

Children with Medical Complexity, Rare Conditions and Neurodisabilities Bulletin

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8. Parents' Trigger Tool for Children with Medical Complexity - PAT-CMC: Development of a recognition tool for clinical deterioration at home

27. Measurement properties and feasibility of chronic pain assessment tools for use with children and young people with cerebral palsy

36. Patient and Public Involvement Work With Parents of Children With Life-Limiting Conditions and Bereaved Parents: A Rapid Systematic Review

48. Home mechanical ventilation in children: evolving indications in an era of new

1. Healthcare professionals' discussion of loss and grief with parents of children with life-limiting severe neurological impairment: Findings from a scoping review

Authors: Brennan, Elaine; Clarke, Marian Mya and Guerin, Suzanne

Journal: Palliative & Supportive Care 2025, 23, pp. e58

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39981679/>

2. Family expectations and demand for home-based videogaming therapy in children with cerebral palsy in Costa Rica: a mixed methods study

Authors: Chan-Viquez, Daniela, et al

Journal: Disability and Rehabilitation 2025, 47(4), pp. 1012–1023

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38946018/>

3. COVID-19 vaccine effectiveness and uptake in a national cohort of English children and young people with life-limiting neurodisability

Authors: Cruz, Joana, et al

Journal: Archives of Disease in Childhood 2025, 110(2), pp. 158–164

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39406462/>

4. Mapping Surgical Intervention Trajectories in Seriously Ill Children Receiving Palliative Care

Authors: Ellis, Danielle I., et al

Journal: Journal of Pediatric Surgery 2025, 60(1), pp. 161905

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39332972/>

5. Development and validation of the PACPN: Parents' Attitudes Towards Crying Pediatricians and pediatric Nurses questionnaire

Authors: Foijer, M.; Spek, B.; de Vos, M. A.; Verhagen, A. A. E. and Aris-Meijer, J. L.

Journal: European Journal of Pediatrics 2025, 184(3), pp. 203–x

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39961806/>

6. Home Health Care Research for Children With Disability and Medical Complexity

Authors: Foster, Carolyn, et al

Journal: Pediatrics 2025, 155(2), pp. e2024067966. doi: 10.1542/peds.2024–067966

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39808130/>

7. Contemporary uses of "lethal" or "life limiting" terminology in perinatal research

Authors: Gatta, Luke A.; McCarthy, Allison M. and Osmundson, Sarah S.

Journal: Current Opinion in Obstetrics & Gynecology 2025, 37(2), pp. 49–54

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39773661/>

8. Parents' Trigger Tool for Children with Medical Complexity - PAT-CMC: Development of a recognition tool for clinical deterioration at home

Authors: Genna, Catia, et al

Journal: Journal of Advanced Nursing 2025, 81(1), pp. 383–398

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38661213/>

9. A Qualitative Descriptive Study Exploring the Systemic Challenges of Caring for Children With Medical Complexity at Home

Authors: Geyer, David; Flanagan, Jane M.; van de Water, Brittney; McCarthy, Susan and Vessey, Judith A.

Journal: Journal of Pediatric Health Care : Official Publication of National Association of Pediatric Nurse Associates & Practitioners 2025, 39(1), pp. 24–32

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39373673/>

10. Knowledge translation strategies used to promote evidence-based interventions for children with cerebral palsy: a scoping review

Authors: Hanson, Jessica; Sasitharan, Akash; Ogourtsova, Tatiana and Majnemer, Annette

Journal: Disability and Rehabilitation 2025, 47(4), pp. 827–839

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38850195/>

11. Hospital to home transition of children with medical complexities in the Netherlands: current practice

Authors: Haspels, H. N., et al

Journal: European Journal of Pediatrics 2025, 184(1), pp. 122–2

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39779542/>

12. Outcomes of delivery in patients with diagnosed life-limiting fetal condition and evaluation of perinatal palliative care program: a retrospective review of palliative care service over 7 years

Authors: Korzeniewska-Eksterowicz, Aleksandra; Moczulska, Hanna; Grzesiak, Mariusz and Kaczmarek, Piotr

Journal: BMC Palliative Care 2025, 24(1), pp. 38–z

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39934760/>

13. Magic-themed motor training for daily bimanual task performance in children with unilateral spastic cerebral palsy: A systematic review and meta-analysis

Authors: Lee, Kuan-Ting; Cheng, Kai-Wen; Yang, Yi-Ching and Wang, Wei-Li

Journal: Developmental Medicine and Child Neurology 2025, 67(1), pp. 49–58

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39133768/>

14. A Socioecological Approach to Support the Transition to Adult Care for Youth With Medical Complexity: Family Perspectives and Recommendations

Authors: Li, Lin, et al

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

Health Policy 2025, 28(1), pp. e70077

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39737625/>

15. Caregiver Values and Preferences Related to Surgical Decision-Making for Children with Medical Complexity

Authors: Lin, Jody L., et al

Journal: The Journal of Pediatrics 2025, 276, pp. 114366

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39428089/>

16. Outcomes Associated With Care Models for Neonates With Complex Medical Needs: A Scoping Review to Support Program Evaluation

Authors: Loewen, Nicole; Ranger, Manon and Kieran, Emily

Journal: Advances in Neonatal Care : Official Journal of the National Association of Neonatal Nurses 2025, 25(1), pp. 77–83

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39774346/>

17. Exploration of the Evidence on Discharge From Hospital to Home for Children With Medical Complexity and Their Parents: A Review of the Literature

Authors: Mackay, Lyndsay; Dewan, Tammie; Lal, Jaanvi; Hayden, K. Alix and Chang, Una

Journal: Child: Care, Health and Development 2025, 51(1), pp. e70031

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39843972/>

18. Differences in the Oral Health of Children With Medical Complexity

Authors: Malik, Kristina E., et al

Journal: Academic Pediatrics 2025, 25(1), pp. 102552

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39096999/>

19. Noninvasive Ventilation or CPAP in the Initial Treatment Phase of Small Infants With Respiratory Failure

Authors: Miller, Andrew G., et al

Journal: Respiratory Care 2025, 70(2), pp. 161–169

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39096999/>

20. Global predictors of tracheostomy-related pressure injury in the COVID-19 era: A study of secondary data

Authors: Moser, Chandler H., et al

Journal: Intensive & Critical Care Nursing 2025, 86, pp. 103720

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38802295/>

21. Deaths in children in England from SARS-CoV-2 infection during the first 2 years of the pandemic: a cohort study

Authors: Odd, David, et al

Journal: BMJ Open 2025, 15(2), pp. e092627–092627

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39909515/>

22. Televisit with TytoHome™ device in medically complex child in long-term mechanical ventilation: a pilot study

Authors: Onofri, Alessandro, et al

Journal: Italian Journal of Pediatrics 2025, 51(1), pp. 45–0

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39939975/>

23. Development of a new social prescribing intervention for families of children with cerebral palsy

Authors: Ostojic, Katarina, et al

Journal: Developmental Medicine and Child Neurology 2025, 67(2), pp. 223–234

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39031596/>

24. Nutrition support in children with medical complexity and chronic critical illness: A narrative review

Authors: Perez, Jennifer M.; Graham, Robert J.; Mehta, Nilesh M. and Martinez, Enid E.

Journal: Nutrition in Clinical Practice : Official Publication of the American Society for Parenteral and Enteral Nutrition 2025, 40(1), pp. 54–63

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39369297/>

25. Influences of a Remote Monitoring Program of Home Nasogastric Tube Feeds on Transition from NICU to Home

Authors: Quinn, Megan; Banta-Wright, Sandra and Warren, Jamie B.

Journal: American Journal of Perinatology 2025, 42(2), pp. 250–255

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38889888/>

26. Sexual History Documentation in Pediatric Patients with Technology Dependence

Authors: Sahoo, Ankita and Carter, Rebecca

Journal: Clinical Pediatrics 2025, 64(2), pp. 205–209

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38808679/>

27. Measurement properties and feasibility of chronic pain assessment tools for use with children and young people with cerebral palsy

Authors: Smith, Nadine L., et al

Journal: Disability and Rehabilitation 2025, 47(4), pp. 840–854

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38856092/>

28. Cross-sectional study of the perceived wellbeing of children in palliative care

Authors: Toro-Pérez, Daniel, et al

Journal: Anales De Pediatria 2025, 102(1), pp. 503720

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39753457/>

29. Hypoxic-Ischemic Encephalopathy: Pathogenesis and Promising Therapies

Authors: Yang, Mingming; Wang, Kexin; Liu, Boya; Shen, Yuntian and Liu, Guangliang

Journal: Molecular Neurobiology 2025, 62(2), pp. 2105–2122

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39073530/>

30. Translating a Clinical Practice Guideline to a Portuguese, Spanish and English Practice Brief to promote exercise therapy for paediatric Charcot-Marie-Tooth disease

Authors: de Paula, Caroline Soares, et al

Journal: Physiotherapy 2024, 125, pp. 101419

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39395361/>

31. "In God We Trust": An Exploratory Study of the Associations Between Religiosity and the Caregiving Experiences of Parents of Children with Rare Diseases in Poland

Authors: Domaradzki, Jan and Walkowiak, Dariusz

Journal: Journal of Religion and Health 2024, 63(6), pp. 4079–4109

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39103591/>

32. Life After Neonatal Seizures: Characterizing the Longitudinal Parent Experience

Authors: Field, Natalie K., et al

Journal: Pediatric Neurology 2024, 161, pp. 76–83

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39103591/>

33. Research staff's experiences of how the COVID-19 pandemic impacted recruitment for a paediatric network study

Authors: Fishman, Isobel; Henderson, Suzanne and Vadeboncoeur, Christina

Journal: International Journal of Qualitative Studies on Health and Well-Being 2024, 19(1), pp. 2419158

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39437222/>

34. Beyond presence of symptoms: Self-reported psychosocial distress interference among outpatient youth with cancer and other life-limiting conditions

Authors: Gordon, Mallorie L., et al

Journal: Pediatric Blood & Cancer 2024, 71(12), pp. e31273

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39317851/>

35. Impact of care coordination on service utilisation for children with medically complex cerebral palsy

Authors: Harvey, Adrienne, et al

Journal: Journal of Paediatrics and Child Health 2024, 60(12), pp. 815–824

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39385404/>

36. Patient and Public Involvement Work With Parents of Children With Life-Limiting Conditions and Bereaved Parents: A Rapid Systematic Review

Authors: Holder, Pru; Page, Bethan; Hackett, Julia; Mitchell, Sarah and Fraser, Lorna K.

Journal: Health Expectations : An International Journal of Public Participation in Health Care and Health Policy 2024, 27(6), pp. e70120

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39648508/>

37. Correlation of Comorbidities and Variability of Tics in Children with Chronic Tic Disorder

Authors: Jensen, Ida and Debes, Nanette Marinette Monique Mol

Journal: Neuropediatrics 2024, 55(6), pp. 382–388

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38991524/>

38. Caregiver Perspectives on Provider Continuity During Prolonged PICU Hospitalizations: A Single-Center Qualitative Study, 2021-2022

Authors: Jiménez, Patricia Peña, et al

Journal: Pediatric Critical Care Medicine : A Journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies 2024, 25(12), pp. 1159–1167

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39630068/>

39. "What about me?": lived experiences of siblings living with a brother or sister with a life-threatening or life-limiting condition

Authors: Kittelsen, Trine Brun; Castor, Charlotte; Lee, Anja; Kvarme, Lisbeth Gravdal and Winger, Anette

Journal: International Journal of Qualitative Studies on Health and Well-Being 2024, 19(1), pp. 2321645

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38404038/>

40. Pediatric Rare Diseases Development in the Pharmaceutical Industry: An International Consortium for Innovation and Quality in Pharmaceutical Development, Clinical Pharmacology Leadership Group-Pediatrics Working Group, Rare Diseases Subteam Whitepaper Examining the Current Landscape and Recommendations for the Future

Authors: Krishna, Rajesh, et al

Journal: Clinical Pharmacology and Therapeutics 2024, 116(6), pp. 1433–1441

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39145605/>

41. Maltreatment, homicide and access to specialised palliative care among children and young adults with a life-limiting condition: a nationwide population-based study

Authors: Lin, Shih-Chun; Chang, Hsin-Yi and Huang, Mei-Chih

Journal: BMJ Paediatrics Open 2024, 8(1), pp. e002571. doi: 10.1136/bmjpo-002571

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39145605/>

42. Children with medical complexity in the emergency department: Parent experiences and information needs

Authors: Lysak, Danielle; Ali, Samina; Neufeld, Susan and Scott, Shannon D.

Journal: International Emergency Nursing 2024, 77, pp. 101532

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39514932/>

43. The NICU tracheostomy team: multidisciplinary collaboration for improvement in survival of complex patients

Authors: Machry, Joana Silva, et al

Journal: Journal of Perinatology : Official Journal of the California Perinatal Association 2024, 44(12), pp. 1854–1862

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38914748/>

44. Psychosocial experiences of clinicians providing care for children with severe neurological impairment

Authors: Nevin, Suzanne M., et al

Journal: Developmental Medicine and Child Neurology 2024, 66(12), pp. 1622–1631

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38837791/>

45. The experiences of families of children with cerebral palsy and complex disability after three years accessing the National Disability Insurance Scheme

Authors: O'Neill, Maddison; Bourke-Taylor, Helen; Bhojti, Anoo and Cotter, Claire

Journal: Australian Occupational Therapy Journal 2024, 71(6), pp. 910–924

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38839565/>

46. Usability and Feasibility of an in-Home Remote Exam Device in Children with Medical Complexity During the COVID-19 Pandemic

Authors: Pfarr, Marie A., et al

Journal: Telemedicine Journal and E-Health : The Official Journal of the American Telemedicine Association 2024, 30(12), pp. 2870–2875

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39163318/>

47. Promoting Intensive Transitions for Children and Youth with Medical Complexity from Paediatric to Adult Care: the PITCare study-protocol for a randomised controlled trial

Authors: Santos, Sara, et al

Journal: BMJ Open 2024, 14(12), pp. e086088–086088

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39653557/>

48. Home mechanical ventilation in children: evolving indications in an era of new treatment options

Authors: Tan, Hui-Leng and Chawla, Jasneek

Journal: European Respiratory Review : An Official Journal of the European Respiratory Society 2024, 33(174), pp. 240154. doi: 10.1183/16000617.0154-2024. Print 2024 Oct

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39694585/>

49. The Genetic Puzzle of Cerebral Palsy: Results of a Monocentric Study

Authors: Thys, Liene, et al

Journal: Pediatric Neurology 2024, 161, pp. 1–8

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39213953/>

50. Ethical issues in perinatal communication

Authors: Turchiano, F., et al

Journal: European Journal of Pediatrics 2024, 184(1), pp. 106–2

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39724206/>

51. Nice to know 2: The impact of NICE guidelines on ketogenic diet services in the UK and Ireland - An update

Authors: Whiteley, Victoria J.;Schoeler, Natasha E. and Ketogenic Dietitians Research Network

Journal: Journal of Human Nutrition and Dietetics : The Official Journal of the British Dietetic Association 2024, 37(6), pp. 1432–1437

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39155639/>

52. Children's complex health: Maternal experiences of care and decision making

Authors: Willis, Eleanor and Godbold, Rosemary

Journal: Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community 2024, 28(4), pp. 786–803

PubMed: <https://pubmed.ncbi.nlm.nih.gov/36857439/>

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