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## Children with Medical Complexity, Rare Conditions and Neurodisabilities bulletin

August 2024 ~ library@each.org.uk

### Bulletin No. 4

21/05/2024 - 20/08/2024

#### 1. A longitudinal follow-up study of parent-reported family impact and quality of life in young patients with traumatic and non-traumatic brain injury

**Authors:** Allonsius, F.;de Kloet, A. J.;van Markus-Doornbosch, F.;Vliet Vlieland, T. P. M. and van der Holst, M.

**Journal:** Disability and Rehabilitation 2024

46(11), pp. 2240–2250

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37295937/>

#### 2. Scoliosis and rare diseases: our experience with the Prader-Willi syndrome

**Authors:** Andaloro, Antonio Angelo, et al

**Journal:** European Spine Journal : Official Publication of the European Spine Society, the European Spinal Deformity Society, and the European Section of the Cervical Spine Research Society 2024

33(6), pp. 2463–2468

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38630248/>

#### 3. Stress Among Parents of Children With Severe Neurological Impairment in the Pediatric Intensive Care Unit

**Authors:** Bogetz, Jori, et al

**Journal:** Journal of Palliative Medicine 2024

27(7), pp. 869–878

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38546796/>

**4. A qualitative exploration of children's lives with rare diseases**

**Authors:** Buckle, Niamh, et al

**Journal:** Child: Care, Health and Development 2024

50(4), pp. e13294

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38924454/>

**5. Evaluating caregiver-clinician communication for tracheostomy placement in the neonatal intensive care unit: a qualitative inquiry**

**Authors:** Bushroe, Kylie M.; Crisp, Kelly D.; Politi, Mary C.; Brennan, Steven K. and Houston, Ashley J.

**Journal:** Journal of Perinatology : Official Journal of the California Perinatal Association 2024

44(7), pp. 963–969

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37833495/>

**6. Exploring Health-Related Social Needs and Components of Social Competence Following Childhood Traumatic Brain Injury**

**Authors:** Dart, Libby and Ciccia, Angela

**Journal:** American Journal of Speech-Language Pathology 2024

33(4), pp. 1792–1801

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38723268/>

**7. Commentary: Lost in Transition? Future Directions for Healthcare Transition Research with Rare Diseases**

**Authors:** Dattilo, Taylor M. and Mullins, Larry L.

**Journal:** Journal of Pediatric Psychology 2024

49(6), pp. 392–393

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38613822/>

**8. Invisible patients in rare diseases: parental experiences with the healthcare and social services for children with rare diseases. A mixed method study**

**Authors:** Domaradzki, Jan and Walkowiak, Dariusz

**Journal:** Scientific Reports 2024

14(1), pp. 14016–4

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38890437/>

**9. Transitions in tracheostomy care: from childhood to adulthood**

**Authors:** Edwards, Louise and McRae, Jackie

**Journal:** Current Opinion in Otolaryngology & Head and Neck Surgery 2024

32(3), pp. 172–177

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37548524/>

**10. Undiagnosed Disease Network collaborative approach in diagnosing rare disease in a patient with a mosaic CACNA1D variant**

**Authors:** Ezell, Kimberly M., et al

**Journal:** American Journal of Medical Genetics. Part A 2024

194(7), pp. e63597

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38511854/>

**11. Learning to Trust Yourself: Decision-Making Skills Among Parents of Children With Medical Complexity**

**Authors:** Finlay, Melissa, et al

**Journal:** Journal of Pain and Symptom Management 2024

68(3), pp. 237–245.e5

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38810951/>

**12. Continuity of care and medical complexity in children and young people with cerebral palsy are distinct interrelated concepts**

**Authors:** Fortin, Olivier

**Journal:** Developmental Medicine and Child Neurology 2024

66(6), pp. 685–686

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37968866/>

**13. Standardizing Medical Complexity: Fruitful, Formidable, or Futile?**

**Authors:** Gerber, Danielle M. and Coller, Ryan J.

**Journal:** Pediatrics 2024

153(6), pp. e2023065014. doi: 10.1542/peds.2023–065014

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38804060/>

**14. Seizures, medical child abuse, and the pediatric neurologist**

**Authors:** Goulbourne, Mica and Huber, Catherine M.

**Journal:** Seminars in Pediatric Neurology 2024

50, pp. 101137

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38964818/>

**15. Comprehensive care programmes for children with medical complexity**

**Authors:** Harvey, Adrienne R., et al

**Journal:** The Cochrane Database of Systematic Reviews 2024

5(5), pp. CD013329

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38813833/>

**16. Chronic pain in children and young people with cerebral palsy: a narrative review of challenges, advances, and future directions**

**Authors:** Harvey, Adrienne; Smith, Nadine; Smith, Meredith; Ostojic, Katarina and Berryman, Carolyn

**Journal:** BMC Medicine 2024

22(1), pp. 238–0

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38862988/>

**17. Update on pediatric tracheostomy**

**Authors:** Komori, Manabu

**Journal:** Auris, Nasus, Larynx 2024

51(3), pp. 429–432

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38520972/>

**18. Bridging the gaps in pediatric complex healthcare: the case for home nursing care among children with medical complexity**

**Authors:** Koob, Caitlin, et al

**Journal:** BMC Health Services Research 2024

24(1), pp. 814–1

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/39010079/>

**19. Long-Term Quality of Life After Pediatric Traumatic Brain Injury Treated in the Intensive Care Unit**

**Authors:** Kyösti, Elina, et al

**Journal:** Pediatric Neurology 2024

157, pp. 50–56

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38865950/>

**20. Feeding and Swallowing Outcomes in Children Who Use Long-Term Ventilation: A Scoping Review**

**Authors:** Lee, Sabrena; Marshall, Jeanne; Clarke, Michael and Smith, Christina H.

**Journal:** Dysphagia 2024

39(4), pp. 666–683

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38180625/>

**21. Holistic support for children with rare disease**

**Authors:** Li, Siyuan and Hua, Yingqi

**Journal:** The Lancet. Child & Adolescent Health 2024

8(6), pp. 397

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38367637/>

**22. Advance Care Planning for Children With Rare Diseases: A Pilot RCT**

**Authors:** Lyon, Maureen E., et al

**Journal:** Pediatrics 2024

153(6), pp. e2023064557. doi: 10.1542/peds.2023–064557

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38699801/>

**23. The Clinical Definition of Children With Medical Complexity: A Modified Delphi Study**

**Authors:** Millar, Kyle, et al

**Journal:** Pediatrics 2024

153(6), pp. e2023064556. doi: 10.1542/peds.2023–064556

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38804054/>

**24. Clinical description and evaluation of 30 pediatric patients with ultra-rare diseases: A multicenter study with real-world data from Saudi Arabia**

**Authors:** Muthaffar, Osama Y., et al

**Journal:** PloS One 2024

19(7), pp. e0307454

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/39024300/>

**25. Mental health of caregivers of children with medical complexity: group-based trajectory modelling**

**Authors:** Nathwani, Apsara Ali; Fayed, Nora; Grandi, Sonia M.; Orkin, Julia and Cohen, Eyal

**Journal:** Archives of Disease in Childhood 2024

109(7), pp. 563–569

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38388207/>

**26. "Filling in the gap": A qualitative case study about identity construction of siblings of youth with a neurodisability**

**Authors:** Nguyen, Linda, et al

**Journal:** Journal of Adolescence 2024

96(6), pp. 1354–1367

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38797961/>

**27. Child maltreatment in children with medical complexity and disability**

**Authors:** Park, Clair; Alley, Samantha; Reinke, Whitney; Yarlagaadda, Shravya and Hansen, Jennifer

**Journal:** Seminars in Pediatric Neurology 2024

50, pp. 101134

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38964809/>

**28. Time to diagnosis for a rare disease: managing medical uncertainty. A qualitative study**

**Authors:** Phillips, Christine, et al

**Journal:** Orphanet Journal of Rare Diseases 2024

19(1), pp. 297–2

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/39143641/>

**29. The use of creative case studies to explore non-verbal and non-ambulant children and young people's well-being**

**Authors:** Pickering, Dawn M.; Gill, Paul and Reagon, Carly

**Journal:** Physiotherapy 2024

123, pp. 1–10

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38244485/>

**30. Medical Complexity, Language Use, and Outcomes in the Pediatric ICU**

**Authors:** Pilarz, Mary S., et al

**Journal:** Pediatrics 2024

153(6), pp. e2023063359. doi: 10.1542/peds.2023–063359

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38747049/>

**31. 'There was nothing, just absolute darkness': Understanding the needs of those caring for children and young people with complex neurodisability in a diverse UK context: A qualitative exploration in the ENCOMPASS study**

**Authors:** Prest, Kirsten, et al

**Journal:** Child: Care, Health and Development 2024

50(4), pp. e13303

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38991712/>

**32. Pediatric Population Management Classification for Children with Medical Complexity**

**Authors:** Pulcini, Christian D., et al

**Journal:** Population Health Management 2024

27(3), pp. 192–198

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38613470/>

**33. Promoting Language Justice for Children With Medical Complexity and Their Families: An Urgent Call to Action**

**Authors:** Ragavan, Maya I.; Méndez, Dara D. and Caballero, Tania Maria

**Journal:** Hospital Pediatrics 2024

14(8), pp. e358–e361

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39069818/>

**34. A Systematic Review of Botulinum Toxin Injection in Pediatric Dystonia**

**Authors:** Rasera, Andrea; Squintani, Giovanna Maddalena and Cerruto, Maria Angela

**Journal:** Toxins 2024

16(7), pp. 289. doi: 10.3390/toxins16070289

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39057929/>

**35. What are the experiences of non-invasive ventilation for sleep-disordered breathing in children and young people and what outcomes matter? Perspectives of children and young people, their parents and the staff who care for them**

**Authors:** Russell, Jessica, et al

**Journal:** Child: Care, Health and Development 2024

50(4), pp. e13292

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38927003/>

**36. Quantifying the insurance value for rare diseases: Duchenne muscular dystrophy**

**Authors:** Shafrin, Jason, et al

**Journal:** The American Journal of Managed Care 2024

30(7), pp. e217–e222

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38995826/>

**37. Implementing Strategies to Prevent Home Medication Administration Errors in Children With Medical Complexity**

**Authors:** Shaikh, Ulfat; Kim, Julia M. and Yin, Shonna H.

**Journal:** Clinical Pediatrics 2024

63(7), pp. 877–881

PubMed: <https://pubmed.ncbi.nlm.nih.gov/37644803/>

**38. Equitable Care for Children With a Tracheostomy: Addressing Challenges and Seeking Systemic Solutions**

**Authors:** Sherman, Jules; Zalzal, Habib and Bower, Kyle

**Journal:** Health Expectations : An International Journal of Public Participation in Health Care and Health Policy 2024

27(4), pp. e14158

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39056161/>

**39. Reported costs of children with medical complexity-A systematic review**

**Authors:** Sidra, Michael; Sebastianski, Meghan; Ohinmaa, Arto and Rahman, Sholeh

**Journal:** Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community 2024

28(2), pp. 377–401

PubMed: <https://pubmed.ncbi.nlm.nih.gov/35751147/>

**40. Examining tools for assessing the impact of chronic pain on emotional functioning in children and young people with cerebral palsy: stakeholder preference and recommendations for modification**

**Authors:** Smith, Meredith Grace; Gibson, Rachel J.; Russo, Remo N.; Karanicolas, Sophie and Harvey, Adrienne R.

**Journal:** Quality of Life Research : An International Journal of Quality of Life Aspects of



Treatment, Care and Rehabilitation 2024

33(8), pp. 2247–2259

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38795198/>

**41. The decision-making task: Development and evaluation in a paediatric traumatic brain injury population**

**Authors:** Sood, Nikita Tuli, et al

**Journal:** Neuropsychological Rehabilitation 2024

34(7), pp. 919–937

PubMed: <https://pubmed.ncbi.nlm.nih.gov/37542710/>

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