

Children with Medical Complexity, Rare Conditions and Neurodisabilities Bulletin

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- 4. Parental experience of having a child with hypoxic ischaemic encephalopathy: a qualitative study
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- 20. Bullying experiences of youth with neuromuscular disorders and their well-being: A survey study
- 30. Carrying the unspoken: A phenomenological study of the existential experiences of siblings of children with complex care needs
- 33. Interventions supporting the empowerment of parent carers of children with neurodisability and other long-term health conditions: A scoping review

1. Neurodegenerative Diseases in Children: A Comprehensive Review

Authors: Ailioaie, Constantin ;Ailioaie, Laura Marinela; Stan, Cristinel Ionel; Sava, Anca and Chiran, Dragos Andrei

Journal: International Journal of Molecular Sciences 2026, 27(9), pp. 4096. doi:

<https://pubmed.ncbi.nlm.nih.gov/41994538/>

2. Predictors of quality of life in parents of children with rare diseases: a tertiary care center cross-sectional study in Saudi Arabia

Authors: Alkhani, Abdullah, et al

Journal: Frontiers in Public Health 2026, 14, pp. 1767604

<https://pubmed.ncbi.nlm.nih.gov/41994538/>

3. Discrimination in Health Care Against Children With Medical Complexity and Caregiver Mental Health

Authors: Ames, Stefanie G., et al

Journal: Hospital Pediatrics 2026, 16(5), pp. 435–445

<https://pubmed.ncbi.nlm.nih.gov/41974442/>

4. Parental experience of having a child with hypoxic ischaemic encephalopathy: a qualitative study

Authors: Bache, Alexandra, et al

Journal: Archives of Diseases in Childhood. Fetal and Neonatal Edition 2026, 111(3), pp F219-

<https://pubmed.ncbi.nlm.nih.gov/41087080/>

5. Palliative Care for Children and Adolescents with Non-curative Brain Tumors: A Scoping Review

Authors: Bakhtary, Marmareen; Sharma, Pragati; Raspin, Sarah; Vemuri, Sidharth and McCarthy, Maria

Journal: Journal of Palliative Medicine 2026, 29(5), pp. 682–691

<https://pubmed.ncbi.nlm.nih.gov/40293742/>

6. Content validity, face validity and comprehensiveness of generic quality-of-life measures in adults and children with rare genetic conditions and their carers: a think aloud qualitative study

Authors: Bourke, Mackenzie, et al

Journal: Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation 2026, 35(8), pp. 221.

<https://pubmed.ncbi.nlm.nih.gov/40293742/>

7. The sudden unexpected death in epilepsy grief study

Authors: Buchhalter, Jeffrey, et al

Journal: Epilepsy & Behavior : E&B 2026, 177, pp. 110932

<https://pubmed.ncbi.nlm.nih.gov/41702217/>

8. Assessing the impact of e-learning in caregiver training on paediatric epilepsy awareness and buccal Midazolam administration: A Scottish quality improvement study

Authors: Campbell, Jo, et al

Journal: Epilepsy & Behavior : E&B 2026, 177, pp. 110942

<https://pubmed.ncbi.nlm.nih.gov/41707291/>

9. Spiritual well-being, caregiver burden, depression, and quality of life in parents of children with spinal muscular atrophy: A cross-sectional study

Authors: Cansel, Neslihan; Özgör, Bilge and Yücel, Gül

Journal: Medicine 2026, 105(25), pp. e49156

<https://pubmed.ncbi.nlm.nih.gov/42332491/>

10. Life-Sustaining Treatment Decisions and Parent Caregiving Experiences for Children With Medical Complexity

Authors: Chuang, Shun-Wei; Lin, Jaiinn-Jim; Sheu, Shuh-Jen and Lin, Cheng-Pei

Journal: JAMA Network Open 2026, 9(6), pp. e2617970

<https://pubmed.ncbi.nlm.nih.gov/42275061/>

11. Health-related quality of life (HRQOL) of primary caregivers of children with epilepsy in the United Kingdom

Authors: Coates, Sasha; McLaughlin, Marian; Mallett, John and Reilly, Colin

Journal: Epilepsy & Behavior : E&B 2026, 180, pp. 111017

<https://pubmed.ncbi.nlm.nih.gov/41926899/>

12. Coping with Loss in Caregiving: Comparing the Experiences of Dementia Family Caregivers and Parents of Medically Complex Children

Authors: Cooper, R. Amanda; Burke, Tricia J. and DeGroot, Jocelyn

Journal: Health Communication 2026, 41(4), pp. 695–705

<https://pubmed.ncbi.nlm.nih.gov/40621752/>

13. Improving Emergency Care for Children With Medical Complexity: A Pragmatic Review

Authors: Dallas, Abbey and Pulcini, Christian D.

Journal: Pediatric Emergency Care 2026, 42(7), pp. 563–570

<https://pubmed.ncbi.nlm.nih.gov/40621752/>

14. Association between a diagnostic journey in Angelman syndrome and caregivers' quality of life

Authors: Domaradzki, Jan and Walkowiak, Dariusz

Journal: Journal of Neurodevelopmental Disorders 2026, 18(1), pp. 30. doi: 10.1186/s11689–1

<https://pubmed.ncbi.nlm.nih.gov/41975265/>

15. Weaning from ketogenic diet therapy in children with epilepsy: Insights from a retrospective study

Authors: Donnard, Noémie, et al

Journal: Epilepsia 2026, 67(4), pp. 1817–1826

<https://pubmed.ncbi.nlm.nih.gov/41443991/>

16. Health Disparities and Ableism in Children With Medical Complexity

Authors: Fatola, Tolulope; Trivedi, Krishna and Shear, Talia S.

Journal: Pediatric Annals 2026, 55(5), pp. e182–e187

<https://pubmed.ncbi.nlm.nih.gov/42065954/>

17. The Forgotten Caregivers: A Qualitative Study Exploring the Experiences of Fathers of Children With Medical Complexity

Authors: Fong, Vanessa C.; Bandara, Nilanga Aki and Baumbusch, Jennifer

Journal: Journal of Clinical Nursing 2026, 35(4), pp. 1807–1816

18. Epilepsy in Paediatric Palliative Care: Prevalence, Clinical Correlations and the Development of a Consensus-Based Seizure Management Protocol

Authors: Hizanu Dumitrache, Mihaela, et al

Journal: Medicina (Kaunas, Lithuania) 2026, 62(6), pp. 1150. doi: 10.3390/medicina62061150

<https://pubmed.ncbi.nlm.nih.gov/42356162/>

19. Emotional dysregulation as a moderating factor on the relationship between the severity of anxiety and depressive symptoms and high caregiving intensity among mothers caring for children diagnosed with life-limiting conditions

Authors: Ibdah, Rufaida Hassan; Zaben, Fadi; Al-Sarayreh, Rozan and Hamdan-Mansour, Ayman

Journal: Palliative & Supportive Care 2026, 24, pp. e106

<https://pubmed.ncbi.nlm.nih.gov/41969128/>

20. Bullying experiences of youth with neuromuscular disorders and their well-being: A survey study

Authors: Ippolito, Christina; Deguise, Marc-Olivier; Lochmüller, Hanns; McMillan, Hugh J. and McAdam, Laura

Journal: Journal of Neuromuscular Diseases 2026, 13(3), pp. 248–254

<https://pubmed.ncbi.nlm.nih.gov/40853190/>

21. Transitional Life Events in Friedreich Ataxia: Differential Age at Onset Perspectives

Authors: Iskandar, Audrey, et al

Journal: Cerebellum (London, England) 2026, 25(4), pp. 96. doi: 10.1007/s12311–7

<https://pubmed.ncbi.nlm.nih.gov/42334716/>

22. Pregnancies in women with rare diseases: Selected maternal and perinatal outcomes

Authors: Kosian, Philipp, et al

Journal: Acta Obstetrica Et Gynecologica Scandinavica 2026, 105(6), pp. 1088–1095

<https://pubmed.ncbi.nlm.nih.gov/41949150/>

23. Barriers and enablers to community living: A mixed-methods systems study of young adults with life-limiting conditions

Authors: Lakhani, Ali;Senyel, Deniz;Mackenzie-Stewart, Ruth and Stuckey, Rwth

Journal: Palliative Medicine 2026, 40(4), pp. 565–573

<https://pubmed.ncbi.nlm.nih.gov/41724576/>

24. Caregiver-Reported Epilepsy Management in Juvenile-Onset Huntington Disease

Authors: Lammert, Dawn B.; Shenoy, Sanaya; Bang, Jee A.; Stafstrom, Carl E. and Riordan, Heather

Journal: Pediatric Neurology 2026, 179, pp. 49–53

<https://pubmed.ncbi.nlm.nih.gov/41921424/>

25. Shared Decision-Making for Children with Medical Complexity and Their Caregivers in the Perioperative Time

Authors: Lin, Jody L.; Gentry, Katherine; Kaphingst, Kimberly A. and Murphy, Nancy

Journal: Pediatric Clinics of North America 2026, 73(2), pp. 239–254

<https://pubmed.ncbi.nlm.nih.gov/42020034/>

26. Multiprofessional Clinician Perspectives on Communicating About Brain Death in Children

Authors: Martz, Katherine; Mirpuri, Karan K.; Malone, Sara and Kolmar, Amanda

Journal: Journal of Pain and Symptom Management 2026, 71(5), pp. 618–629.e3

<https://pubmed.ncbi.nlm.nih.gov/41587626/>

27. Rare SMA Patients: A Comprehensive Look at Clinical Features, Genetic Profiles and Therapeutic Approaches

Authors: Mikhalchuk, Kristina, et al

Journal: International Journal of Molecular Sciences 2026, 27(10), pp. 4301. doi:

10.3390/ijms27104301

<https://pubmed.ncbi.nlm.nih.gov/42196280/>

28. Measuring transition success from paediatric to adult epilepsy services and its association with seizure outcomes: a UK retrospective cohort study

Authors: Modi, Shivana Neeta; Bagkeris, Emmanouil; Suarez-Rivera, Catalina; Petropoulos, Maria-Christina and Hargreaves, Dougal

Journal: Archives of Disease in Childhood 2026, 111(7), pp. 598–605

<https://pubmed.ncbi.nlm.nih.gov/42082329/>

29. "It's a Production": Bringing Children With Medical Complexity to In-Person Clinic Visits

Authors: Nageswaran, Savithri; Dailey-Farley, Heather and Golden, Shannon L.

Journal: Clinical Pediatrics 2026, 65(6), pp. 747–757

<https://pubmed.ncbi.nlm.nih.gov/41546135/>

30. Carrying the Unspoken: A Phenomenological Study of the Existential Experiences of Siblings of Children With Complex Care Needs

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

Journal: Journal of Clinical Nursing 2026, 35(4), pp. 1838–1850

<https://pubmed.ncbi.nlm.nih.gov/41328550/>

31. The discharge process for a child with complex healthcare needs dependent on respiratory technology: A scoping review protocol

Authors: O'Leary, Cora; Flynn, Rachel; FitzGerald, Serena; Mulcahy, Helen and Curtin, Margaret

Journal: PloS One 2026, 21(5), pp. e0349670

<https://pubmed.ncbi.nlm.nih.gov/42201920/>

32. Parenting adolescents with rare diseases: representations of youth strengths and difficulties and perceived parental competence

Authors: Polizzi, Concetta, et al

Journal: Acta Psychologica 2026, 266, pp. 106938

<https://pubmed.ncbi.nlm.nih.gov/42034761/>

33. Interventions supporting the empowerment of parent carers of children with neurodisability and other long-term health conditions: A scoping review

Authors: Reeder, Jim, et al

Journal: Developmental Medicine and Child Neurology 2026, 68(4), pp. 489–500

<https://pubmed.ncbi.nlm.nih.gov/41139287/>

34. "It's just us": Families' experiences with temporary tube feeding

Authors: Reilly, Claire; Marshall, Jeanne; Foley, Jasmine; Thapar, Nikhil and Packer, Rebecca

Journal: Nutrition in Clinical Practice : Official Publication of the American Society for Parenteral and Enteral Nutrition 2026, 41(2), pp. 647–661

<https://pubmed.ncbi.nlm.nih.gov/40836419/>

35. Evaluating virtual reality for anxiety reduction in children and adolescents with life-limiting conditions: a randomized pilot study

Authors: Šebová, Anna; Fajnerová, Iveta; Drnková, Lenka and Hrdličková, Lucie

Journal: BMC Palliative Care 2026, 25(1), pp. 192. doi: 10.1186/s12904–7

<https://pubmed.ncbi.nlm.nih.gov/42163189/>

36. Gaming Technology in Pediatric Cerebral Palsy and Related Neuromuscular Conditions: A Scoping Review

Authors: Stevenson, Jordan; Martin, Susanna E.; English, Mahala G.; Pawliuk, Colleen and Robillard, Julie M.

Journal: NeuroRehabilitation 2026, 58(4), pp. 503–519

<https://pubmed.ncbi.nlm.nih.gov/42206959/>

37. Complications and factors associated with emergency department presentation for pediatric tracheostomy patients

Authors: Trope, Michal; Tabangin, Meredith; Hart, Catherine K.; Benscoter, Dan T. and Smith, Matthew M.

Journal: International Journal of Pediatric Otorhinolaryngology 2026, 203, pp. 112776

<https://pubmed.ncbi.nlm.nih.gov/41785817/>

38. The rare disease tree: adolescent voices, family narratives, and health professionals' views in Greece

EACH Library & Information Service, July 2026

Authors: Tsitsani, Pelagia and Soteriades, Elpidoforos S.

Journal: European Journal of Pediatrics 2026, 185(7), pp. 524. doi: 10.1007/s00431–1

<https://pubmed.ncbi.nlm.nih.gov/42347978/>

39. Coping with the challenges of caregiving: A qualitative exploration of the experiences of family caregivers of children with rare diseases in South Africa

Authors: van Niekerk, Jodie; Gush, Marianne Moosa, Shahida and Pretorius, Chrisma

Journal: Journal of Genetic Counseling 2026, 35(2), pp. e70205

<https://pubmed.ncbi.nlm.nih.gov/41958204/>

40. Characterization of Safety Signals for Spinal Muscular Atrophy Treatments in Children Aged 0 to 3 Years Potential Safety Patterns for Further Investigation

Authors: Zhang, Yupeng; Tang, Xinghang and Chen, Li

Journal: Pediatric Neurology 2026, 180, pp. 90–96

<https://pubmed.ncbi.nlm.nih.gov/42161221/>

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