

EACH Library & Information Service



Children with Medical Complexity, Rare Conditions and Neurodisabilities bulletin

Quarterly Bulletin November 2024 ~ library@each.org.uk

Bulletin No. 5

20/08/2024 – 11/11/2024

Selected abstracts include:

- 24. Young adults' narratives about living with home mechanical ventilation
- 26. Exploring What Motivates Parents of Children Living With Medical Complexity to Participate in Research
- 42. Blended diets for children and young people: applying the evidence to nursing practice

1. Living with epilepsy in adolescence and young adulthood transitioning from pediatric to adult hospital services: A systematic review and meta-synthesis of qualitative studies

Authors: Abildgaard Hansen, Ole, et al

Journal: Epilepsy & Behavior : E&B 2024, 158, pp. 109955

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39059136/>

2. Blenderized tube feeding in pediatrics - current evidence, guidelines, and considerations

Authors: Allen, Lindsay; Min, James and Zong, Wenjing

Journal: Current Opinion in Pediatrics 2024, 36(5), pp. 519–523

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38957106/>

3. Impact of disability-based discrimination in healthcare on parents of children with medical complexity

Authors: Ames, Stefanie G., et al

Journal: Developmental Medicine and Child Neurology 2024
66(9), pp. 1226–1233

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38327250/>

4. Stigma, seizure self-efficacy, and quality of life in children with epilepsy

Authors: Aydin, Seren; Öz Tunçer, Gökçen; Genç, Şeyma; Kurt Bayir, Gülbahar and Aksoy, Ayşe

Journal: Child's Nervous System : ChNS : Official Journal of the International Society for Pediatric Neurosurgery 2024, 40(11), pp. 3721–3728

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39212677/>

5. Communication Strategies for Transferring Medically Complex Children Out of Intensive Care

Authors: Bloomhardt, Hadley, et al

Journal: Clinical Pediatrics 2024, 63(10), pp. 1337–1342

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38205734/>

6. The effectiveness of the use of a technology toolkit on activities and mother-child interactions: children with complex care needs

Authors: Bos, G. F.; van Wingerden, E. and Sterkenburg, P. S.

Journal: Disability and Rehabilitation: Assistive Technology 2024, 19(7), pp. 2545–2556

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38112320/>

7. Experiences and the psychosocial situation of parental caregivers of children with spinal muscular atrophy against the background of new treatment options: a qualitative interview study

Authors: Brandt, Maja, et al

Journal: BMC Psychology 2024, 12(1), pp. 566–4

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39420400/>

8. 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, 29(5), pp. 880–886

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38168048/>

9. Characteristics and outcomes of home parenteral nutrition among children with severe neurological impairment

Authors: D'Arienzo, David, et al

Journal: Journal of Pediatric Gastroenterology and Nutrition 2024, 79(5), pp. 1031–1039

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39252541/>

10. Peer support in adolescents and young adults with chronic or rare conditions in northern America and Europe: Targeted literature review

Authors: Dave, Sneha, et al

Journal: Journal of Pediatric Nursing 2024, 78, pp. e31–e40

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38964964/>

11. The Complex Impact of Health Literacy Among Parents of Children With Medical Complexity

Authors: Desmarais, Aline V.; Kevill, Katharine and Glick, Alexander F.

Journal: Hospital Pediatrics 2024, 14(10), pp. e449–e451

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39308308/>

12. Experiences of Inpatient Healthcare Services Among Children With Medical Complexity and Their Families: A Scoping Review

Authors: Dewan, Tammie, et al

Journal: Health Expectations : An International Journal of Public Participation in Health Care and Health Policy 2024. 27(5), pp. e14178

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39229799/>

13. An emotional journey: caregiver experiences with gastrostomy tube decision-making for children with cystic fibrosis

Authors: Dickinson, Kimberly M., et al

Journal: Journal of Cystic Fibrosis : Official Journal of the European Cystic Fibrosis Society 2024, 23(5), pp. 1000–1006

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38320875/>

14. Time to diagnosis and determinants of diagnostic delays of people living with a rare disease: results of a Rare Barometer retrospective patient survey

Authors: Faye, Fatoumata, et al

Journal: European Journal of Human Genetics : EJHG 2024, 32(9), pp. 1116–1126

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38755315/>

15. Integrated care for children and young people with special health and care needs: a systematic review

Authors: Ghotane, Swapnil, et al

Journal: Archives of Disease in Childhood 2024, 109(11), pp. 924–931

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39079899/>

16. Parental Health Literacy and Acute Care Utilization in Children With Medical Complexity

Authors: Goodwin, Emily J., et al

Journal: Hospital Pediatrics 2024, 14(10), pp. e426–e431

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39308304/>

- 17. Neurocognitive functioning among children and young people with Duchenne Muscular Dystrophy: A systematic review and meta-analysis**
Authors: Gregg, Jayne; Wilson, Colin; Curran, David and Hanna, Donncha
Journal: The Clinical Neuropsychologist 2024, 38(8), pp. 1806–1833
PubMed: <https://pubmed.ncbi.nlm.nih.gov/38509463/>
- 18. The disequilibrium of hope: A grounded theory analysis of parents' experiences of receiving a "no primary finding" result from genome sequencing**
Authors: Gurasashvili, Jana, et al
Journal: Journal of Genetic Counseling 2024, 33(5), pp. 1089–1102
PubMed: <https://pubmed.ncbi.nlm.nih.gov/37929616/>
- 19. Fifteen-minute consultation: Assessment of pain in a non-verbal child**
Authors: Haddick, Anne; Thompson, Sam and Lundy, Claire
Journal: Archives of Disease in Childhood. Education and Practice Edition 2024, 109(5), pp. 228–232
PubMed: <https://pubmed.ncbi.nlm.nih.gov/38242683/>
- 20. Factors associated with dementia-related stigma in British adolescents**
Authors: Hassan, Esra; Hicks, Ben; Tabet, Naji and Farina, Nicolas
Journal: BMC Public Health 2024, 24(1), pp. 2896–7
PubMed: <https://pubmed.ncbi.nlm.nih.gov/39434071/>
- 21. Parent perspectives on education to support hospital discharge for children with invasive mechanical ventilation**
Authors: High, Michelle S.; Lynch, Emma and Sobotka, Sarah A.
Journal: Journal of Pediatric Nursing 2024, 78, pp. e167–e174
PubMed: <https://pubmed.ncbi.nlm.nih.gov/39025713/>
- 22. Early motor, cognitive, language, behavioural and social emotional development in infants and young boys with Duchenne Muscular Dystrophy- A systematic review**
Authors: Hoskens, Jasmine, et al
Journal: European Journal of Paediatric Neurology : EJPN : Official Journal of the European Paediatric Neurology Society 2024, 52, pp. 29–51
PubMed: <https://pubmed.ncbi.nlm.nih.gov/39003996/>
- 23. The transition from children to young people living with home mechanical ventilation**
Authors: Israelsson-Skogsberg, Åsa; Palm, Andreas; Ekström, Magnus; Markström, Agneta and Lindahl, Berit
Journal: International Journal of Qualitative Studies on Health and Well-Being 2024, 19(1), pp.

2399432

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39229970/>

24. Young adults' narratives about living with home mechanical ventilation - a phenomenological hermeneutical study

Authors: Israelsson-Skogsberg, Åsa; Palm, Andreas; Lindahl, Berit; Markström, Agneta and Ekström, Magnus

Journal: Disability and Rehabilitation 2024, 46(19), pp. 4495–4502

PubMed: <https://pubmed.ncbi.nlm.nih.gov/37933171/>

25. Interventions to promote medication adherence among children with epilepsy: An integrative review

Authors: Kangwal, Chutimaporn; Thato, Ratsiri; Ua-Kit, Noraluk and Visudtibhan, Anannit

Journal: Journal of Pediatric Nursing 2024, 78, pp. e51–e58

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38944619/>

26. Exploring What Motivates Parents of Children Living With Medical Complexity to Participate in Research

Authors: Kim, Laesa; Hermansen, Anne-Mette; Cook, Karen and Siden, Harold

Journal: Child: Care, Health and Development 2024, 50(5), pp. e13331

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39300755/>

27. Smartphone applications for the management of epilepsy in children and adolescents

Authors: Laguna, Gabriela Garcia de Carvalho, et al

Journal: Revista Paulista De Pediatria : Orgao Oficial Da Sociedade De Pediatria De Sao Paulo 2024, 43, pp. e2024066–0462/2025/43/2024066. eCollection 2024

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39258666/>

28. The profile of social communication in Dravet syndrome

Authors: Laña, Borja; Crespo-Eguilaz, Nerea and Sánchez-Carpintero, Rocío

Journal: Epilepsy & Behavior : E&B 2024, 159, pp. 110007

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39208587/>

29. The incidence of sudden unexpected death in epilepsy (SUDEP) in the Republic of Ireland

Authors: Langan, Yvonne and Lynn, Ena

Journal: Seizure 2024, 122, pp. 34–38

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39316942/>

30. An Evaluation of an Australian Pediatric Neuromuscular Transition Model

Authors: Leung, Rebecca; Munro, Kate and Cairns, Anita

Journal: Pediatric Neurology 2024, 160, pp. 60–69

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39191086/>

31. Neurodevelopmental and Mental Health Conditions in Children With Medical Complexity

Authors: Leyenaar, JoAnna K., et al

Journal: Pediatrics 2024, 154(3), pp. e2024065650. doi: 10.1542/peds.2024–065650

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39099441/>

32. Tracheostomy Decision Making and Counseling: Comparing Providers' and Caregivers' Perspectives and Perceptions

Authors: Liu, Andy; Hammack-Aviran, Catherine and Turnbull, Jessica

Journal: Journal of Palliative Medicine 2024, 27(9), pp. 1163–1170

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38990602/>

33. Needs of children with neurodevelopmental disorders and medical complexity: Caregiver perspectives

Authors: Materula, Dércia, et al

Journal: Research in Developmental Disabilities 2024, 153, pp. 104815

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39142086/>

34. Self-Reported Well-Being of Family Caregivers of Children with Medical Complexity

Authors: McLachlan, Lydia M., et al

Journal: Academic Pediatrics 2024, 24(7), pp. 1133–1140

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38609015/>

35. Orphan and paediatric medical devices in Europe: recommendations to support their availability for on-label and off-label clinical indications

Authors: Melvin, Tom, et al

Journal: Expert Review of Medical Devices 2024, 21(10), pp. 893–901

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39302881/>

36. Professional perspectives on facilitators and barriers for high quality provision of health, education and social care services to disabled children in England during the COVID-19 pandemic: a qualitative stud

Authors: Merrick, Hannah, et al

Journal: BMJ Open 2024, 14(8), pp. e085143–085143

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39181564/>

37. Hospitalization- and death-related financial and employment effects in parents of children with life-limiting conditions: a fixed-effects analysis

Authors: Mitterer, Stefan, et al

Journal: European Journal of Pediatrics 2024, 183(10), pp. 4215–4227

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38985175/>

38. Intranasal Versus Buccal Versus Intramuscular Midazolam for the Home and Emergency Treatment of Acute Seizures in Pediatric Patients: A Randomized Controlled Trial

Authors: Mohammed, Maha Z.; Elagouza, Iman; El Gaafary, Maha; El-Garhy, Rana and El-Rashidy, Omnia

Journal: Pediatric Neurology 2024, 158, pp. 135–143

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39047345/>

39. Complexity Plus: The Importance of Co-Occurring Conditions in Children With Medical Complexity

Authors: Oreskovic, Nicolas M. and Cohen, Eyal

Journal: Pediatrics 2024, 154(3), pp. e2024067259. doi: 10.1542/peds.2024–067259

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39099440/>

40. Getting Wheels: development and evaluation of a psychoeducational resource for parents of children with a neuromuscular condition following recommendation of wheelchair equipment

Authors: Paguinto, Sarah-Grace, et al

Journal: Disability and Rehabilitation. Assistive Technology 2024, 19(7), pp. 2630–2640

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38308497/>

41. The Association between Healthcare Satisfaction and Social Support and Stress, Depression, and Life Satisfaction in Female Caregivers: The Moderating Role of Dependence of a Sick Child

Authors: Pavić, Jadranka, et al

Journal: International Journal of Environmental Research and Public Health 2024, 21(9), pp. 1245.

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39338128/>

42. Blended diets for children and young people: applying the evidence to nursing practice

Authors: Phillips, Gemma and Jane, Coad

Journal: British Journal of Nursing (Mark Allen Publishing) 2024 33(19), pp. S18–S24

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39445750/>

43. Current Advances and Gaps in Knowledge on Personalizing Masks for Noninvasive Respiratory Support

Authors: Pigmans, Rosemijne R. W. P., et al

Journal: Respiratory Care 2024, 69(9), pp. 1201–1211

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39445750/>

44. Influence of the functional intervention on the development of essential social skills in children with life-limiting conditions

Authors: Ptak, Agnieszka; Stefańska, Małgorzata and Demczuk-Włodarczyk, Ewa

Journal: Scientific Reports 2024, 14(1), pp. 25953–y

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39472672/>

45. Companion animals and child development outcomes: longitudinal and cross-sectional analysis of a UK birth cohort study

Authors: Purewal, Rebecca, et al

Journal: BMC Pediatrics 2024, 24(1), pp. 578–7

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39272016/>

46. "Pain is one piece of a complex jigsaw puzzle" - experiences of raising a child with cerebral palsy who has pain

Authors: Rinde, Elisabeth Rønning; Anderzén-Carlsson, Agneta; Jahnsen, Reidun Birgitta and Andersen, Randi Dovland

Journal: Disability and Rehabilitation 2024, 46(20), pp. 4763–4771

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38069685/>

47. Anxiety, depression, and support needs of the mothers of children with cerebral palsy and determining their opinions: Mixed methods study

Authors: Sarman, Abdullah; Tuncay, Suat; Budak, Yusuf; Demirpolat, Eyyüp and Bulut, İrem

Journal: Journal of Pediatric Nursing 2024, 78, pp. e133–e140

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38997912/>

48. Informing creation of the FEEDS Toolkit to support parent-delivered interventions for eating, drinking and swallowing difficulties in young children with neurodisability: intervention use by neurodevelopmental diagnosis and healthcare professional role

Authors: Shaw, Emogene, et al

Journal: BMJ Paediatrics Open 2024, 8(1), pp. e002394. doi: 10.1136/bmjpo-002394

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39181695/>

49. Development of GO Move: A Website for Children With Unilateral Cerebral Palsy

Authors: Shierk, Angela, et al

Journal: OTJR : Occupation, Participation and Health 2024, 44(4), pp. 589–596

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38281146/>

50. Religious Coping as Mediator of Sense of Competence and Post-traumatic Growth in Mothers of Children With Cerebral Palsy

Authors: Ul Ain, Noor;Ali, Anam and Bashir, Nazia

Journal: Child: Care, Health and Development 2024, 50(5), pp. e13322

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39143848/>

51. Exploring Parents' Experiences and Needs During Disclosure of a Cerebral Palsy Diagnosis of Their Young Child: A Scoping Review

Authors: van der Kemp, J., et al

Journal: Child: Care, Health and Development 2024, 50(6), pp. e13327

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39343726/>

52. Recommendations for the Management of Initial and Refractory Pediatric Status Dystonicus

Authors: Vogt, Lindsey M., et al

Journal: Movement Disorders : Official Journal of the Movement Disorder Society 2024 39(9), pp. 1435–1445

PubMed: <https://pubmed.ncbi.nlm.nih.gov/38619077/>

53. Facilitators of and Barriers to Caregiver Adherence to Home Therapy Recommendations for Infants and Children With Neuromotor and Neuromuscular Diagnoses: A Scoping Review

Authors: Wingrat, Jennifer; Price, Carrie and Wright, Tess

Journal: The American Journal of Occupational Therapy : Official Publication of the American Occupational Therapy Association 2024, 78(5), pp. 7805205070. doi: 10.5014/ajot.2024.050567

PubMed: <https://pubmed.ncbi.nlm.nih.gov/39083636/>

The bulletin is produced by the EACH Library & Information Service

For more information or to subscribe to receiving this bulletin by email,
please contact

library@each.org.uk