

Exploring Quality of Life in Pediatric Cerebral Palsy: Insights from Child Self-Reports and Parent Proxy-Reports questionnaires

Leonardi Matilde¹, Pedrinelli Ilaria², Biagi Sofia², Romeo Domenico Marco³, Musto Elisa³, Fagiani Valeria⁴, Lanza Martina¹, Guastafierro Erika¹, Colombo Alice¹, Giordano Andrea¹, Montomoli Cristina⁵, Rezzani Cristiana⁵, Casalino Tiziana², Mercuri Eugenio³, Riva Daria², Eldahaby Daniela⁶, Baranello Giovanni⁷, Pagliano Emanuela²

¹Neurology, Public Health and Disability Unit, Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy, ²Pediatric Neuroscience Department, Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy, ³Catholic University Paediatric Neurology Unit, Rome, Italy, ⁴Emergency Department, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico Milan, Italy, ⁵Department of public health Neuroscience, experimental and forensic medicine University of Pavia, Italy, ⁶University of Milan, Italy, ⁷Paediatric Neurology/ Neuromuscular Disorders University College London Great Ormond Street Institute of Child Health & Great Ormond Street Hospital NHS Foundation Trust, London.

BACKGROUND

The **Pediatric Quality of Life Inventory** (PedsQL™), developed with a multidimensional assessment through the two modules **Generic Core Scale** (GCS) and **Cerebral Palsy Module** (CPM), is used in this study to evaluate **quality of life** (QoL) in **children with cerebral palsy** (CP).

This neurological disability required treatment that addresses not only physical symptoms from both child and parent perspectives but also encompassing physical, **psychological** (emotional and cognitive), and **social dimensions**.

RESULTS

Children with CP that showed **higher GMFCS** and **MACS levels** (lower functional abilities) reported significantly **lower QoL scores** in all subscales of parent proxy-reports and in most subscales of child self-reports of the CPM, while **child self-report scores** were always higher than proxy-report scores for both modules.

METHOD

Cross-sectional Multicenter Study

- Carlo Besta Neurological Institute Foundation (Milan)
- Catholic University (Rome)

Instrument used

- PedsQL™ 4.0 Generic Core Scale
- PedsQL™ 4.0 Cerebral Palsy Module

Children with CP
(n=125)
Age: 2-18 years old

Healthy controls
(n=121)
Age: 2-18 years old

CONCLUSION

We found a **significant negative correlation between physical impairment and QoL**. Interestingly, in both CPM and the GCS, parents rated their children's QoL lower than the children did themselves across all domains. Conversely parents of a healthy sample tend to rate their children's QoL higher compared to children self-reports.

Our findings seem to confirm that **parents of children with CP** may underestimate their child's overall well-being. An underestimated QoL from the parents' point of view may have an impact on **disability awareness** and consequently on the effectiveness of **individualized and multidisciplinary rehabilitation**.



24-28 Ottobre 2025
Padova Congress

**55° CONGRESSO
SOCIETÀ ITALIANA
DI NEUROLOGIA**