

## Health Related Quality of Life

### Research Overview

Health-Related Quality of Life (HRQL) is a multidimensional measure of physical, mental, emotional, and social well-being, assessed in individuals with HME using the 36 Short Form Health Survey (SF-36), a survey covering eight domains of health; the Short-Form Six-Dimension (SF-6D), a utility-based index that quantifies overall health on a 0-1 scale; the Child Health Questionnaire (CHQ PF-50), a parent-reported tool evaluating children's physical, emotional, and social health; and utility scores, which provide standardized comparisons of health outcomes across different populations and conditions.

### Key Findings from the Study

- Pain and Physical Functioning: Pain can be a major challenge for HME patients, with adults and children scores reporting significantly more bodily pain compared to population norms. Effective pain management strategies are essential to health and wellness.
- Emotional and Social Well-being: Despite physical challenges, emotional self-esteem and mental health scores were relatively better than physical domains, indicating resilience. Lower social function scores indicate that the condition can limit participation in social activities.
- Quality of Life Variability: Some individuals with HME report a quality of life similar to or better than individuals with rheumatoid arthritis, while others score near the lowest levels, indicating significant impairment in day to day activities.

### How Can Families Use This Information?

- Pain Management: Work with your care team to find treatments that improve comfort and mobility, identify forms of self care that help improve pain and function.
- Emotional Support: Connecting with mental health resources, support groups like the MHE Coalition, and online support groups may help reduce stress and improve coping strategies.
- Advocacy: These findings highlight the need for greater awareness and research on HME to improve treatment options.

This study provides data that helps researchers and clinicians track HME disease progression and assess treatment over time. Understanding the impact of HME on quality of life helps guide future treatments and interventions. Continued research will focus on improving pain management, surgical options, and overall well-being for individuals with HME.

[Chhina, H., Davis, J. C., & Alvarez, C. M. \(2012\). Health-related Quality of Life in People With Hereditary Multiple Exostoses. \*Journal of Pediatric Orthopaedics\*. 32\(2\), 210–214.](#)

**The best clinical decisions are made with a trusted physician. This is not intended to replace a discussion with your clinical team.**