

Background

Cerebral Palsy

- Cerebral palsy (CP) is the most common motor disability of childhood.
- CP patients often experience motor disorders causing activity limitation along with disturbances of sensation, perception, cognition, communication, and behavior. Patients may also experience epilepsy and secondary musculoskeletal issues.¹
- The clinical manifestations of CP vary greatly from patient to patient and there is a wide array of development, level of functioning, and social comfort among the CP population.¹

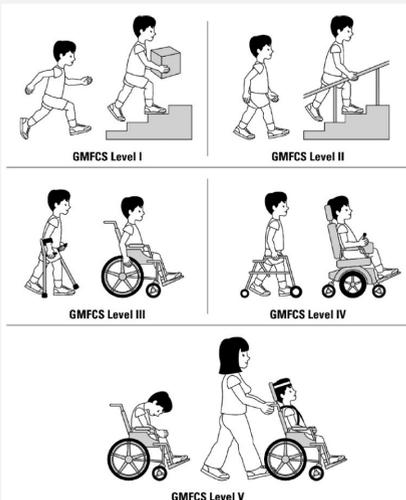


Figure 1. The Gross Motor Function Classification System (GMFCS)

- Clinical manifestations of CP have traditionally been graded on a scale from I-V according to the Gross Motor Function Classification System, which is based on self-initiated movement, with emphasis on sitting transfers and mobility.
- Figure 1**
- Most people affected by CP live into adulthood with a life expectancy close to that of the general population.²
- However, there is no cure and patients will battle symptoms associated with the disability throughout their lifetime².
- Health-related quality of life and burden of disease among CP patients is not well known and has not been quantified to our knowledge.

Health-Related Quality of Life

- The EQ-5D was developed by the EuroQol Group to be a standardized method to measure health status and provide a simple and straight forward method of obtaining information that can be used in both clinical and economic evaluation of a subset of the population.³
- The EQ-5D-Y is the child and youth version of the EQ-5D-3L and has been proven to be feasible, reliable, and valid for populations between 8 and 18 years old.⁴
- The questionnaire consists of consists of a single question in each of five domains: Mobility, Self-Care, Usual activity, Pain/Discomfort, and Anxiety/Depression.⁵
- EQ-5D scores can converted to a single index value, which can then be used to calculate Quality Adjusted Life Years (QALYs)
- QALYs have long been used as a measure of health status and health improvement

Objectives

Primary Objective

- Collect EQ-5D-Y surveys from patients with Cerebral Palsy at Shriners Hospital for Children, Northern California
- Quantify health-related quality of life (HRQoL) and the burden of disease in cerebral palsy patients at Shriners Hospital for Children, Sacramento by administering the EQ-5D-Y survey to CP patients aged 8 to 18 years old
- Compare EQ-5D-Y results in Cerebral Palsy patients to previously collected EQ-5D-Y data among normal functioning children.
- Hypothesis: EQ-5D-Y scores will be lower in children with Cerebral Palsy patients than in normal functioning children

Secondary Objective

- Calculate Quality Adjusted Life Years (QALYs) for children diagnosed with cerebral palsy at Shriners Hospital for Children, Northern California.

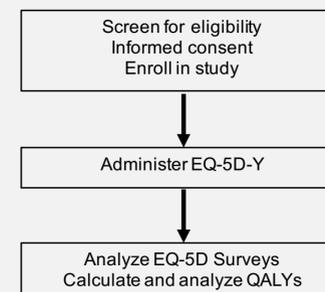
Methods

Survey Design

- Cross sectional study that will administer the EQ-5D-Y questionnaire over the course of a year to patient's at Shriners Hospital for Children, Northern California.

Data Collection

- Participants will identified by the following criteria:
 - Age >7 and <19 at the time of completing the questionnaire
 - Diagnosed with Cerebral Palsy
 - In a GMFCS category between I and V
- Data collection will take place over the course of one year, in which time we will aim to collect about 100 surveys.
- Each participant will need to allocate one 10-15 minute period to fill out the questionnaire during an existing appointment time.
- The EQ-5D-Y is validated in over 40 languages.
- Additional information about the participant such as demographics, social economic status, household, family, and resiliency measures will be collected.



Analysis

- Compare EQ-5Y scores in cerebral palsy patients to previously collected controls. Results will be stratified by GMFCS level.
- Convert EQ-5D to to an index value to calculate Quality Adjusted Life Years (QALYs)

Conclusions/Next Steps

- Once the preliminary data is collected at Shriners Hospital for Children, Northern California, the study design and materials will be easily translatable to other settings such as other Shriners hospitals.
- We would also like to perform the study in other countries to compare HRQoL between high and low income countries.
- The EQ-5D values and QALYs can be used to compare the health states of CP patients in high income versus low income settings and to aid decision making about resource allocation.
- Having HRQoL and QALYs will help us compare the two and to make comparisons between populations and to better advocate for resources to be allocated toward helping CP patients.
- Our study will provide important data and methods that will provide unique insight and perspectives into the burden of disease of cerebral palsy both in Sacramento and around the world

References

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Acknowledgement and Contact

- Funding provided by UC Davis Medical Student Research Fellowship.
- Special thanks to Dr. Michael Wilkes and his contribution.
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