Exertion during Caregiving for Children with Cerebral Palsy following Intrathecal Baclofen

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Introduction

Caring for children with CP, particularly those with significant motor limitations, is physically demanding. Previous analysis demonstrated that caregiver perceptions of the difficulty of completing dressing and transfer tasks is associated with actual exertion as measured through indirect calorimetry. The purpose of the study reported here was to determine whether intrathecal baclofen therapy among children with cerebral palsy is effective in reducing caregiver burden. We were further interested in whether objective measures of actual exertion in a clinic setting versus reported perceptions of the difficulty of completing tasks in the natural environment would be sensitive to change over time.

Hypotheses

Caregivers will experience:
- a decrease in the difficulty of dressing following treatment.
- an increase in the difficulty of transfers following treatment.

Research Design & Methods

Design:
Longitudinal, prospective study with data collected pre-ITB treatment and 6-, 12- and 24-months post-initiation of ITB.

Participants:
Primary caregivers (N=15) of children/young adults with spastic and/or dyskinetic CP (3-22 years old) receiving ITB

Measures of Exertion:
Objective -
- Indirect calorimetry during actual transfer and dressing tasks in the clinical setting (N=12)
Subjective -
- Borg's Rating of Perceived Exertion (BPE) Scale (N=12),
- Dressing & transfer questions from the Caregiver Priorities and Child Health Index of Life with Disabilities (CP-Child),
- Canadian Occupational Performance Measure (COPM) dressing (N=9) or transfer (N=9) goals

Analysis:
Change scores compared using T-tests for the continuous data. Wilcoxon signed ranks tests were used to compare perception ratings across time.

Results

A significant improvement was found in:
- performance of and satisfaction with dressing-related goals (COPM),
- the difficulty of lower, but not upper, extremity dressing at 6- and 24-months (CP-Child),
- and in the difficulty of transfers at 6- and 24-months (CP-Child).

For transfer goals on the COPM (data not shown), caregiver perceptions were quite variable with 66.6% of caregivers rating improved performance and satisfaction. Results of the clinic-based measures (indirect calorimetry and BPE) were also quite variable and did not indicate a significant change in exertion over time.

Conclusions

Consistent with our first hypothesis, the intervention reduced caregiver ratings of the difficulty of completing lower extremity dressing while changes in difficulty of upper extremity dressing were not perceptible. Counter to our second hypothesis, perceptions of the difficulty of transfer tasks declined. Detecting change in caregiving burden appears to vary by the measure used, setting and timing of data collection. To capture objective changes over time following interventions such as ITB, measures of exertion during caregiving tasks should be administered in the natural setting at multiple time points to account for the wide variability in the daily caregiving experience.

Implications for Practice

- Caregivers should be informed of potential variation in the outcomes of ITB.
- Setting realistic caregiving goals with families prior to ITB may facilitate satisfaction with outcomes.
- Assessment in the natural environment may provide a clearer picture the impact of ITB on caregiving than laboratory-based measures.

References


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