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## Children with Complex Needs, Rare Conditions and Neurodisabilities bulletin

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### Bulletin No. 3

01/02/2024 - 21/05/2024

- 1. The efficacy and safety of cannabidiol (CBD) in pediatric patients with Dravet Syndrome: a narrative review of clinical trials**  
**Authors:** Aderinto, Nicholas, et al  
**Journal:** European Journal of Medical Research 2024, 29(1), pp. 182-6  
**PubMed :** <https://pubmed.ncbi.nlm.nih.gov/38500226/>
- 2. A quantitative and qualitative analysis of patient group narratives suggests common biopsychosocial red flags of undiagnosed rare disease**  
**Authors:** Al-Attar, Mariam; Butterworth, Sondra and McKay, Lucy  
**Journal:** Orphanet Journal of Rare Diseases 2024, 19(1), pp. 172-8  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38641814/>
- 3. Current Concepts in the Management of Sanfilippo Syndrome (MPS III): A Narrative Review**  
**Authors:** Alyazidi, Anas S., et al  
**Journal:** Cureus 2024 16(4), pp. e58023  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38738088/>
- 4. Losing Our Way In A Rare Disease Diagnostic Odyssey**  
**Authors:** Ayik, Kara A.  
**Journal:** Health Affairs (Project Hope) 2024, 43(3), pp. 452-455  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38437605/>

- 5. Spinal Muscular Atrophy Type 1 Survival Without New Pharmacotherapies: Two Treatment Paradigms**

**Authors:** Bach, John R.; Saporito, Louis and Weiss, William

**Journal:** American Journal of Physical Medicine & Rehabilitation 2024, 103(3), pp. 233-237

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37881957/>
- 6. Telehealth and Children with Medical Complexity**

**Authors:** Kaushik, Ruchi

**Journal:** Pediatric Annals 2024, 53(3), pp. e74-e81

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38466329/>
- 7. Sim-Based Home Tracheostomy Care: A Mixed Methods Study on Outcomes and Parental Preparedness**

**Authors:** Bergman, Charles M., et al

**Journal:** Hospital Pediatrics 2024, 14(4), pp. 251-257

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38545677/>
- 8. Assessing the Benefits and Harms Associated with Early Diagnosis from the Perspective of Parents with Multiple Children Diagnosed with Duchenne Muscular Dystrophy**

**Authors:** Bhattacharyya, Oindrila, et al

**Journal:** International Journal of Neonatal Screening 2024, 10(2), pp. 32.

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38651397/>
- 9. Developmental Skills and Neurorehabilitation for Children With Batten Disease: A Retrospective Chart Review of a Comprehensive Batten Clinic**

**Authors:** Bican, Rachel, et al

**Journal:** Pediatric Neurology 2024, 152, pp. 107-114

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38242022/>
- 10. Pediatric long-term noninvasive respiratory support in children with central nervous system disorders**

**Authors:** Carrara, Marion, et al

**Journal:** Pediatric Pulmonology 2024, 59(3), pp. 642-651

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38088209/>

11. **Drug-resistant epilepsy and ketogenic diet therapy - a qualitative study of families' experiences**  
**Authors:** Carroll, Jennifer H., et al  
**Journal:** Seizure 2024, 118, pp. 137-147  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38703599/>
  
12. **"Unable to Feed My Hungry Child": Experiences of Mothers Caring for Children With Prader-Willi Syndrome**  
**Authors:** Currie, Genevieve; Estefan, Andrew and Caine, Vera  
**Journal:** Global Qualitative Nursing Research 2024, 11,  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38559700/>
  
13. **Exploring the role of digital tools in rare disease management: An interview-based study**  
**Authors:** Chang, Andrea, et al  
**Journal:** Journal of Genetic Counseling 2024  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38741243/>
  
14. **The natural history and burden of illness of metachromatic leukodystrophy: a systematic literature review**  
**Authors:** Chang, Shun-Chiao; Eichinger, Christian Stefan and Field, Polly  
**Journal:** European Journal of Medical Research 2024, 29(1), pp. 181-1  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38494502/>
  
15. **Genetic therapies and respiratory outcomes in patients with neuromuscular disease**  
**Authors:** Chen, Diana; Ni, Jeff and Buu, MyMy  
**Journal:** Current Opinion in Pediatrics 2024, 36(3), pp. 296-303  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38655811/>
  
16. **Development of respiratory care guidelines for Duchenne muscular dystrophy in the UK: key recommendations for clinical practice**  
**Authors:** Childs, Anne-Marie, et al  
**Journal:** Thorax 2024, 79(5), pp. 476-485  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38123347/>

17. **Examining the economic impacts of caregiving among families of children of medical complexity: A qualitative study to inform inclusive economic models**  
**Authors:** Keim-Malpass, Jessica;Muir, K. Jane;Letzkus, Lisa C.;Scheer, Eleanore and Valdez, Rupa S.  
**Journal:** Journal of Participatory Medicine 2024  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38758728/>
18. **Fatigue in Spinal Muscular Atrophy: a fundamental open issue**  
**Authors:** Crisafulli, Oscar;Berardinelli, Angela and D'Antona, Giuseppe  
**Journal:** Acta Myologica : Myopathies and Cardiomyopathies : Official Journal of the Mediterranean Society of Myology 2024, 43(1), pp. 1-7  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38586164/>
19. **Quality of life assessment instruments in children and adolescents with neuromuscular diseases: a systematic scoping review**  
**Authors:** Cruz, Karoliny Lisandra Teixeira; Santos, Isadora Cristina Sousa; de Jesus Alves de Baptista, Cyntia Rogean and Mattiello-Sverzut, Ana Claudia  
**Journal:** Health and Quality of Life Outcomes 2024, 22(1), pp. 18-3  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38360791/>
20. **Levodopa for Dystonia in Children: A Case Series and Review of the Literature**  
**Authors:** DeArias, Alexandra Lesenskyj and Bamford, Nigel S.  
**Journal:** Pediatric Neurology 2024, 152, pp. 16-19  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38176223/>
21. **Parents' experience of children with acquired brain injury undergoing neurorehabilitation: a systematic review**  
**Authors:** Fernandes, Marta; Rathinam, Chandrasekar and Topping, Anne Elizabeth  
**Journal:** BMJ Paediatrics Open 2024, 8(1), pp. e002288. doi: 10.1136/bmjpo-002288  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38519065/>
22. **'No One Is Talking About This' - rare diseases in childhood**  
**Authors:** Fisayo, Temitope

**Journal:** Archives of Disease in Childhood 2024, 109(5), pp. 436-437

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

**23. Navigating Difficult Conversations in Caring for Children with Medical Complexity**

**Authors:** DeForest, Patricia K.

**Journal:** Pediatric Annals 2024, 53(3), pp. e99-e103

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38466332/>

**24. 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 2024

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

**25. A Communication and Decision-Making Framework for Pediatric Precision Medicine**

**Authors:** Greene, Brittany L.; Rosenberg, Abby R. and Marron, Jonathan M.

**Journal:** Pediatrics 2024, 153(4), pp. e2023062850. doi: 10.1542/peds.2023-062850

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38505927/>

**26. Validation of the Sibling Perception Questionnaire in healthy siblings of children with chronic illnesses**

**Authors:** Gutierrez, Abbi L. and Limbers, Christine A.

**Journal:** Journal of Health Psychology 2024,

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38485711/>

**27. Breaking the silence: A qualitative exploration of parental perspectives of children with Goldenhar Syndrome**

**Authors:** Hitchen, Rebecca; Woolhouse, Maxine and Holch, Patricia

**Journal:** Heliyon 2024, 10(3), pp. e24328

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38318028/>

**28. Telemedicine for Ketogenic Dietary Treatment in Refractory Epilepsy and Inherited Metabolic Disease: State of Play and Future Perspectives**

**Authors:** Höller, Alexander, et al

**Journal:** Studies in Health Technology and Informatics 2024, 313, pp. 160-166

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38682524/>

**29. Current state of home health in children with medical complexity**

**Authors:** Kodiak, Teresa;Quinn, Megan and Zekas, Linda

**Journal:** Journal of Pediatric Nursing 2024, 77, pp. 180-182

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38531175/>

**30. Increasing participation in computer activities using eye-gaze assistive technology for children with complex needs**

**Authors:** Hsieh, Yu-Hsin; Granlund, Mats;Odom, Samuel L.; Hwang, Ai-Wen and Hemmingsson, Helena

**Journal:** Disability and Rehabilitation. Assistive Technology 2024, 19(2), pp. 492-505

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/35861506/>

**31. Self- and Caregiver-Reported Participation, Quality of Life, and Related Mood and Behavior Challenges in People Living With Dystrophinopathies**

**Authors:** Jesus, Anna; Bennett, Carolyn;Masterson, Chelsea;Brenner, Laurie and Scharf, Rebecca

**Journal:** Pediatric Neurology 2024, 151, pp. 37-44

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38101306/>

**32. Exploring the support needs of Australian parents of young children with Usher syndrome: a qualitative thematic analysis**

**Authors:** Johansen, L., et al

**Journal:** Orphanet Journal of Rare Diseases 2024, 19(1), pp. 129-

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38515174/>

**33. Intraventricular baclofen for palliative management of acquired generalized dystonia in pediatric patients: a case series and literature review**

**Authors:** Krouma, M., et al

**Journal:** Child's Nervous System : ChNS : Official Journal of the International Society for Pediatric Neurosurgery 2024, 40(3), pp. 895-903

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37975904/>

34. **The creation of an adaptable informed consent form for research purposes to overcome national and institutional bottlenecks in ethics review: experience from rare disease registries**  
**Authors:** Landi, Annalisa, et al  
**Journal:** Frontiers in Medicine 2024, 11, pp. 1384026  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38695032/>
35. **Feasibility of a mindfulness app in parents of a child with medical complexity: A pilot study**  
**Authors:** Gallegos, Cara;Kausler, Ryoko and Cacchillo, Natalie  
**Journal:** Applied Nursing Research : ANR 2024, 76, pp. 151767  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38641378/>
36. **Factors associated with sleep disturbances in children and adolescents with Angelman Syndrome**  
**Authors:** Leader, Geraldine, et al  
**Journal:** Sleep Medicine 2024, 117, pp. 9-17  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38479041/>
37. **"What choice do you have knowing your child can't breathe?!": Adaptation to Parenthood for Children Who Have Received a Tracheostomy**  
**Authors:** Ledin, Ellinor Rydhamn; Eriksson, Andrea and Mattsson, Janet  
**Journal:** SAGE Open Nursing 2024, 10, pp. 23779608241245502  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38601012/>
38. **'They don't know what to do with our children': Experiences and views on feeding and swallowing from parents of children who use long-term ventilation**  
**Authors:** Lee, Sabrena; Marshall, Jeanne; Clarke, Michael and Smith, Christina  
**Journal:** Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community 2024a pp. 13674935241242824  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38590229/>
39. **Feeding and swallowing outcomes of children receiving long-term ventilation: A scoping review protocol**

**Authors:** Lee, Sabrena; Marshall, Jeanne; Clarke, Michael and Smith, Christina H.

**Journal:** PloS One 2024b, 19(2), pp. e0287872

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38386657/>

**40. Holistic support for children with rare disease**

**Authors:** Li, Siyuan and Hua, Yingqi

**Journal:** The Lancet .Child & Adolescent Health 2024, 8(6), pp. 397

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38367637/>

**41. Psychological Care of the Family of Children with Medical Complexities**

**Authors:** Scheid, Andrea and Sahai, Shashi

**Journal:** Pediatric Annals 2024, 53(3), pp. e93-e98

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38466327/>

**42. Improving the care of children with GENetic Rare disease: Observational Cohort study (GenROC)-a study protocol**

**Authors:** Low, Karen Jaqueline, et al

**Journal:** BMJ Open 2024, 14(5), pp. e085237-085237

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38760043/>

**43. Advance Care Planning for Children With Rare Diseases: A Pilot RCT**

**Authors:** Lyon, Maureen E., et al

**Journal:** Pediatrics 2024

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38699801/>

**44. Tracheostomy and long-term invasive ventilation decision-making in children: A scoping review**

**Authors:** Mack, Cheryl, et al

**Journal:** Pediatric Pulmonology 2024, 59(5), pp. 1153-1164

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38289099/>

**45. Lived experiences of caregivers with infants treated at home with continuous invasive or noninvasive ventilation**

**Authors:** Maniaci, Jon;Kearney, Matthew D.; DeMauro, Sara B. and Panitch, Howard



**Journal:** Pediatric Pulmonology 2024

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38751012/>

**46. A systematic review of psychosocial interventions for children and young people with epilepsy**

**Authors:** Mercier, Anthony and Dorris, Liam

**Journal:** European Journal of Paediatric Neurology : EJPN : Official Journal of the European Paediatric Neurology Society 2024, 49, pp. 35-44

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38364750/>

**47. Caring for children with medical complexity at home: An integrative review**

**Authors:** Geyer, David and Vessey, Judith A.

**Journal:** Journal of Pediatric Nursing 2024, 76, pp. 167-175

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38412708/>

**48. Modification of the Paediatric Gastro-oesophageal Reflux Disease Symptom and Quality of Life Questionnaire (PGSQ) for children with cerebral palsy: a preliminary study**

**Authors:** Mills, Sarah; Tuffrey, Catherine; Tbaily, Lee and Tighe, Mark

**Journal:** BMJ Paediatrics Open 2024, 8(1), pp. e002256. doi: 10.1136/bmjpo-002256

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38378669/>

**49. Who really decides? Feeding decisions 'made' by caregivers of children with cerebral palsy**

**Authors:** Naidoo, Lavanya; Pillay, Mershen and Naidoo, Urisha

**Journal:** The South African Journal of Communication Disorders 2024, 71(1), pp. e1-e14

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38572900/>

**50. Pediatric Nurses' Experiences With Professional Boundaries and Ethical Challenges: A Secondary Analysis**

**Authors:** Neal, Kathleen Wilson

**Journal:** Research and Theory for Nursing Practice 2024, 38(1), pp. 124-136

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38350688/>

51. **Being a sibling of a youth with a neurodisability: A qualitative study about the roles and responsibilities during the transition to adulthood**  
**Authors:** Nguyen, Linda, et al  
**Journal:** Child: Care, Health and Development 2024, 50(2), pp. e13241  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38445673/>
52. **Gastrostomy Tubes: Indications, Types, and Care**  
**Authors:** Novak, Inna and Velazco, Nerissa K.  
**Journal:** Pediatrics in Review 2024, 45(4), pp. 175-187  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38556513/>
53. **Parents' understanding of medication at discharge and potential harm in children with medical complexity**  
**Authors:** Selzer, Axana, et al  
**Journal:** Archives of Disease in Childhood 2024, 109(3), pp. 215-221  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38041681/>
54. **Natural History of Neuronal Ceroid Lipofuscinosis Type 6, Late Infantile Disease**  
**Authors:** O'Neal, Matthew, et al  
**Journal:** Pediatric Neurology 2024, 154, pp. 51-57  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38531163/>
55. **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, pp. 1-11  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38308497/>
56. **A systematic review of the Mozart effect in adult and paediatric cases of drug-resistant epilepsy: A sound approach to epilepsy management**  
**Authors:** Piccicacchi, Lucrezia Maria and Serino, Domenico  
**Journal:** Epilepsy & Behavior 2024, 154, pp. 109743  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38636110/>

57. **A kaleidoscope of well-being to authentically represent the voices of children and young people with complex cerebral palsy: a case study series**  
**Authors:** Pickering, Dawn M.; Gill, Paul and Reagon, Carly  
**Journal:** Disability and Rehabilitation 2024, 46(7), pp. 1339-1353  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37098804/>
58. **Adolescents with Rett syndrome at critical care pathway junctures: Examining clinicians' decision to initiate invasive long-term ventilation**  
**Authors:** Quirke, Mary Brigid, et al  
**Journal:** European Journal of Paediatric Neurology : EJPN : Official Journal of the European Paediatric Neurology Society 2024, 49, pp. 113-119  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38484415/>
59. **Polypharmacy-An Important Contributor to Health and Safety for Children With Medical Complexity: How Can We Improve Care for This Vulnerable Population?**  
**Authors:** Grossberg, Richard  
**Journal:** The Journal of Pediatric Pharmacology and Therapeutics : JPPT : The Official Journal of PPAG 2024, 29(2), pp. 96-99  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38596412/>
60. **Provider moral distress in caring for tracheostomy and ventilator dependent children: A single institution cross-sectional evaluation**  
**Authors:** Redmann, Andrew J., et al  
**Journal:** Pediatric Pulmonology 2024, 59(4), pp. 880-885  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38165151/>
61. **Predictors of overload in parents of children with neuromuscular diseases**  
**Authors:** Rodríguez, A. A., et al  
**Journal:** Frontiers in Neurology 2024, 15, pp. 1349501  
**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38585358/>
62. **How parents of children with ataxia-telangiectasia use dynamic coping to navigate cyclical uncertainty**  
**Authors:** Schiller, Julia; Towne, Meghan C.; Epstein, Rachel; Thornton, Jennifer Karlin and

Suslovitch, Victoria

**Journal:** Journal of Genetic Counseling 2024, 33(2), pp. 301-313

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37183503/>

**63. The parent and family impact of CLN3 disease: an observational survey-based study**

**Authors:** Schulz, Angela, et al

**Journal:** Orphanet Journal of Rare Diseases 2024, 19(1), pp. 125-8

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38500130/>

**64. Caregiver perceptions of the impact of Dravet syndrome on the family, current supports and hopes and fears for the future: A qualitative study**

**Authors:** Soto Jansson, Josefin; Bjurulf, Björn; Dellenmark Blom, Michaela; Hallböök, Tove and Reilly, Colin

**Journal:** Epilepsy & Behavior 2024a, 156, pp. 109790

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38692022/>

**65. Family perspectives on provider conversations about housing needs for children with medical complexity**

**Authors:** Smith, Brandon M.; Donohue, Pamela K. and Seltzer, Rebecca R.

**Journal:** Child: Care, Health and Development 2024, 50(2), pp. e13253

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38529766/>

**66. Enhancing caregivers self-management for their children who require medical technology: A feasibility study for the COPE-STAR intervention**

**Authors:** Spratling, Regena; Ali, Syeda Zahra; Faulkner, Melissa Spezia; Feinberg, Iris & Hayat, Matthew J.

**Journal:** Journal of Pediatric Nursing 2024, 75, pp. 23-30

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38096760/>

**67. Symptom and Technology Management Intervention Usefulness for Caregivers of Children With Tracheostomies and Feeding Tubes**

**Authors:** Spratling, Regena; Tennant, Monica Nelson and Lee, Jiwon

**Journal:** Western Journal of Nursing Research 2024, 46(5), pp. 366-373

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38545957/>

**68. Efficacy of a Resourcefulness Intervention to Enhance the Physical and Mental Health of Parents Caring for Technology-dependent Children at Home: A Randomized Controlled Trial**

**Authors:** Toly, Valerie Boebel, et al

**Journal:** Journal of Pediatric Health Care : Official Publication of National Association of Pediatric Nurse Associates & Practitioners 2024, 38(3), pp. 337-353

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37897454/>

**69. Co-Creation of a Novel Childhood Onset Rare Disease Self-Care Support Tool**

**Authors:** Twomey, Christine; McGonigle, Enda and Solebo, Ameenat Lola

**Journal:** Academic Pediatrics 2024, 24(2), pp. 369-372

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/37743014/>

**70. Between equilibrium and chaos, with little restitution: a narrative analysis of qualitative interviews with clinicians and parent carers of children with medical complexity**

**Authors:** Hodgson, Stephanie; Noack, Kirsten; Griffiths, Ashleigh and Hodgins, Michael

**Journal:** BMC Health Services Research 2024, 24(1), pp. 504-6

**PubMed:** <https://pubmed.ncbi.nlm.nih.gov/38654202/>

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