



Bulletin No. 2

01/08/2023 - 31/01/2024

- 1. Addressing Emerging Needs Through the COVID-19 and Children With Medical Complexity ECHO**
Authors: Boothby, Christina; Lail, Jennifer; Agrawal, Rishi; Corcoran, Peter and Comeau, Meg
Journal: Pediatrics 2024 153(Suppl 1)
PubMed Link - <https://pubmed.ncbi.nlm.nih.gov/38165236/>
- 2. Parents' experiences of their children's medical journeys with tracheostomies: A Focus Group Study.**
Authors: Castro-Codicil, Maria; Ofosu, Daniel Baah; Mack, Cheryl; Majaesic, Carina and van Manen, Michael
Journal: Paediatrics & Child Health 2024, 29(1), pp. 36-42
PubMed Link - <https://pubmed.ncbi.nlm.nih.gov/38332972/>
- 3. A national survey of current practice on patients with long term and additional needs in paediatric intensive care units.**
Authors: Cuevas-Asturias, Sofia; Arambepola, Devika; Cunningham, Helen and Fraser, James
Journal: Nursing in Critical Care 2024
PubMed Link: <https://pubmed.ncbi.nlm.nih.gov/38168048/>
- 4. Becoming a Rare Disease Parent: An Interpretative Phenomenological Analysis of Parent-Caregivers' Postpartum Experiences.**
Authors: Davidson, Hannah Rochelle; Gelles, Shani; Keller, Krystyna R.; Zajdel, Melissa and Koehly, Laura .
Journal: Qualitative Health Research 2024, 34(1-2), pp. 126-140
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37879105/>

- 5. Blended feeding in gastrostomy-fed children-A scoping review**
Authors: Doyle, Carmel; Louw, Julia; Shovlin, Amanda;Dowd, Laura and Kavanagh, Maria
Journal: Child: Care, Health & Development 2024, 50(1), pp. e13222
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38265135/>
- 6. Interventions to improve continence for children and young people with neurodisability: a national survey of practitioner and family perspectives and experiences.**
Authors: Eke, Helen, et al
Journal: BMJ Paediatrics Open 2024, 8(1)
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38242630/>
- 7. Assessing the suitability of the Carer Support Needs Assessment Tool (CSNAT-Paediatric) for use with parents of children with a life-limiting condition: A qualitative secondary analysis.**
Authors: Fisher, Victoria; Atkin, Karl; Ewing, Gail; Grande, Gunn and Fraser, Lorna K.
Journal: Palliative Medicine 2024, 38(1), pp. 100-109
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38142279/>
- 8. Incorporating parental values in complex paediatric and perinatal decisions**
Authors: Geurtzen, Rosa and Wilkinson, Dominic J. C.
Journal: The Lancet Child & Adolescent Health 2024, (3), pp. 225-235
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38219752/>
- 9. What Families of Children With Medical Complexity Say They Need: Humanism in Care Delivery Change.**
Authors: Houlihan, Bethlyn Vergo; Coleman, Cara;Kuo, Dennis Z.; Plant, Benjamin and Comeau, Meg
Journal: Pediatrics 2024, 153(Suppl 1)
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38165241/>
- 10. Clinical Trials for Special Populations: Children, Older Adults, and Rare Diseases**
Authors: Jacobson, Robert M.; Pignolo, Robert J. and Lazaridis, Konstantinos N.
Journal: Mayo Clinic Proceedings 2024, 99(2), pp. 318-335
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38309939/>
- 11. 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

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

12. **Outcomes of patients supported by mechanical ventilation and their families two months after discharge from pediatric intensive care unit.**
Authors: MacDonald, Simon, et al
Journal: Frontiers in Pediatrics 2024, 12, pp. 1333634
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38362003/>
13. **Stress, coping, and positive aspects of caregiving among caregivers of children with rare disease.**
Authors: Manalel, Jasmine A., et al
Journal: Psychology & Health 2024, 39(2), pp. 216-232
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/35620936/>
14. **Telehealth for Children With Medical Complexity During the COVID Pandemic: A Qualitative Study Exploring Caregiver Experiences.**
Authors: Nageswaran, Savithri; Dailey-Farley, Heather and Golden, Shannon L.
Journal: Clinical Pediatrics 2024, 63(1), pp. 53-65
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37840305/>
15. **The experiences of parents of children diagnosed with cerebral adrenoleukodystrophy.**
Authors: Piercy, Hilary and Nutting, Charlotte
Journal: Child: Care, Health & Development 2024, 50(1), pp. e13184
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37850425/>
16. **Measuring What Matters to Children With Medical Complexity and Their Families.**
Authors: Randolph, Greg; Coleman, Cara; Allshouse, Carolyn; Plant, Benjamin and Kuo, Dennis Z.
Journal: Pediatrics 2024, 153(Suppl 1)
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38165239/>
17. **"100 Things I Wish Someone Would Have Told Me": Everyday Challenges Parents Face While Caring for Their Children With a Tracheostomy.**
Authors: Sherman, Jules; Bower, Kyle L. and Eskandanian, Kolaleh
Journal: Qualitative Health Research 2024.
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38193439/>
18. **The impact of the COVID-19 pandemic on families of children with medical complexity: A qualitative study of caregivers' experiences.**

Authors: Tager, Julia B., et al

Journal: Child: Care, Health & Development 2024, 50(1), pp. e13187

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37855455/>

19. Understanding anxiety experienced by young males with Duchenne muscular dystrophy: a qualitative focus group study.

Authors: Trimmer, Rachel E.; Mandy, William P. L.; Muntoni, Francesco and Maresh, Kate E.

Journal: Neuromuscular Disorders 2024, 34, pp. 95-104

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38159461/>

20. A perfect storm in a pandemic-a child with complex medical history and special diet encounters COVID

Item Type: Report

Authors: Waldrop, S.W. and Krebs, N.F.

Publication Date: 2024

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38233266/>

21. Epilepsy and cannabis: So near, yet so far.

Journal: Developmental Medicine & Child Neurology 2023, 65(11), pp. e119

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37592390/>

22. An After-Hours Virtual Care Service for Children With Medical Complexity and New Medical Technology: Mixed Methods Feasibility Study.

Authors: Babayan, Katherine; Keilty, Krista; Esufali, Jessica and Grajales Iii, Francisco J.

Journal: JMIR Pediatrics and Parenting 2023, 6, pp. e41393

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37938869/>

23. Barriers to the spiritual care of parents taking care of their child with a life-limiting condition at home.

Authors: Brouwer, Marije A., et al

Journal: European Journal of Pediatrics 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37950793/>

24. A cross-sectional survey of healthcare professionals supporting children and young people with epilepsy and their parents/carers: which topics are raised in clinical consultations and can healthcare professionals provide the support needed?.

Authors: Cook, Georgia, et al

Journal: Epilepsy & Behavior 2023, 149, pp. 109543

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38006842/>

25. What matters to parents? A scoping review of parents' service experiences and needs regarding genetic testing for rare diseases

Authors: Crellin, Erin; Martyn, Melissa; McClaren, Belinda and Gaff, Clara

Journal: European Journal of Human Genetics 2023, 31(8), pp. 869-878

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37308600/>

26. Ultra-rare ultra-care: Assessing the impact of caring for children with ultra rare diseases.

Authors: Domaradzki, Jan and Walkowiak, Dariusz

Journal: European Journal of Paediatric Neurology 2023, 48, pp. 78-84

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38071849/>

27. 'No One Is Talking About This' - rare diseases in childhood.

Authors: Fisayo, Temitope

Journal: Archives of Disease in Childhood 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38041665/>

28. Safety, resource use and nutritional content of home-blended diets in children who are gastrostomy fed: findings from 'YourTube' - a prospective cohort study.

Authors: Fraser, Lorna K., et al

Journal: Archives of Disease in Childhood 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38129118/>

29. 'YourTube' the role of different diets in gastrostomy-fed children: Baseline findings from a prospective cohort study.

Authors: Fraser, Lorna K., et al

Journal: Developmental Medicine & Child Neurology 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37946550/>

30. Experiences of Parents of Children With Medical Complexity in the Pediatric Intensive Care Unit: A Scoping Review.

Authors: Gallegos, Cara and Cacchillo, Natalie

Journal: Critical Care Nurse 2023, 43(4), pp. 20-28

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37524368/>

31. **Parents' process of recognition and response to clinical deterioration of their children with medical complexity at home: A grounded theory.**
Authors: Genna, Catia, et al
Journal: Journal of Clinical Nursing 2023, 32(15-16), pp. 4677-4693
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36101491/>
32. **The impact of clinical trial participation on quality of life and psychosocial well-being in children with Duchenne muscular dystrophy and their parents.**
Authors: Geuens, Sam, et al
Journal: Neuromuscular Disorders 2023, 33(11), pp. 877-881
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37926639/>
33. **Social prescribing for children and young people with neurodisability and their families initiated in a hospital setting: a systematic review.**
Authors: Gordon, Katie; Gordon, Laura and Basu, Anna Purna
Journal: BMJ Open 2023, 13(12), pp. e078097
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38135327/>
34. **Uncertainty and the NICU Experience: A Qualitative Evaluation of Family and Provider Perspectives.**
Authors: Gorsky, Katharine Griffin, et al
Journal: Children 2023, 10(11)
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38002836/>
34. **Nutritional Management in Children and Adolescents with Severe Neurological Impairment-Who Cares? A Web-Based Survey Among Pediatric Specialists in Germany.**
Authors: Hommel, Sara; Lucke, T. and Schmidt-Choudhury, A.
Journal: Neuropediatrics 2023, 54(6), pp. 371-380
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37607575/>
35. **The Lived Experience of Pediatric Gene Therapy: A Scoping Review**
Authors: Kimberly, Laura, et al
Journal: Human Gene Therapy 2023, 34(23-24), pp. 1180-1189
PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37964764/>
36. **Health care utilisation and education outcomes of children with rare diseases: a born in Bradford cohort study.**

Authors: Lodh, Rajib, et al

Journal: European Journal of Pediatrics 2023, 182(12), pp. 5511-5517

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37782349/>

37. Measure what matters: considerations for outcome measurement of care coordination for children with neurodevelopmental disabilities and medical complexity.

Authors: Materula, Dercia, et al

Journal: Frontiers in Public Health 2023, 11, pp. 1280981

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38026305/>

38. Understanding parents' experiences of care for children with medical complexity in England: a qualitative study.

Authors: McLorie, Emma Victoria; Hackett, Julia and Fraser, Lorna Katharine

Journal: BMJ Paediatrics Open 2023, 7(1), pp. 08

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37550084/>

39. How are children with medical complexity being identified in epidemiological studies? A systematic review.

Authors: Oliveira, Patricia Vicente; Enes, Carla C. and Nucci, Luciana B.

Journal: World Journal of Pediatrics 2023, 19(10), pp. 928-938

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36574212/>

40. Blended diets for tube-fed children and young people: a rapid review update

Authors: Phillips, Gemma and Coad, Jane

Journal: Archives of Disease in Childhood 2023, 108(12), pp. 1014-1018

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37595987/>

41. Pain in Children and Adolescents with Spinal Muscular Atrophy: A Longitudinal Study from a Patient Registry.

Authors: Pitarch-Castellano, Inmaculada, et al

Journal: Children 2023, 10(12)

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38136082/>

42. Caring for children with new medical technology at home: parental perspectives.

Authors: Pitch, Natalie, et al

Journal: BMJ Paediatrics Open 2023, 7(1), pp. 10

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37865398/>

43. Caregiver-reported impact of access to switch-adapted toys on play for children with complex medical conditions.

Authors: Rasmussen, Kial-Ann M.; Chole, Dana M.; Hughes, Rachel; Threlkeld, Katie and Janes, William E.

Journal: Child: Care, Health & Development 2023, 49(6), pp. 955-960

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36791764/>

44. Ensuring access to innovative therapies for children, adolescents, and young adults across Canada: The single patient study experience

Authors: Revon-Riviere, Gabriel, et al

Journal: Paediatrics & Child Health 2023, 28(7), pp. 399-403

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37885599/>

45. Management of neurological problems in children on home invasive mechanical ventilation.

Authors: Sayar, Yavuz; Yildirim, Mirac and Teber, Serap

Journal: Pediatric Pulmonology 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/38131516/>

46. The critical role of technologies in neonatal care

Authors: Taha, Syed; Simpson, Rosalind B. and Sharkey, Don

Journal: Early Human Development 2023, 187, pp. 105898

PubMed link:

47. Parent Perspectives on the Child Experience of Pediatric Home Ventilation via Tracheostomy.

Authors: Vo, Holly Hoa, et al

Journal: Hospital Pediatrics 2023, 13(12), pp. 1124-1133

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37944264/>

48. Navigating the complexities of medicating paediatric patients: Insights from an enteral feeding tube workshop.

Authors: Walsh, Jennifer; Hermans, Esmerald and Salunke, Smita

Journal: European Journal of Pharmaceutics & Biopharmaceutics 2023, 191, pp. 259-264

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37633500/>

49. **Living with a rare disease - experiences and needs in pediatric patients and their parents.**

Authors: Witt, Stefanie; Schuett, Katharina; Wiegand-Grefe, Silke ;Boettcher, Johannes and Quitmann, Julia

Journal: Orphanet Journal of Rare Diseases 2023, 18(1), pp. 242

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37568186/>

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