Determinants of Ease of Care Giving of Young Children with Cerebral Palsy

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Objective

- Ease of care giving > level of difficulty in assisting a child to perform self-care activities
- Ease of care giving > important outcome of family-centered services for young children with cerebral palsy
- To identify the child, family, and service determinants that are associated with ease of care giving of young children with cerebral palsy
  - Implications for practice > enable health care professionals to provide evidence-based interventions and support children and families
Setting and Participants

- 4 regions in the United States and 6 provinces in Canada
- Convenience sample of 387 children with CP and parents
  - Children
    - 215 boys, 172 girls
    - 18-60 months of age
      - Mean age 3y 2mo, SD 11mo
    - Varied gross motor abilities across all GMFCS levels
  - Parents
    - 94% mothers
Methods

- Cohort study
  - Secondary data analysis
- Data collected in children’s homes or therapy clinics
- 3 data collection sessions over a one-year period
Measures

Child Factors: Beginning of study

Parent Completed
- Adaptive Behavior: Early Coping Inventory
- Associated Conditions & Co-morbidities: Child Health Conditions Questionnaire
- Endurance: Early Activity Scale for Endurance

Therapist Administered
- Spasticity: Modified Ashworth Scale
- Quality of Movement: Gross Motor Performance Measure
- Balance: Early Clinical Assessment of Balance
- Muscle Strength: Functional Strength Assessment
- Range of Motion: Spinal Alignment and Range of Motion Measure
- Distribution of Involvement
- Gross Motor Function: Gross Motor Function Classification System
Measures

Parent Completed

Family Factors Demographics: Beginning of study
- Age & education of parent
- Total number of children & adults in household

Family Factors: Middle of study
- Family Expectations of Child: Questionnaire
- Family Supports: Family Support Scale

Service Factors: Middle of study: Questionnaire
- Amount of Physical & Occupational Therapy Services
- Family-centeredness of services
- Coordination of services
- Extent services meeting child needs
- Focus of services on activity, self-care, & environment
Measures: Outcome

Parent Completed: At End of Study

Ease of Caregiving: Supplement to the Child Engagement in Daily Life Measure

- 12 items
- Example: How difficult is it for you to help your child eat?
- 5-point likert scale:
  - 1 = very difficult to 5 = no help is needed
Data Analysis

- Sequential multiple linear regression
  - Calculated Pearson’s correlations between Ease of Caregiving and child, family, & service factors
    - All child factors correlated (moderate to high)
    - Family expectations only family factor correlated (moderate)
    - All service variables except family-centeredness correlated (low to moderate)
  - Calculated intercorrelations among predictors
    - Multi-collinearity (r≥0.80)
    - GMFCS highly related to balance & muscle strength
## Results

<table>
<thead>
<tr>
<th>GMFCS Levels</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
<th>V</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ease of Caregiving</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>x (sd)</td>
<td>4.4 (0.4)</td>
<td>3.9 (0.6)</td>
<td>3.9 (0.5)</td>
<td>3.4 (0.7)</td>
<td>3.0 (0.7)</td>
<td>3.8 (0.8)</td>
</tr>
<tr>
<td>Median</td>
<td>4.5 (3.0 – 5.0)</td>
<td>3.9 (2.8 – 4.6)</td>
<td>4.0 (2.8 – 4.8)</td>
<td>3.5 (2.1 – 4.8)</td>
<td>3.1 (1.2 – 4.3)</td>
<td>4.0 (1.2 – 5.0)</td>
</tr>
</tbody>
</table>
Results

- Child factor model accounted for 55% of the variance of ease of care giving ($p<0.001$)
- Addition of one family factor added 1% ($p<0.02$)
- Addition of service factors added an additional 1% ($p<0.01$)
- Final model > significant variables
  - Gross motor ability ($\beta = -0.35$)
  - Impact of health conditions ($\beta = -0.17$)
  - Spasticity ($\beta = -0.14$)
  - Family expectations ($\beta = 0.09$)
  - Coordination of services ($\beta = 0.09$)
  - Needs being met ($\beta = 0.09$)
Implications for Practice: To Support Ease of Caregiving for the Family

- Optimize gross motor abilities
  - Enhance balance
  - Prevent secondary impairments
- Promote health: minimize the impact of health conditions
- Manage spasticity
- Support families in encouraging children to fully participate to their abilities in self-care
- Collaborate with others and coordinate care
- Address family priorities and needs for their child
Questions, Comments, Thoughts??

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