

Children with Medical Complexity, Rare Conditions and Neurodisabilities Bulletin

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Highlighted abstracts:

- 4. Weathering the Storm: Climate-Related Weather Event Experiences of Families of Children With Medical Complexity
- 12. Qualitative evaluation of a hospital-inpatient service for children with medical complexity
- 17. "I need everybody to understand that he's a whole child": A mixed-methods study exploring caregivers' experiences with their children with medical complexities
- 19. The struggle to belong: a qualitative exploration of challenges in social spaces faced by children with Duchenne muscular dystrophy attending neuromuscular disorders clinic
- 23. Assessing the use of the distress and discomfort assessment tool (DisDat) in a pediatric population
- 28. Ethical Challenges in Pediatric Medical Complexity: A Survey of Parents

1. Co-creation and evaluation of online care maps for children with medical complexity

Authors: Adams, Sherri, et al

Journal: BMC Pediatrics 2025, 25(1), pp. 329–5

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40281538/>

2. Children with medical complexity care journey during COVID-19 from providers perspective: a qualitative study

Authors: Asan, Onur, et al

Journal: BMC Health Services Research 2025, 25(1), pp. 740–9

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40399952/>

3. Home Enteral Tube Feeding in Children and Young People: A Review of Current Literature on Optimum Frequency and Mode of Dietetic Assessment and Monitoring in the Community Setting

Authors: Baker, Hannah; Durnan, Sarah and Pugh, Pearl

Journal: Journal of Human Nutrition and Dietetics : The Official Journal of the British Dietetic Association 2025, 38(2), pp. e70044

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40159683/>

4. Weathering the Storm: Climate-Related Weather Event Experiences of Families of Children With Medical Complexity

Authors: Baumbusch, Jennifer; Fong, Vanessa; Lee, Esther; Bandara, Nilanga Aki and Khan, Koushambhi Basu

Journal: Child: Care, Health and Development 2025, 51(2), pp. e70068

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40102035/>

5. Caregivers of Children With Medical Complexity: A Qualitative Study of Their Adaptation

Authors: Bayer, Nathaniel D., et al

Journal: Hospital Pediatrics 2025, 15(5), pp. 407–415

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40288781/>

6. Experiences of mothers caring for children with rare diseases in Turkey

Authors: Bayraktar, Sema, et al

Journal: Journal of Genetic Counseling 2025, 34(2), pp. e1978

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39327410/>

7. The spiritual needs and care of children and young people with life-threatening or life-shortening conditions, and parents (SPARKS): mixed-method investigation

Authors: Beresford, Bryony, et al

Journal: Health Soc Care Deliv Res. 2025 May;13(16):1-119.

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40455663/>

8. Functions of communication during emergency care of children with medical complexity: Caregiver perspectives

Authors: Ciurria, Julia A.;Lin, Jennifer Reyes; Pruitt, Cassandra M. and Sisk, Bryan A.

Journal: Patient Education and Counseling 2025, 134, pp. 108667

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39842067/>

9. Complex Care Needs a Team Approach: How Implementation of a Nurse Key-Worker Can Improve Care for Children With Medical Complexity and Their Families

Authors: Diaczun, Tessa, et al

Journal: Child: Care, Health and Development 2025, 51(3), pp. e70093

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40371685/>

10. "Who Has the Relationship?": Caring for a Shared Population of Children with Medical Complexity

Authors: DiDomizio, P. Galen; Johnson, Madeleine and Friedrich, Annie

Journal: Journal of Palliative Medicine 2025, 28(3), pp. 358–364

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39718772/>

11. Development and Implementation of a Protocol for NICU Discharge With Nasogastric Tube Feedings: Successes, Barriers, and Lessons Learned

Authors: Dozier-Lineberger, Mayah; Orth, Erin; Hueckel, Rémi and Brandon, Debra

Journal: Advances in Neonatal Care : Official Journal of the National Association of Neonatal Nurses 2025, 25(3), pp. 218–225

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40146974/>

12. Qualitative evaluation of a hospital-inpatient service for children with medical complexity

Authors: Ghotane, Swapnil; Page, Bethan; Ramachandran, Rohana; Wolfe, Ingrid and Fraser, Lorna Katharine

Journal: BMJ Paediatrics Open 2025, 9(1), pp. e003101. doi: 10.1136/bmjpo-003101

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40146974/>

13. Effects of Family Caregiver-Nurse Communication on Family Management and Family Caregiver Uncertainty Regarding the Care of Children With Long-Term Ventilator Dependence

Authors: Giambra, Barbara K., et al

Journal: Journal of Family Nursing 2025, 31(2), pp. 106–121

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39491333/>

14. Proof of concept, feasibility, and acceptability of spiritual care assessment and intervention-pediatric with caregivers of children receiving home mechanical ventilation

Authors: Grossoehme, Daniel H., et al

Journal: Journal of Health Care Chaplaincy 2025, 31(2), pp. 147–160

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39388192/>

15. Bridging hospital to home for children with medical complexity and their families: an observational prospective cohort study protocol to assess the effectiveness of an innovative transitional care unit in the Netherlands (BRIDGE study)

Authors: Haspels, Heleen N., et al

Journal: BMJ Open 2025, 15(4), pp. e093693–093693

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40254310/>

16. Building independence in self-care and household tasks: a qualitative study with adolescents with cerebral palsy and their caregivers

Authors: Iscorsoni, Fernanda; Bueno, Kátia M. P.; Feitosa, Aline M.; Mancini, Marisa C. and Brandão, Marina B.

Journal: Disability and Rehabilitation 2025, 47(10), pp. 2647–2654

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39254491/>

17. "I need everybody to understand that he's a whole child": A mixed-methods study exploring caregivers' experiences with their children with medical complexities

Authors: Jensen, Emily J.; Douglas, Sarah N.; Khan, Sarah and Bullock, Katharine

Journal: Journal of Pediatric Nursing 2025, 82, pp. 1–10

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39919612/>

18. Variability in treatment of postoperative pain in children with severe neurologic impairment

Authors: Keys, Jordan, et al

Journal: Journal of Hospital Medicine 2025, 20(5), pp. 446–453

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39449156/>

19. The struggle to belong: a qualitative exploration of challenges in social spaces faced by children with Duchenne muscular dystrophy attending neuromuscular disorders clinic

Authors: Kumar, Dinesh, et al

Journal: Disability and Rehabilitation 2025, 47(9), pp. 2358–2365

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39180333/>

20. Incidence of Pediatric to Adult Transition Among Tracheotomy Patients

Authors: Lee, Rebecca, et al

Journal: The Laryngoscope 2025, 135(3), pp. 1186–1191

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39377191/>

21. Goals of Care Discussion Characteristics and Disparities in Children With Medical Complexity

Authors: Monroe, Bryan S., et al

Journal: Academic Pediatrics 2025, 25(4), pp. 102786

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39826888/>

22. "I Am Forever Changed": A Phenomenological Study of the Existential Experiences of Parents of Children and Young People With Complex Care Needs

Authors: Nygård, Carina;Clancy, Anne and Kitzmüller, Gabriele

Journal: Journal of Advanced Nursing 2025, 81(5), pp. 2631–2643

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39355997/>

23. A qualitative study investigating the experiences of unmet social needs for children with cerebral palsy and their families: perspectives of parents and clinicians

Authors: Ostojic, Katarina, et al

Journal: Disability and Rehabilitation 2025, 47(9), pp. 2278–2287

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39155439/>

23. Assessing the use of the distress and discomfort assessment tool (DisDAT) in a pediatric population

Authors: Parks, Rachel, et al

Journal: Journal of Pediatric Nursing 2025, 83, pp. 140–145

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40328182/>

24. Saving lives, one breath at a time: The key role of noninvasive ventilation interfaces

Authors: Praud, Jean-Paul

Journal: Pediatric Pulmonology 2025, 60 Suppl 1(Suppl 1), pp. S117–S119

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39347589/>

25. Using experience-based co-design to explore care experiences and identify practice change priorities for children with medical complexity in the paediatric intensive care unit

Authors: Rennick, Janet E., et al

Journal: BMJ Open 2025, 15(5), pp. e096181–096181

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40379350/>

26. Perspectives in childhood-onset disabilities: integrating 21st-Century concepts to expand our horizons

Authors: Rosenbaum, Peter L.; Imms, Christine; Miller, Laura; Hughes, Debra and Cross, Andrea

Journal: Disability and Rehabilitation 2025, 47(10), pp. 2682–2692

PubMed:

27. Impact of Systems of Care on Emotional Well-Being of Primary Family Caregivers of Children with Medical Complexity

Authors: Schnell, Jessica L., et al

Journal: Maternal and Child Health Journal 2025, 29(3), pp. 405–414

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39185771/>

28. Ethical Challenges in Pediatric Medical Complexity: A Survey of Parents

Authors: Shapiro, Miriam C., et al

Journal: The Journal of Pediatrics 2025, 279, pp. 114478

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39864504/>

29. Assessing the supportive care needs of parents of children with rare diseases in Ireland

Authors: Somanadhan, Suja, et al

Journal: Journal of Pediatric Nursing 2025, 81, pp. 31–42

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39837019/>

30. Use of blended feeds in children requiring tube feeding

Authors: Sun, Jessica, et al

Journal: Journal of Paediatrics and Child Health 2025, 61(3), pp. 382–386

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39707605/>

31. Caregivers' experiences of feeding children with cerebral palsy: a systematic review of qualitative evidence

Authors: Taylor, Christine; Badawi, Nadia; Novak, Iona and Foster, Jann

Journal: JBI Evidence Synthesis 2025, 23(4), pp. 704–755

PubMed: <https://pubmed.ncbi.nlm.nih.gov/40012369/>

32. Functional outcomes in children and adolescents with neurodisability accessing music therapy: A scoping review

Authors: Twyford, Karen, et al

Journal: Developmental Medicine and Child Neurology 2025, 67(4), pp. 428–442

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39469827/>

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