An Exploratory Study of Pain and Quality of Life in Children with Cerebral Palsy prior to Intrathecal Baclofen Pump Placement

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Introduction

Cerebral palsy (CP) is a common movement disorder of childhood and is associated with a variety of problems that adversely affect quality of life (QOL). The vast majority of children with CP have the spastic type, which is often associated with increased pain throughout daily life. A new treatment option for these children involves implantation of an intrathecal baclofen pump (ITBP) that delivers antispasmodic medication directly to the spinal cord. While research shows that pump placement is effective in reducing muscle spasticity (1), no research was found in the literature that directly assesses the impact of ITB pump placement on pain and QOL among children with CP.

Purpose of Study

To determine if there is a relationship between pain level and quality of life in children with cerebral palsy prior to implantation of an ITB pump.

Participants

Convenience sample of primary caregivers of children with CP ages 3-20. Participants were enrolled in a baclofen pump implantation study at the Waisman Center and their children were scheduled for pump placement in the week following their assessment. (N=7)

Data Analysis

- Pain reports from OCPChild (2) and the Pain Scale for Nonverbal Children (3) were collapsed into a composite pain score.
- QOL score from the OCPChild was compared to the composite pain score.
- OCPChild scores for contribution of activities to QOL was grouped by activity domain with specific sum scores.
- QOL domain sum scores were compared to composite pain scores.

Design & Methods

- Single group exploratory design
- Participants recruited from a larger longitudinal study investigating the effects of ITBP pump placement and associated therapy interventions on children or young adults with cerebral palsy and their caregivers.
- Prior to ITBP pump implantation, caregivers completed an assessment battery that included reports of the pain level experienced by their child and their child’s quality of life.
- Caregiver-proxy reporting was used for all children due to limited cognitive and communication abilities.

Results

- Visual analysis showed a moderate relationship between child QOL and pain level, with higher pain levels associated with higher QOL.
- Differences emerged between the pain groups in the importance they placed on different domains in contributing to QOL.
- Little to no relationship was seen between pain level and the importance of ADL activities to quality of life.
- A weak relationship was seen between pain level and the importance of social participation in contributing to QOL.
- A moderate relationship was seen between pain level and the importance of mobility and comfort/emotions in contributing to QOL.
- A relatively strong relationship was seen between pain level and the importance of communication in contributing to QOL.

Conclusions/Discussion

- While several trends were seen in the data, due to the small sample size no firm conclusions can be drawn.
- Parents of children with high pain levels report their child’s quality of life as better than do parents of children with low pain levels. This may reflect the difficulty parents have in rating their child’s QOL as high when taking into consideration the challenges they face.
- Communication and comfort/emotions are more important in QOL in children with high pain levels, while mobility is more important in those with low pain levels.
- Assessment of children with CP should address both QOL and the specific factors the client uses in determining it.
- Practitioners need to consider changes to both pain and QOL when evaluating treatment effectiveness.
- To improve client QOL treatment goals must be individualized to address the specific life domains that they consider to be most important.

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References