

UC Davis
Neurology

Title

Health Related Quality of Life in Cerebral Palsy Patients at Shriners Hospital for Children, Northern California

Permalink

<https://escholarship.org/uc/item/7hm5c26v>

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Publication Date

2020

Data Availability

The data associated with this publication are not available for this reason: N/A

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

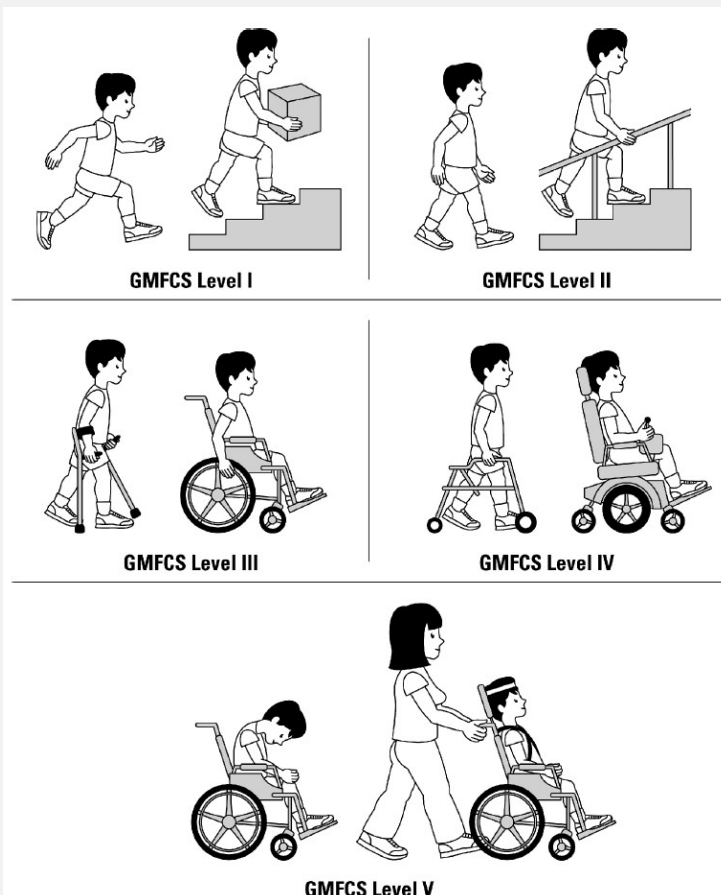


Figure 1. The Gross Motor Function Classification System (GMFCS)

- 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.

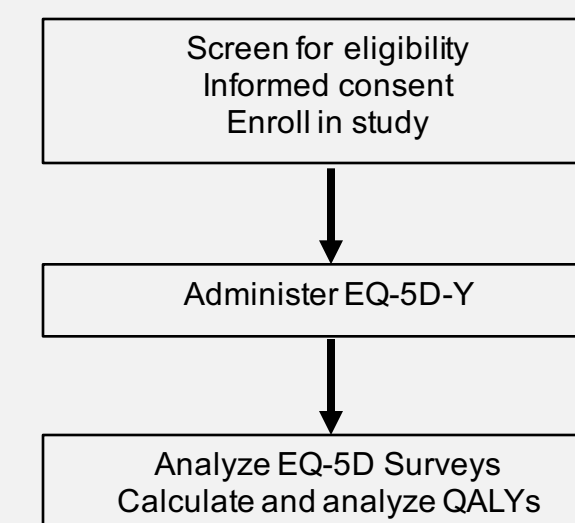
Methods

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

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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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