (500 pairs)
- Child/parent comparison (818 observations)
- Parent/ professional comparison (204 pairs)
Walking ability in each group

Gross motor function (GMFCS)

Parent/professional group
204 children

Child self-report and child/parent group
500 children

Total sample
818 children

V Moving severely lim.
IV Moving limited
III Walks with lim.
II Walks inside
I Walks, climbs stairs

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Intellectual impairment in each group (IQ)

Total sample group (parent group)
- IQ < 50: 30%
- IQ 50-70: 23%
- IQ > 70: 47%

Child self-report and child/parent group
- IQ < 50: 24%
- IQ 50-70: 73%
- IQ > 70: 20%

Parent/professional group
- IQ < 50: 80%

818 children
500 children
204 children
Child self-reported QoL (1)

• Aims:
  – describe QoL of children with CP as reported by the children themselves
  – identify factors that affect QoL
  – compare with QoL of children in the general population

Number of children in the group: $N=500$

Dickinson et al., 2007, Lancet
Child self-reported QoL (2)

- QoL of self-reporting children with CP similar to QoL of children in general population
  - except for the *School environment domain* (explores the child’s perceptions of their cognitive capacity, learning and concentration and their feelings about school) where children with CP reported a significant better QoL
  - *Physical well-being* domain not formally analyzed: slight modification to one item for children with CP

- Perspective of the child
  - sense of self from birth incorporates their impairment
  - lives as most children
Child self-reported QoL (3)

• Specific impairments associated with poorer QoL (4 domains)
  – poorer walking ability with poorer Physical well-being,
  – intellectual impairment (IQ<70) with poorer Moods and emotions and with less Autonomy
  – speech difficulty with poorer Relationships with parents

• In most aspects, QoL not associated with impairments: likely to be determined by social and environmental factors
  – cross-sectional study design
  – BUT improvement in physical function, speech or communication might enhance QoL
Child self-reported QoL (4)

- Children who reported pain tended to have lower QoL in all domains
  - significant association in Physical well-being, Moods and emotions, Self-perception, Autonomy, Relationships with parents and School environment.
- 54% experienced pain/discomfort in the previous week (> general population)

- Important and consistent association
- BUT
  - Source of the pain not studied
  - Children with poor QoL might perceive pain differently or report emotional distress as pain
Parent-reported child QoL (1)

Aim:
• **Determine** whether the type and severity of the child’s motor and associated impairments, as well as the family context (socio-economic factors and parental stress), influence the child’s QoL as reported by the parents

Number of children in the group : **N=818**

**Arnaud et al., 2008, Pediatrics**
## Parent-reported child QoL (2)

<table>
<thead>
<tr>
<th>Domains</th>
<th>Responders</th>
<th>Median</th>
<th>IQR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical well-being</td>
<td>97%</td>
<td>55</td>
<td>40 - 70</td>
</tr>
<tr>
<td>Autonomy</td>
<td>95%</td>
<td>65</td>
<td>50 - 75</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>96%</td>
<td>75</td>
<td>63 - 83</td>
</tr>
<tr>
<td>Mood and Emotions</td>
<td>94%</td>
<td>82</td>
<td>75 - 93</td>
</tr>
<tr>
<td>Self perception</td>
<td>93%</td>
<td>80</td>
<td>70 - 90</td>
</tr>
<tr>
<td>Parent relations and home life</td>
<td>96%</td>
<td>79</td>
<td>67 - 92</td>
</tr>
<tr>
<td>Peer and social support</td>
<td>93%</td>
<td>50</td>
<td>33 - 67</td>
</tr>
<tr>
<td>School life</td>
<td>95%</td>
<td>75</td>
<td>63 - 83</td>
</tr>
<tr>
<td>Bullying (social acceptance)</td>
<td>94%</td>
<td>92</td>
<td>75 - 100</td>
</tr>
<tr>
<td>Financial resources</td>
<td>79%</td>
<td>75</td>
<td>50 - 92</td>
</tr>
</tbody>
</table>
Parent-reported child QoL (3)
Factors associated with poor QoL (scores <25<sup>e</sup> p)

- **Motor function**
  - QoL worsens in the *Physical* and *Autonomy* domains as severity of motor impairment increases
  - **BUT** children with least motor impairment have worst QoL at *School* and for *Social acceptance*

<table>
<thead>
<tr>
<th>Motor function</th>
<th>Physical</th>
<th>Autonomy</th>
<th>School</th>
<th>Bullying</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walks, stairs</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Walks inside</td>
<td>2.2</td>
<td>0.8</td>
<td>0.6</td>
<td>0.7</td>
</tr>
<tr>
<td>Walking limited</td>
<td>3.4</td>
<td>2.1</td>
<td>0.4</td>
<td>0.4</td>
</tr>
<tr>
<td>Moving limited</td>
<td>4.7</td>
<td>1.6</td>
<td>0.3</td>
<td>0.2</td>
</tr>
<tr>
<td>Moving sev. lim.</td>
<td>12.4</td>
<td>2.6</td>
<td>0.4</td>
<td>0.1</td>
</tr>
</tbody>
</table>
Parent-reported child QoL (4)
Factors associated with poor QoL (scores <25th p)

- **IQ level**
  - QoL in the *Social support* domain decreases as severity of intellectual impairment increases
  - **BUT** children with IQ<50 have better QoL in terms of *Moods and Emotions* and *Self-perception* than less impaired children

<table>
<thead>
<tr>
<th>IQ level</th>
<th>Moods</th>
<th>Self-percep.</th>
<th>Soc. supp.</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;70</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>50-70</td>
<td>0.7</td>
<td>0.6</td>
<td>1.7</td>
</tr>
<tr>
<td>&lt;50</td>
<td>0.3</td>
<td>0.3</td>
<td>2.7</td>
</tr>
</tbody>
</table>

- **Pain** (parent reports, p=70%) increases risk of poor QoL in the *Physical, Psychological WB* and *Self-perception* domains
Parent-reported child QoL (5)

Family and environment factors

• Parents with higher levels of stress were more likely to report poor QoL for their child in all domains

  Cause or consequence?
  Importance of considering mothers (both parents) well-being

• Parents with high educational qualifications: increased risk of poor QoL in the Parental relations

  Higher expectations for their child, differences between expectations and reality negatively influence their assessment

• Those living in single parent households had poor QoL in the Mood and emotions domain
Comparing child and parent reports of child QoL

Aims:
• **Examine** child and parent perspectives of QoL
• **Interpret** parent scores in cases where child unable to respond

**Underlying conceptual basis:**

 disagreement should not be considered as bias but reflects different perspectives

Number of children in the group: **N=500**

White-Koning *et al.*, 2007, Pediatrics
Quality of life according to child and parent reports (by domain)

Distribution of raw scores

- Physical
- Autonomy
- Psychological
- Emotions
- Self-perception
- Home life
- Social support
- School
- Social acceptance
- Finances

[Box plots showing distribution of raw scores for different domains, with child and parent reports indicated]

Child report
Parent report
Distribution of child/parent disagreement

Definition of agreement = | Child score – Parent score | ≤ SD / 2
Main factors associated with parent<child disagreement

- **High levels of parental stress**
  - child/parent disagreement \( \text{(OR} \sim 2.5) \)
  - Parental relations, Physical WB and School environment domains

- **Intellectual impairments**
  - child/parent disagreement
  - child/parent disagreement \( \text{Autonomy OR} = 1.8 \)
  - child/parent disagreement \( \text{School OR} = 0.1 \)

- **Communication impairments**
  - child/parent disagreement \( \text{(OR} \sim 0.2) \)
  - Emotions and Bullying

- **Behavioural and emotional health**
  - child/parent disagreement
  - Social support \( \text{OR} = 1.9 \)
  - Bullying \( \text{OR} = 2.6 \)
Main factor associated with parent-child disagreement

<table>
<thead>
<tr>
<th>Child pain (child report)</th>
<th>Physical</th>
<th>Autonomy</th>
<th>Psychological</th>
<th>Emotions</th>
<th>School</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>95%CI</td>
<td>OR</td>
<td>95%CI</td>
<td>OR</td>
</tr>
<tr>
<td>No pain</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Slight pain</td>
<td>0.7 [0.3 1.7]</td>
<td>1.7 [0.8 3.7]</td>
<td>1.0 [0.4 2.3]</td>
<td>0.9 [0.4 2.0]</td>
<td>1.5 [0.8 3.1]</td>
</tr>
<tr>
<td>Moderate pain</td>
<td>1.4 [0.7 2.8]</td>
<td>2.0 [1.0 3.8]</td>
<td>1.6 [0.8 3.5]</td>
<td>1.5 [0.8 2.8]</td>
<td>1.4 [0.7 2.7]</td>
</tr>
<tr>
<td>Severe pain</td>
<td>2.0 [0.8 4.8]</td>
<td>2.1 [1.0 4.6]</td>
<td>1.8 [0.7 4.3]</td>
<td>2.3 [1.1 5.0]</td>
<td>2.4 [1.1 5.2]</td>
</tr>
<tr>
<td>Very severe pain</td>
<td>3.4 [1.2 9.7]</td>
<td>5.0 [1.9 13.3]</td>
<td>4.8 [1.5 15.5]</td>
<td>4.1 [1.7 9.9]</td>
<td>5.7 [2.2 14.6]</td>
</tr>
</tbody>
</table>

Pain (child report)

In 5 domains, children reporting **severe and frequent pain** were more likely to rate their QoL significantly lower than their parents.
The QoL of children with severe CP according to parents and professionals

Aims

• Determine the factors associated to low QoL in children with CP and intellectual impairment (IQ<70) according to parents and professionals (teachers, carers and therapists)

• Examine the differences between respondents

Number of children : N=204

White-Koning et al., 2008, Dev Med & Child Neurol
# Parent and professional reports of child QoL (2)

<table>
<thead>
<tr>
<th></th>
<th>Parent reports</th>
<th>Professional reports</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>37.8 (21.2)</td>
<td>44.4 (22.2)</td>
<td>0.002</td>
</tr>
<tr>
<td>Physical</td>
<td>47.6 (19.9)</td>
<td>46.7 (18.9)</td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td>57.3 (21.0)</td>
<td>55.7 (21.2)</td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td>71.1 (16.3)</td>
<td>67.2 (15.8)</td>
<td>0.009</td>
</tr>
<tr>
<td>School</td>
<td>74.2 (17.8)</td>
<td>71.5 (16.8)</td>
<td></td>
</tr>
<tr>
<td>Parent relations</td>
<td>79.0 (13.6)</td>
<td>80.5 (18.2)</td>
<td></td>
</tr>
<tr>
<td>Self-perception</td>
<td>82.8 (14.4)</td>
<td>81.8 (13.9)</td>
<td></td>
</tr>
<tr>
<td>Emotions</td>
<td>83.0 (13.0)</td>
<td>81.3 (13.1)</td>
<td></td>
</tr>
<tr>
<td>Social acceptance</td>
<td>92.4 (10.8)</td>
<td>92.6 (9.7)</td>
<td></td>
</tr>
</tbody>
</table>

October 22, 2008
Parent and professional reports of child QoL (3)

Similarities

• Parents and professionals disagreed less concerning the QoL of children with more severe physical and intellectual impairment
• Factors associated with both groups’ reports of child QoL
  – Severe physical impairment (ORs ~ 3.5) → lower QoL
  – Children in special schools (ORs ~ 0.2) → higher QoL in Self-perception
Parent and professional reports of child QoL (4)

Differences

- **Parental stress** and **child pain** were associated with greater odds of disagreement between parents and professionals.

- **High parental stress** associated with lower parent-reported child QoL in 6/9 domains (ORs between 3 and 10).

- **Child pain** associated with lower QoL in different domains:
  - **Parents**: Physical (OR=4.3) and Psychological well-being (OR=4.9)
  - **Professionals**: Emotions (OR=5.8) and Social support (OR=6.3)
  - **Parent > professional score**: Physical well-being and Parental relations
Discussion (1)

• **SPARCLE**: large population-based study of children with CP across full spectrum of disability

• Most children (including those with moderate intellectual impairment) can and should **self-report QoL**, using instruments which are
  – **Generic**: same universal standards of QoL
  – **Subjective and objective**
  – Based on **children’s perspective**
  – Preceded by **assessment of child’s ability** to understand and use Likert scales

• 500/818 children self-reported including 134 with intellectual impairment
Discussion (2)

• **Child pain**: most important factor associated with child QoL according to all respondents
  – Need more detailed information concerning location and cause
  – Efforts should be made to evaluate and alleviate pain in CP children

• **Children, parents and professionals have different perspectives**
  – Need *multiple informants* for valid assessment of child QoL

• **Child/parent and parent/professional comparisons**
  – Children rate their QoL higher than their parents
  – Parents and professionals disagree but no consistent pattern

• Take *parental stress* into account
  – in *research* → as affects parents’ reports of child QoL
  – in *practice* → pay attention to parent’s well-being
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- The children and their parents
- The Research Associates who collected the data

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Directorate F: HEALTH RESEARCH
Study of Participation of Children with Cerebral Palsy Living in Europe

Welcome to this site about a research study called SPARCLE which aims to discover the best ways of promoting the quality of life and participation of children with cerebral palsy in Europe.

SPARCLE stands for the Study of PARticipation of Children with cerebral palsy Living in Europe.

"The individual is rarely going to be altered very much whereas the environment slowly but surely can"

Tom Shakespeare