E-Poster

EP-563

The PolyRENE Network for Polyhandicap/PMID Individuals: Illustration Through an Observationnal Study on Scoliosis

Topic: Organizational Development (International Associations)

Hugo Bessaguet[1], Bruno Dohin[2], Etienne Ojardias[1], Marie-Christine Rousseau[3]

[1]*PRM, CHU Saint-Etienne, Saint-Etienne, France*
[2]*Pediatric Orthopedic Surgery, CHU Saint-Etienne, Saint-Etienne, France*
[3]*PRM, APHM, Marseille, France*

BACKGROUND

The Ithaca European Reference Network (ERN) for congenital malformations and rare intellectual disabilities has agreed on the term Profound Intellectual Multiple Disability (PIMD)/Polyhandicap, as a complex disability condition occurring in an immature brain, leading to profound intellectual disabilities and severe motor disabilities, manifesting in as being dependent on human and technical assistance. Owing to advances in medical management, a large majority of children with PIMD/Polyhandicap now reach adulthood. As such, scoliosis constitutes a prevalent comorbidity in adolescents with polyhandicap and frequently leads to other severe impairments, impacting abilities and requiring complex caregiving strategies. Therefore, spinal fusion surgeries are commonly performed to alleviate pain and provide more comfort. However, spine stabilization has not previously been proven to improve the severity health status of adolescents with polyhandicap according to specific clinical scales.

METHODS

A monocentric retrospective observational study (IRBN492021/CHUSTE) was conducted in the university hospital centre of Saint-Etienne, France. We included between 2009 to 2020, 30 scoliotic adolescents with polyhandicap who underwent spinal fusion performed with the same surgical technique and the same surgeon. The main outcome was the variation in the Polyhandicap Severity Scale (PSS) score after surgery. Secondary outcomes were variations in PSS subscores, quality of life scores, fronto-sagittal X-ray parameters, and measures of surgical complication rates and lengths of stay.

RESULTS

Among 30 adolescents, 27 PSS analyses were performed. We found a significant improvement between pre- and postoperative PSS scores, mainly for pain and respiratory, digestive, and skin disabilities. These improvements were accompanied by significant reductions in pelvic obliquity, in frontal and sagittal curves. The mean hospital length of stay was 45 days. During postoperative period, patients received a personalized postoperative rehabilitation procedure with spasticity and pain treatments, physiotherapy, and verticalization (wheelchair sitting and positioning devices such as contoured seat intended to increase postural stability). The mortality rate was estimated at 7%. At least one complication per patient occurred.

CONCLUSION

We confirm that spinal fusion surgeries lower the severity health status and confer some clinical benefits. However, a 100% complication rate is highlighted, that confirms the complexity of these surgeries. The French collaborative network PolyRENE offers a valuable opportunity to unite diverse actors, fostering optimized research approaches with specific tools.

Statement of Disclosures

None

Doi: 10.5606/archisprm.2026.EP-563

Corresponding Author:
Hugo Bessaguet
PRM, CHU Saint-Etienne, Saint-Etienne, France
Email: hugo.bessaguet@univ-st-etienne.fr