Development of a Screening Tool for Feeding Difficulties and Undernutrition in Children with Cerebral Palsy

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Cerebral Palsy in Australia

• 37,000 individuals in Australia
• Will increase to >47,000 by 2050
• 1 in 700 Australian babies are diagnosed

• Primarily a disorder of movement and/ or posture, and motor function
• Other associated impairments/ complications can include:
  • Hearing, vision, speech, intellectual
  • Epilepsy, sleep disorders, hip displacement, pain
  • 1 in 5 have a feeding tube

• Care costs > $43,000/ year

Australian CP Register Report 2018
1/3 of children with CP are undernourished
2/3 have feeding and swallowing difficulties

Bell 2018 DMCN, Benfer 2014 DMCN

**Undernutrition is linked to health outcomes:**

- Reduced participation in school and family activities (NAGCPP 2002)
- Longer recovery from surgery and increased length of stay
- Reduced cerebral function
- Impaired immune function
- Reduced respiratory muscle strength (Kuperminc 2013)
- Increased morbidity and mortality (Brookes 2011)
Aim

Develop a valid screening tool for feeding difficulties and undernutrition in children with cerebral palsy.

Participants

- 89 children with CP
- 71% male
- Mean age 7yr ± 4yr (2-18yrs)
- 31% - Seizures
- 12% - ASD

Motor Type:
- Spasticity (n=61)
- Dystonia (n=20)
- Other (n=8)
Screening Tool Development and Validation

33 Potential Screening Questions

6 Domains
- Respiratory Health
- Feeding Duration
- Stress of feeding
- Nutritional status
- Gastrointestinal factors
- General eating and drinking ability

2 Primary Outcomes

Feeding & swallowing difficulties:
- Clinical Feeding Assessment
- Videofluoroscopic swallow study

Undernutrition
- Pediatric SGNA
- Anthropometry

Primary outcome 1:
Feeding & Swallowing Evaluation

Clinical feeding & swallowing evaluation
- Consumed a range of food and fluids textures
- Rated using the Dysphagia Disorders Survey (DDS)
  - Cut-offs applied (Benfer 2015 DMCN)

17 clinical signs of aspiration using cervical auscultation

Videofluoroscopic Study (n = 7) if:
- 1 pharyngeal phase sign observed 2 or more times
- Or 2 or more pharyngeal signs observed
Primary Outcome 2:

Pediatric Subjective Global Nutrition Assessment (SGNA)

**Nutrition-Focused Medical History**
- Current and historical weight and growth
- Adequacy of dietary intake
- Recent changes in dietary intake
- Gastrointestinal symptoms
- Impact of nutritional status on function

**Physical Examination**
- Loss of subcutaneous fat stores
- Muscle wasting
- Nutrition related oedema

Overall Rating of:

- **A: Well-Nourished**
- **B: Moderately Malnourished**
- **C: Severely Malnourished**

Secker AJCN 2007;85(4):1083-9

Undernutrition

• Z-scores for:
  • Height/ length (cm), or knee length (cm) Stevenson 1995
  • Weight (kg)
  • Mid upper arm circumference
  • Skinfold: triceps and subscapular (mm)
  • Body Mass Index (kg/m2)

• Moderate undernutrition: z scores -2 to -3
• Severe undernutrition: z scores <-3
• (WHO classification)

Statistical Analysis

Development of the screening tool

• Questions with the best diagnostic properties for each primary outcome determined using $\chi^2$
• Successive versions of the screening tool were constructed and tested using different question combinations

Validation

• Rotation estimation using 10 fold cross validation approach
  • Data set divided into 10 approx. equal size subsets
  • Each sub set omitted in turn and diagnostic statistics(sensitivity and specificity) calculated for each primary outcome measure
Results

Nutritional status (SGNA)

Well nourished: 71%
Moderately malnourished: 29%
Severely malnourished: 20%
Well nourished: 13%
Moderately or Severely Undernourished: 63%

Nutritional Status (SGNA) by EDACS
Results

<table>
<thead>
<tr>
<th>6 Domains</th>
<th>Related to feeding difficulties</th>
<th>Related to undernutrition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory Health</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Feeding Duration</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Stress of feeding</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Nutritional status</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Gastrointestinal factors</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>General eating and drinking ability</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Final Questions

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>Feeding &amp; swallowing difficulties</th>
<th>Nutritional status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sensitivity</td>
<td>Specificity</td>
</tr>
<tr>
<td>Do you think your child is underweight?</td>
<td>58%</td>
<td>54%</td>
</tr>
<tr>
<td>Does your child have problems gaining weight?</td>
<td>77%</td>
<td>41%</td>
</tr>
<tr>
<td>Rate on a scale from 0 – 10, whether you think your child has any problems eating compared to other children of his/her age?</td>
<td>81%</td>
<td>64%</td>
</tr>
<tr>
<td>Rate on a scale from 0 – 10, whether you think your child has any problems drinking compared to other children of his/her age?</td>
<td>77%</td>
<td>79%</td>
</tr>
</tbody>
</table>

*Sensitivity* – the percentage of children with the condition that are included

*Specificity* – the percentage of children without the condition that are excluded (rule out)
### Validity of the Final Screening Tool

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>No. disease positive</th>
<th>Sensitivity %</th>
<th>Specificity %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeding Dysfunction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DDS</td>
<td>60</td>
<td>47</td>
<td>79</td>
</tr>
<tr>
<td>EDACS</td>
<td>26</td>
<td>81</td>
<td>79</td>
</tr>
<tr>
<td>Nutrition Assessment (SGNA)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate and severe</td>
<td>26</td>
<td>72</td>
<td>75</td>
</tr>
<tr>
<td>Severe only</td>
<td>6</td>
<td>100</td>
<td>66</td>
</tr>
<tr>
<td>Weight-for-age Z-score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ -2</td>
<td>19</td>
<td>76</td>
<td>77</td>
</tr>
<tr>
<td>≤ -3</td>
<td>9</td>
<td>78</td>
<td>66</td>
</tr>
</tbody>
</table>

**Sensitivity** – the percentage of children with the condition that are included

**Specificity** – the percentage of children without the condition that are excluded (rule out)

### Final Screening Tool

1. **Do you think your child is underweight?**  
   - Yes/no/unsure

2. **Does your child have problems gaining weight?**  
   - Yes/no/unsure

3. **Rate on a scale from 0 – 10, whether you think your child has any problems eating compared to other children of his/her age?**
   
   0 1 2 3 4 5 6 7 8 9 10

4. **Rate on a scale from 0 – 10, whether you think your child has any problems drinking compared to other children of his/her age?**
   
   0 1 2 3 4 5 6 7 8 9 10

**Score 3 or 4 = Refer for further assessment of feeding and nutritional status**
Summary of Screening Study

• All key areas, except meal time duration, were related to feeding difficulties and undernutrition in children with CP.

• The best screening questions: Directly ask about the outcome of interest (ie feeding difficulties and poor nutritional status).

• Parent-reported indicators can successfully be used to screen for feeding and swallowing difficulties and undernutrition in children with cerebral palsy.

Acknowledgements

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