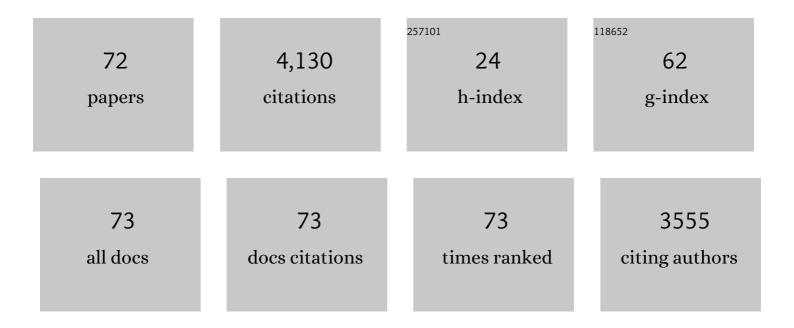
List of Publications by Year in descending order

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#	Article	IF	CITATIONS
1	Intrahepatic Cholestasis Is a Clinically Significant Feature Associated with Natural History of X-Linked Myotubular Myopathy (XLMTM): A Case Series and Biopsy Report. Journal of Neuromuscular Diseases, 2022, 9, 73-82.	1.1	15
2	Teleâ€mental health intervention for caregivers of children on home ventilation: A randomized control trial. Child: Care, Health and Development, 2022, 48, 80-87.	0.8	3
3	Clinical Characteristics and Outcomes of Children with Acute Catastrophic Brain Injury: A 13-Year Retrospective Cohort Study. Neurocritical Care, 2022, 36, 715-726.	1.2	5
4	INCEPTUS Natural History, Run-in Study for Gene Replacement Clinical Trial in X-Linked Myotubular Myopathy. Journal of Neuromuscular Diseases, 2022, 9, 503-516.	1.1	5
5	Outcomes for Children With Pulmonary Hypertension Undergoing Tracheostomy Placement: A Multi-Institutional Analysis*. Pediatric Critical Care Medicine, 2022, 23, 717-726.	0.2	5
6	"New Trach Mom Here…― A qualitative study of internetâ€based resources by caregivers of children with tracheostomy. Pediatric Pulmonology, 2021, 56, 2274-2283.	1.0	10
7	Costs and health resource use in patients with X-linked myotubular myopathy: insights from U.S. commercial claims. Journal of Managed Care & Specialty Pharmacy, 2021, 27, 1-8.	0.5	0
8	Clinical, neuroimaging, and molecular spectrum of <i>TECPR2</i> â€essociated hereditary sensory and autonomic neuropathy with intellectual disability. Human Mutation, 2021, 42, 762-776.	1.1	18
9	Chronic Illness in Pediatric Critical Care. Frontiers in Pediatrics, 2021, 9, 686206.	0.9	24
10	Dysphagia Phenotypes in Spinal Muscular Atrophy: The Past, Present, and Promise for the Future. American Journal of Speech-Language Pathology, 2021, 30, 1008-1022.	0.9	18
11	Health-related quality of life outcome measures for children surviving critical care: a scoping review. Quality of Life Research, 2021, 30, 3383-3394.	1.5	11
12	Outcome Measures Following Critical Illness in Children With Disabilities: A Scoping Review. Frontiers in Pediatrics, 2021, 9, 689485.	0.9	10
13	Mortality and respiratory support in X-linked myotubular myopathy: a RECENSUS retrospective analysis. Archives of Disease in Childhood, 2020, 105, 332-338.	1.0	24
14	Patient and caregiver experiences at a Multidisciplinary Tracheostomy Clinic. International Journal of Pediatric Otorhinolaryngology, 2020, 137, 110250.	0.4	3
15	Home nursing for children with home mechanical ventilation in the United States: Key informant perspectives. Pediatric Pulmonology, 2020, 55, 3465-3476.	1.0	15
16	Ethical decision-making for children with neuromuscular disorders in the COVID-19 crisis. Neurology, 2020, 95, 260-265.	1.5	7
17	Readmission drivers for children with medical complexity: Home nursing shortages cause health crises. Pediatric Pulmonology, 2020, 55, 1474-1480.	1.0	25
18	"This Is How Hard It Isâ€: Family Experience of Hospital-to-Home Transition with a Tracheostomy. Annals of the American Thoracic Society, 2020, 17, 860-868.	1.5	47

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19	Discharge Practices for Children with Home Mechanical Ventilation across the United States. Key-Informant Perspectives. Annals of the American Thoracic Society, 2020, 17, 1424-1430.	1.5	11
20	Xâ€linked myotubular myopathy and pulmonary blebs: Not just a muscle disorder. Muscle and Nerve, 2019, 60, E36-E38.	1.0	4
21	Association of a Multidisciplinary Care Approach With the Quality of Care After Pediatric Tracheostomy. JAMA Otolaryngology - Head and Neck Surgery, 2019, 145, 1035.	1.2	18
22	Bridging the Stressful Gap Between ICU and Home. Pediatric Critical Care Medicine, 2019, 20, e221-e224.	0.2	12
23	Pre-Nusinersen Hospitalization Costs of Children With Spinal Muscular Atrophy. Pediatric Neurology, 2019, 92, 3-5.	1.0	16
24	Pediatric patients with home mechanical ventilation: The health services landscape. Pediatric Pulmonology, 2019, 54, 40-46.	1.0	44
25	Diagnosis and management of spinal muscular atrophy: Part 1: Recommendations for diagnosis, rehabilitation, orthopedic and nutritional care. Neuromuscular Disorders, 2018, 28, 103-115.	0.3	584
26	Tracheal Microbiota in Patients With a Tracheostomy Before, During and After an Acute Respiratory Infection. Pediatric Infectious Disease Journal, 2018, 37, e269-e271.	1.1	13
27	Pediatric Specialty Care Model for Management of Chronic Respiratory Failure. Pediatric Critical Care Medicine, 2018, 19, 412-420.	0.2	26
28	Nusinersen versus Sham Control in Later-Onset Spinal Muscular Atrophy. New England Journal of Medicine, 2018, 378, 625-635.	13.9	977
29	Comprehensive nutritional and metabolic assessment in patients with spinal muscular atrophy: Opportunity for an individualized approach. Neuromuscular Disorders, 2018, 28, 512-519.	0.3	20
30	Diagnosis and management of spinal muscular atrophy: Part 2: Pulmonary and acute care; medications, supplements and immunizations; other organ systems; and ethics. Neuromuscular Disorders, 2018, 28, 197-207.	0.3	421
31	Ethical Challenges Confronted When Providing Nusinersen Treatment for Spinal Muscular Atrophy. JAMA Pediatrics, 2018, 172, 188.	3.3	54
32	861: FAMILY EXPERIENCE OF HOSPITAL-TO-HOME TRANSITION WITH TRACHEOSTOMY: A PHENOMENOLOGIC STUDY. Critical Care Medicine, 2018, 46, 415-415.	0.4	1
33	Chronic respiratory failure: Utilization of a pediatric specialty integrated care program. Healthcare, 2017, 5, 23-28.	0.6	18
34	218th ENMC International Workshop:. Neuromuscular Disorders, 2017, 27, 596-605.	0.3	49
35	Predicting Health Care Utilization for Children With Respiratory Insufficiency Using Parent-Proxy Ratings of Children's Health-Related Quality of Life. Journal of Pediatric Health Care, 2017, 31, 654-662.	0.6	11
36	Understanding the Relationship Between Child Health-Related Quality of Life and Parent Emotional Functioning in Pediatric Hematopoietic Stem Cell Transplant. Journal of Pediatric Psychology, 2017, 42, 804-814.	1.1	14

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37	Leveraging pediatric PROMIS item banks to assess physical functioning in children at risk for severe functional loss. Journal of Patient-Reported Outcomes, 2017, 1, 10.	0.9	5
38	The temporal dynamics of the tracheal microbiome in tracheostomised patients with and without lower respiratory infections. PLoS ONE, 2017, 12, e0182520.	1.1	24
39	Twoâ€year mortality, complications, and healthcare use in children with medicaid following tracheostomy. Laryngoscope, 2016, 126, 2611-2617.	1.1	87
40	The Impact on Family of Pediatric Chronic Respiratory Failure in the Home. Journal of Pediatrics, 2016, 175, 40-46.	0.9	28
41	Nutritional Status and Nutrient Intake Challenges in Children With Spinal Muscular Atrophy. Pediatric Neurology, 2016, 57, 80-83.	1.0	30
42	Impact of Individualized Diet Intervention on Body Composition and Respiratory Variables in Children With Respiratory Insufficiency. Pediatric Critical Care Medicine, 2015, 16, e157-e164.	0.2	8
43	Metabolic Assessment and Individualized Nutrition in Children Dependent on Mechanical Ventilation at Home. Journal of Pediatrics, 2015, 166, 350-357.	0.9	19
44	Evidence-based guideline summary: Evaluation, diagnosis, and management of congenital muscular dystrophy. Neurology, 2015, 84, 1369-1378.	1.5	88
45	Evidence-based guideline summary: Evaluation, diagnosis, and management of congenital muscular dystrophy: Report of the Guideline Development Subcommittee of the American Academy of Neurology and the Practice Issues Review Panel of the American Association of Neuromuscular & Electrodiagnostic Medicine, Neurology, 2015, 85, 1432-1433.	1.5	3
46	Trial of telemedicine for patients on home ventilator support: feasibility, confidence in clinical management and use in medical decision-making. Journal of Telemedicine and Telecare, 2014, 20, 441-449.	1.4	45
47	Current Applications of Metabolic Monitoring in the Pediatric Intensive Care Unit. Nutrition in Clinical Practice, 2014, 29, 338-347.	1.1	18
48	Family-Centered Assessment and Function for Children With Chronic Mechanical Respiratory Support. Journal of Pediatric Health Care, 2014, 28, 295-304.	0.6	30
49	Pediatric Neurocritical Care: A Neurology Consultation Model and Implication for Education and Training. Pediatric Neurology, 2013, 48, 206-211.	1.0	39
50	Long-term ventilation: charting a pathway home. Archives of Disease in Childhood, 2013, 98, 653-653.	1.0	10
51	Chronic conditions among children admitted to U.S. pediatric intensive care units. Critical Care Medicine, 2012, 40, 2196-2203.	0.4	255
52	End-Of-Life Discussions and Advance Care Planning for Children on Long-Term Assisted Ventilation with Life-Limiting Conditions. Journal of Palliative Care, 2012, 28, 21-27.	0.4	32
53	End-of-life discussions and advance care planning for children on long-term assisted ventilation with life-limiting conditions. Journal of Palliative Care, 2012, 28, 21-7.	0.4	10
54	Pediatric Resident Attitudes Toward Caring for Children with Severe Disabilities. American Journal of Physical Medicine and Rehabilitation, 2010, 89, 765-771.	0.7	8

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55	Patient characteristics associated with in-hospital mortality in children following tracheotomy. Archives of Disease in Childhood, 2010, 95, 703-710.	1.0	105
56	Predictors of Clinical Outcomes and Hospital Resource Use of Children After Tracheotomy. Pediatrics, 2009, 124, 563-572.	1.0	164
57	Anesthesia and perioperative medical management of children with spinal muscular atrophy. Paediatric Anaesthesia, 2009, 19, 1054-1063.	0.6	127
58	Successful and safe delivery of anesthesia and perioperative care for children with complex special health care needs. Journal of Clinical Anesthesia, 2009, 21, 165-172.	0.7	22
59	Experiencing the pediatric intensive care unit: Perspective from parents of children with severe antecedent disabilities*. Critical Care Medicine, 2009, 37, 2064-2070.	0.4	86
60	Included but isolated: early intervention programmes provision for children and families with chronic respiratory support needs. Child: Care, Health and Development, 2008, 34, 373-379.	0.8	17
61	Specialty services for children with special health care needs: supplement not supplant the medical home. Archives of Disease in Childhood, 2008, 93, 2-4.	1.0	14
62	Medicine and Children with Special Health Care Needs: Conflict with the Cult of Cure. Journal of Developmental and Behavioral Pediatrics, 2008, 29, 309-310.	0.6	3
63	Chronic Ventilator Need in the Community: A 2005 Pediatric Census of Massachusetts. Pediatrics, 2007, 119, e1280-e1287.	1.0	127
64	Gastric outlet obstruction in an infant: lactobezoar. American Journal of Emergency Medicine, 2007, 25, 98-99.	0.7	11
65	Acute respiratory distress syndrome in children with severe motor and intellectual disabilities. Brain and Development, 2006, 28, 342.	0.6	1
66	Weaning children from mechanical ventilation in a post-acute care setting. Developmental Neurorehabilitation, 2006, 9, 365-372.	1.1	14
67	Jading. Pediatric Critical Care Medicine, 2005, 6, 93.	0.2	1
68	An opportunity: Critical care beyond the intensive care unit. Pediatric Critical Care Medicine, 2005, 6, 327-328.	0.2	8
69	Integrating Palliative Care into Chronic Care for Children with Severe Neurodevelopmental Disabilities. Journal of Developmental and Behavioral Pediatrics, 2005, 26, 361-365.	0.6	59
70	Outcome Rating Scales for Pediatric Head Injury. Journal of Intensive Care Medicine, 2004, 19, 205-219.	1.3	10
71	Congenital neurodevelopmental diagnoses and an intensive care unit: Defining a population*. Pediatric Critical Care Medicine, 2004, 5, 321-328.	0.2	80
72	Airway Bacterial Colonization, Biofilms and Blooms, and Acute Respiratory Infection. Pediatric Critical Care Medicine, 0, Publish Ahead of Print, .	0.2	4