

The impact of the COVID-19 Pandemic on HRQoL Outcomes: Evidence from Syndromic Autistic Children and Children with Intellectual Disabilities

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Background

- **Objective:** To estimate the impact of the COVID-19 pandemic on health-related quality of life (HQoL) outcomes in children with rare disorders. To explore mechanisms which explain how families buffered COVID-19 induced stress.
 - **Methods:** During 2018 and 2021 a total of 691 families of children with Phelan–McDermid syndrome (PMD), Rett Syndrome (RTT) and SYNGAP1-related intellectual disability (SYNGAP1-ID) completed PedQL (V.4) questionnaire to measure proxy-assessed HRQoL outcomes. HRQoL data on 120 identical children collected during 2018 and during the first year of the pandemic was analysed using parametric and nonparametric pairwise comparisons adjusted for socio-economic covariates.
- ## Results and Conclusions
- The overall evidence shows that PedQL scores increased on average by 14 points during the COVID-19 pandemic compared to 2018; results show significant heterogeneity across diagnoses. Emotional functioning and social functioning scores recorded highest gains during the COVID-19 pandemic. Increasing time watching TV and time spent with digital devices during the pandemic were negatively associated with HRQoL.
 - Contrary to studies conducted on overall healthy children, our findings provide evidence that COVID-19 had an overall positive impact on HRQoL in children diagnosed with PMD, RTT and SYNGAP1-ID. Longitudinal studies are needed to understand the magnitude, trajectory and underpinning mechanisms of HRQoL outcomes in children with severe abnormalities and developmental delay.