

Children with Medical Complexity, Rare Conditions and Neurodisabilities Bulletin

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1st June 2025 – 31st August 2025

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3. Definition, investigation and management of gastrointestinal dystonia in children and young people with neurodisability

17. "A very different place from when the pandemic started": Lessons learned for improving systems of care for families of children with medical complexity

19. The risks, benefits, and resource implications of different diets in gastrostomy-fed children: The YourTube mixed method study

30. Anxiety and quality-of-life for parents of children with undiagnosed rare conditions: A multi-site quantitative survey study

51. Safe Enough: Subjective Determinations in Hospital Discharge for Patients With Medical Complexity

1. Breathing easy: A qualitative analysis of caregiver experience with high-fidelity pediatric tracheostomy simulation

Authors: Acorda, Darlene E.; Eggers, Jeannie; Cannon, Akisha; Poncik, April and Roy, Kevin

Journal: International Journal of Pediatric Otorhinolaryngology 2025, 195, pp. 112412

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40482631/>

2. Parental perspectives of trisomy 18: common threads of a life-limiting diagnosis

Authors: Armour, Evelyn; MacPherson, Melissa J.; Mack, Cheryl and van Manen, Michael

Journal: Medical Humanities 2025, 51(3), pp. 352–359

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39961659/>

3. Definition, investigation and management of gastrointestinal dystonia in children and young people with neurodisability

Authors: Barclay, Andrew R., et al

Journal: Archives of Disease in Childhood 2025, 110(9), pp. 742–750

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40306763/>

4. Parents' experiences of the financial and employment impacts of their child receiving end-of-life care: a national qualitative study

Authors: Barrett, Laura, et al

Journal: BMC Palliative Care 2025, 24(1), pp. 157–1

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40468281/>

5. The Home-Built Environment of Children With Medical Complexity

Authors: Batson, Lora, et al

Journal: Clinical Pediatrics 2025, 64(7), pp. 924–935

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39710954/>

6. Support for Siblings of Children With Complex Care Needs: Public Health Nurses' Perceptions of Their Role in Primary Schools

Authors: Bergvoll, Lise-Marie; Clancy, Anne; Martinussen, Monica and Laholt, Hilde

Journal: Journal of Advanced Nursing 2025, 81(6), pp. 3141–3155

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39352098/>

7. Exploring the experience of communication in healthcare settings with parents of children with a rare genetic condition: "It's the more negative ones that you remember"

Authors: Burbury, Lucy; Ayres, Samantha; Boyle, Jackie; Renton, Heather and McInerney-Leo, Aileen

Journal: Journal of Genetic Counseling 2025, 34(4), pp. e70102

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40831303/>

8. Evaluating the measurement properties of patient-reported outcome measures for young adults with life-limiting conditions: A systematic review

Authors: Chambers, Rachel L.; Hocaoglu, Mevhibe B.; Higginson, Irene J.; Sleeman, Katherine E. and Fraser, Lorna K.

Journal: Palliative Medicine 2025, 39(7), pp. 765–791

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40536040/>

9. Experiences and perceptions of multidisciplinary paediatric teams of blended tube feeding in children

Authors: Clancy, Orlaith; McCormack, Siobhan; Graham, Meave; O'Sullivan, Katie and Bennett, Annemarie E.

Journal: Nutrition and Health 2025, 31(2), pp. 681–688

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38281935/>

10. Development and Validation of Health Educational Videos to Enhance the Oral Health Awareness Among the Parents and Caregivers of Children With Cerebral Palsy

Authors: Constance, D. Diana; Sugumaran, Aparna; Kumar, Parangimalai Diwakar Madan; Balabaskar, K. and Rout, Nachiketa

Journal: Special Care in Dentistry : Official Publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry 2025, 45(4), pp. e70072

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40658021/>

11. Needs and experiences of families after a sudden unexplained death in childhood: a qualitative study

Authors: Cooper, Emily; Holmes, Jonathan; Speed, Nikki and Garstang, Joanna Jane

Journal: BMJ Paediatrics Open 2025, 9(1), pp. e003812. doi: 10.1136/bmjpo-003812

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40850909/>

12. Setting Up for Success: Caregiver Perspectives on Emergency Care Plans for Children With Medical Complexity

Authors: Dallas, Abbey, et al

Journal: Pediatric Emergency Care 2025, 41(8), pp. 592–598

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40452296/>

13. Quality of life among children and young adults with rare diseases. A parental perspective

Authors: De Clercq, Eva; Schmieg, Hannah V.; Gregorowius, Daniel and Streuli, Jürg C.

Journal: European Journal of Pediatrics 2025, 184(8), pp. 510–4

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40730885/>

14. 'Fighting every day': exploring caregiver quality of life and perspectives on healthcare services for children with dementia - a cross-sectional, mixed-methods study

Authors: Djafar, Jason, et al

Journal: Archives of Disease in Childhood 2025, 110(7), pp. 566–572

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39832815/>

15. Outcomes of Children With Tracheostomy Before and After Implementing Caregiver Simulation-Based Tracheostomy Education

Authors: Fain, Mary Ellen, et al

Journal: Otolaryngology--Head and Neck Surgery : Official Journal of American Academy of Otolaryngology-Head and Neck Surgery 2025, 173(2), pp. 497–504

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40277186/>

16. Shared Perspectives: Evaluating the impact of tracheostomy on quality of life through the voices of children and their parents

Authors: Fong, Michelle, et al

Journal: International Journal of Pediatric Otorhinolaryngology 2025, 194, pp. 112386

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40367753/>

17. "A very different place from when the pandemic started": Lessons learned for improving systems of care for families of children with medical complexity

Authors: Fong, Vanessa C.; Baumbusch, Jennifer and Basu Khan, Koushambhi

Journal: Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community 2025, 29(2), pp. 339–352

PubMed: <https://pubmed.ncbi.nlm.nih.gov/37740509/>

18. Equity in neuromuscular research: a 20-year analysis of race, ethnicity, sex, and age representation

Authors: Fontanelli, Lorenzo; Vadi, Gabriele; Bellini, Gabriele; Cossu, Andrea and Siciliano, Gabriele

Journal: Journal of Neurology 2025, 272(7), pp. 483–8

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40586989/>

19. The risks, benefits, and resource implications of different diets in gastrostomy-fed children: The YourTube mixed method study

Authors: Fraser, Lorna, et al

Journal: Health Technology Assessment (Winchester, England) 2025, 29(25), pp. 1–21

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40620081/>

20. Cannabidiol in Drug-Resistant Epilepsy (DRE) in Children: A Retrospective Study

Authors: Gowda, Vykuntaraju K.; Simin, Halima; Kinhal, Uddhava V.; Basavaraja, G. V. and Sanjay, K. S.

Journal: Indian Pediatrics 2025, 62(7), pp. 501–505

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40261499/>

21. Living in a bubble with profound difficulties-parents' experiences of extremely preterm survivors

Authors: Hansson, Malin, et al

Journal: Acta Paediatrica (Oslo, Norway : 1992) 2025, 114(6), pp. 1352–1361

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39791460/>

22. Evaluating health related quality of life in paediatric and adult patients who utilise home enteral tube feeding

Authors: Hinchcliff, Mercedes; Clancy, Annabel; Crawford, Courtney and Gray, Sarah

Journal: Clinical Nutrition (Edinburgh, Scotland) 2025, 52, pp. 189–194

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40780130/>

23. Optimising Paediatric Transition to Intensive Care for Adults (OPTICAL): study protocol for a mixed method study

Authors: Huang, Qi, et al

Journal: BMJ Open 2025, 15(7), pp. e101362–101362

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40669895/>

24. My A-T pack: a qualitative study of the utility, acceptability, design, and content of a family-designed and owned information pack relevant to the lives of children and young people living with ataxia telangiectasia

Authors: Khan, Munira, et al

Journal: Orphanet Journal of Rare Diseases 2025, 20(1), pp. 397–6

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40759969/>

25. Technological lifelines: the everyday lived complexities of dependence and care of pediatric long-term tracheostomy

Authors: Ledin, Ellinor Rydhamn; Fasterius, Linda; Björling, Gunilla; Eriksson, Andrea and

Mattson, Janet

Journal: Disability and Rehabilitation 2025, 47(14), pp. 3687–3695

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39555703/>

26. Exploring caregiver perspectives on health service delivery priorities for individuals with complex care needs: a qualitative descriptive study

Authors: MacNeill, Lillian, et al

Journal: BMC Health Services Research 2025, 25(1), pp. 1059–9

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40790758/>

27. Family Caregivers of Individuals With Neuromuscular Disease Participating in a Randomized Controlled Trial of a Digital Peer Support Program: Nested Qualitative Study

Authors: Mekhuri, Samantha, et al

Journal: Journal of Medical Internet Research 2025, 27, pp. e72141

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40720845/>

28. Prevalence of sleep problems in children with cerebral palsy: A systematic review and meta-analysis

Authors: Nadeem, Zain Ali, et al

Journal: Sleep Medicine 2025, 132, pp. 106552

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40328188/>

29. Cultural modulation of family care for technology-dependent children: an ethnographic study

Authors: Neves, Eliane Tatsch, et al

Journal: Revista Da Escola De Enfermagem Da U S P 2025, 59, pp. e20240356–0356en.
eCollection 2025

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40657879/>

30. Anxiety and quality-of-life for parents of children with undiagnosed rare conditions: A multi-site quantitative survey study

Authors: Patel, Ria; Friedrich, Bettina; Sanderson, Saskia C.; Ellard, Holly and Lewis, Celine

Journal: Journal of Genetic Counseling 2025, 34(4), pp. e70085

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40767117/>

31. Risk and Protective Factors for Burnout Among Parents of Children With Complex Care Needs: Parents' Perspectives

Authors: Patty, Nathalie J. S., et al

Journal: Child: Care, Health and Development 2025, 51(4), pp. e70143

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40704533/>

32. Integrating Lived Experience Into Medical Education Related to Children With Medical Complexity or Developmental Disabilities: Protocol for a Scoping Review

Authors: Pollard, Noah; Christensen, Leslie; Kloster, Heidi; Gerber, Danielle and Chödrön, Gail

Journal: JMIR Research Protocols 2025, 14, pp. e64911

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40704533/>

33. Secretion management devices reduce hospitalizations for respiratory exacerbations in children with neurodisability

Authors: Pradon, Jérôme, et al

Journal: Respiratory Medicine 2025, 245, pp. 108183

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40446863/>

34. Economic costs of health and social care for a child with a life-limiting condition in their last year of life: a systematic review

Authors: Prendergast, Louise;Crane, Ellie;Bray, Nathan and Noyes, Jane

Journal: BMJ Paediatrics Open 2025, 9(1), pp. e003526. doi: 10.1136/bmjpo-003526

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40670044/>

35. Adapting a Participatory Group Programme for Caregivers of Children with Complex Neurodisability from Low-, Middle-Income Countries to a High-Income Setting: Moving from "Baby Ubuntu" to "Encompass"

Authors: Prest, Kirsten, et al

Journal: International Journal of Environmental Research and Public Health 2025, 22(7), pp. 1144. doi: 10.3390/ijerph22071144

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40724208/>

36. Challenges of managing pediatric polypharmacy in a pediatric complex care program: A qualitative pilot study

Authors: Reedy, Julia, et al

Journal: Journal of the American Pharmacists Association : JAPhA 2025, 65(4), pp. 102391

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40127839/>

37. Blended diets and effects on gastrointestinal symptoms in children with gastrostomy tubes: A survey study

Authors: Scarpato, Elena, et al

Journal: Journal of Pediatric Gastroenterology and Nutrition 2025, 81(2), pp. 339–345

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40485512/>

38. Readmission and mortality among children requiring long-term mechanical ventilation via tracheostomy: a systematic review

Authors: Scheller, Lindsey, et al

Journal: BMC Pulmonary Medicine 2025, 25(1), pp. 385–3

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40790566/>

39. Components of Family Meetings for Hospitalized Children With Serious Illness: A Scoping Review

Authors: Semple, Aisling, et al

Journal: Hospital Pediatrics 2025, 15(8), pp. e392–e403

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40592505/>

40. Quality of Life of People With Neuromuscular Diseases: The Role of Stigma

Authors: Sommers-Spijkerman, Marion, et al

Journal: Muscle & Nerve 2025, 72(2), pp. 274–285

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40390240/>

41. Evaluation of the Health-Related Quality of Life and Mental Health of Parents With Children and Adolescents With a Rare Disease Based on the Results of a Randomized Controlled Trial to Investigate a Family-Based Intervention and an Online Intervention for Affected Families (CARE-FAM-NET)

Authors: Steinberg, Antonia, et al

Journal: Family Process 2025, 64(2), pp. e70041

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40375458/>

42. Quantifying Antibiotic Prescribing in Children With Tracheostomies

Authors: Steuart, Rebecca, et al

Journal: Pediatric Pulmonology 2025, 60(8), pp. e71216

PubMed:

43. "I'm not a physician, but I'm the expert for my child" experiences of parents caring for their child with a life-limiting condition in an inpatient setting - A qualitative study

Authors: Stößlein, Sophie; Gramm, Julia; Hein, Kerstin Karen; Borasio, Gian Domenico and Führer, Monika

Journal: Palliative & Supportive Care 2025, 23, pp. e127

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40778604/>

44. Gold Standard Home Nasogastric Tube Feeding for Infants and Children

Authors: SUCCEED Child Feeding Alliance, et al

Journal: Journal of Paediatrics and Child Health 2025, 61(7), pp. 1006–1013

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40269492/>

45. Spiritual Communication Between Pediatric Oncologists, Caregivers, and Patients With Brain Tumors

Authors: Superdock, Alexandra K., et al

Journal: Pediatric Blood & Cancer 2025, 72(7), pp. e31721

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40259532/>

46. Qualitative analysis of the needs of parents of children with rare genetic diseases, following their diagnosis obtained by whole-exome sequencing

Authors: Takatsuka, Mii, et al

Journal: Journal of Genetic Counseling 2025, 34(3), pp. e70015

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40305385/>

47. The effects of hydrotherapy on athletic ability in children with cerebral palsy: A systematic review and meta-analysis

Authors: Tao, Ye; Cao, Ziyi; Shin, Min-Chul; Chen, Meijia and Han, Shuaiju

Journal: PloS One 2025, 20(6), pp. e0325517

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40493654/>

48. 'No man's land': the journey of young adults with complex care needs, from paediatric to adult healthcare

Authors: Thomas, Josephine; Anderson, Jemma; Dee-Price, Betty-Jean; Kelly, Janet and Turpin, Kate

Journal: Internal Medicine Journal 2025, 55(7), pp. 1090–1097

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40321058/>

49. Enhancing parental health literacy through educational workshops: improving care for children with complex health needs

Authors: Thomas, Sarah, et al

Journal: BMJ Paediatrics Open 2025, 9(1), pp. e003511. doi: 10.1136/bmjpo-003511

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40685221/>

50. Family Caregiver Knowledge in the Outpatient Management of Pediatric Tracheostomy-Related Emergencies

Authors: Truitt, Brittany A., et al

Journal: Clinical Pediatrics 2025, 64(7), pp. 936–943

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39707594/>

51. Safe Enough: Subjective Determinations in Hospital Discharge for Patients With Medical Complexity

Authors: Võ, Holly Hòa; Seltzer, Rebecca R. ;Scott, Maya; Feudtner, Chris and Foster, Carolyn

Journal: Pediatrics 2025

155(6), pp. e2024067585. doi: 10.1542/peds.2024–067585

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40355131/>

52. An underestimated factor for therapeutic decision-making in rare diseases: parents' (un)knowledge-the example of Duchenne muscular dystrophy caregivers and non-invasive ventilation

Authors: Wasilewska, Eliza, et al

Journal: Orphanet Journal of Rare Diseases 2025, 20(1), pp. 280–9

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40474208/>

53. Advance care planning for children with life-limiting and life-threatening conditions

Authors: Yamaji, Noyuri, et al

Journal: The Cochrane Database of Systematic Reviews 2025, 7(7), pp. CD016106

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40613388/>

54. A Qualitative Study of CMC Caregivers' Perspectives about their Emotional Well-Being

Authors: Yu, Justin A., et al

Journal: Journal of Pain and Symptom Management 2025, 70(1), pp. 46–55.e2

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40187377/>

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