Self Reports of Historical Data and Current Status in Young Adults with Cerebral Palsy

Chris Church, Dhanush Hoskere, Carole Tucker, Nancy Lennon, Tim Niiler, Daveda Taylor, John Henley, Freeman Miller

Nemours duPont Hospital for Children, Wilmington, DE, USA

OBJECTIVES

- Growing interest in examining long term satisfaction and societal outcomes of adults with cerebral palsy (CP).
- Objectives:
  - To describe functional and satisfaction outcomes in a sample of young adults with CP who were treated during childhood at a pediatric specialty care hospital.
  - To examine the ability of young adults with CP to recall from childhood their mobility function and surgical history.

METHODS

- Retrospective cohort study with prospective call back
- 57 adults with spastic CP
  - age 27.2 ± 3.3 years
  - GMFCS levels I (7), II (25), III (16), IV (9)
  - Treated in childhood at duPont Hospital for Children
  - Self-reported measures
    - Pediatric Outcomes Data Collection Instrument (PODCI; compared to published adolescent norms)
    - Patient Reported Outcomes Measurement Information System (PROMIS; compared to age-matched norms)
    - Functional Mobility Scale (FMS)
  - Study specific demographic and surgical history
  - Stable FMS status from early childhood through adulthood with no significant changes over time (Figure 1).
  - Both PROMIS and PODCI reported limitations in gross motor function compared to norms (Figure 2, 3; p<0.05).
  - Descriptive results showed participants dependent for transportation, housing, and economic stability, though PROMIS subscales revealed normal satisfaction with social activities and social roles for age (Figure 3).
  - Happiness subscale of the PODCI results were significantly below typically developing (p<0.05) but happiness subscale of the PROMIS was within age-matched normative values.
  - Self-reported surgical history was under represented compared to actual. Self-reported mobility history correlated highly (r=0.8, p<0.001) with gait analysis FMS records.

RESULTS

- Functional mobility was limited for the young adults with CP in this study, but was mostly stable from early childhood through young adulthood.
- Dependence for community transport, lodging and income was present, though our sample reported satisfaction with their social roles and interaction similar to age-matched peers.
- We found some inconsistencies between the PROMIS and PODCI subscale results suggesting the need for further validation in this population.
- Young adults reliably report mobility history, but are unable to recall specific surgical history consistently

DISCUSSION

- Though functional mobility is limited and community independence is not fully achieved in young adults with CP, this sample maintained childhood levels of functional mobility into young adulthood following specialty care by experienced physicians.

CONCLUSIONS

- Functional mobility was limited for the young adults with CP in this study, but was mostly stable from early childhood through young adulthood.
- Dependence for community transport, lodging and income was present, though our sample reported satisfaction with their social roles and interaction similar to age-matched peers.
- We found some inconsistencies between the PROMIS and PODCI subscale results suggesting the need for further validation in this population.
- Young adults reliably report mobility history, but are unable to recall specific surgical history consistently

METHODS

- Mobility questions asked regarding current status and recall of mobility status in elementary, middle, and high school.
- Gait analysis reports and medical/surgical records were retrospectively reviewed and comparisons were made to self-reported history for mobility and surgery.

RESULTS

- Stability of mobility function across childhood and adulthood.
- Limitations in gross motor function as measured by PROMIS and PODCI.
- Satisfaction with social activities and social roles as assessed by PODCI.
- Self-reported surgical history underrepresented compared to actual surgical history.

CONCLUSIONS

- Though functional mobility is limited and community independence is not fully achieved in young adults with CP, this sample maintained childhood levels of functional mobility into young adulthood following specialty care by experienced physicians.