

Pediatric Long-COVID: Multidisciplinary Approach to Care

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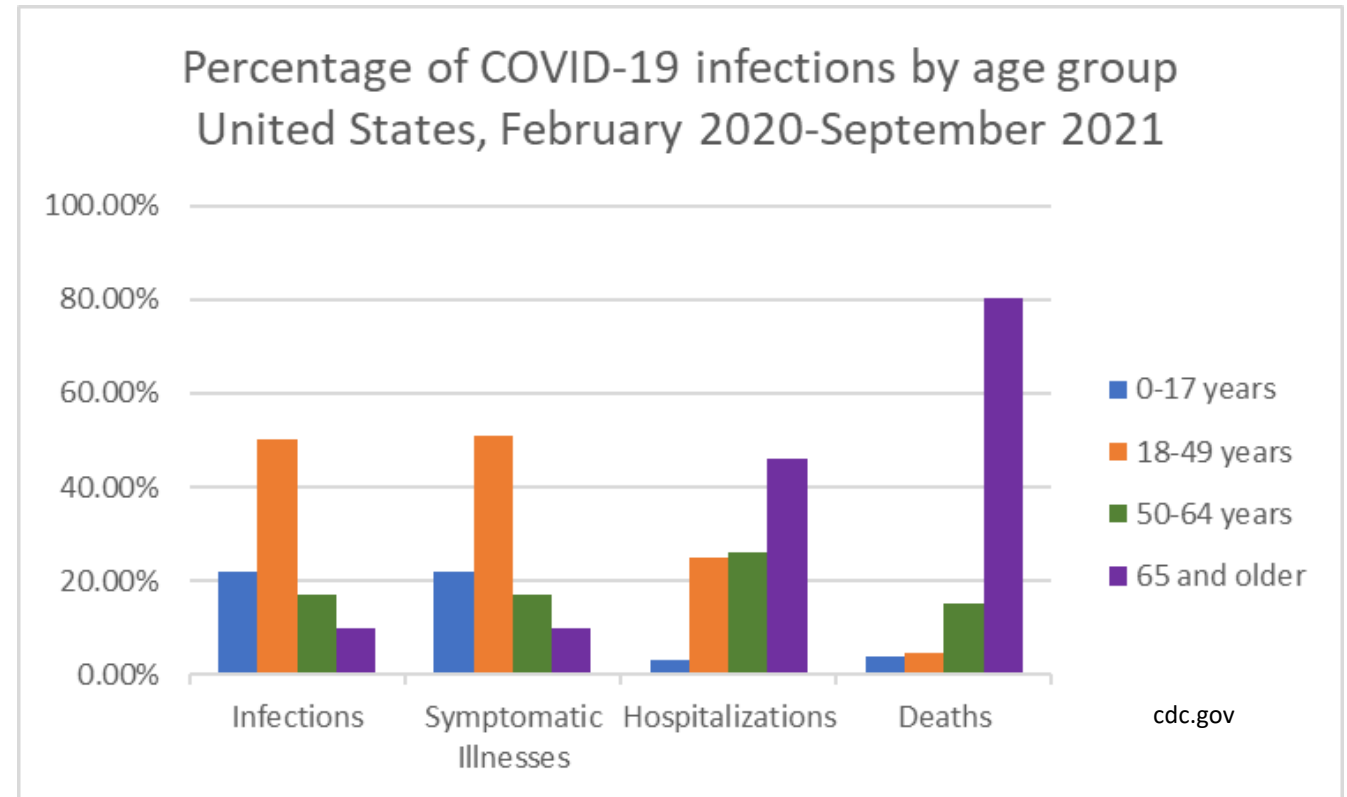
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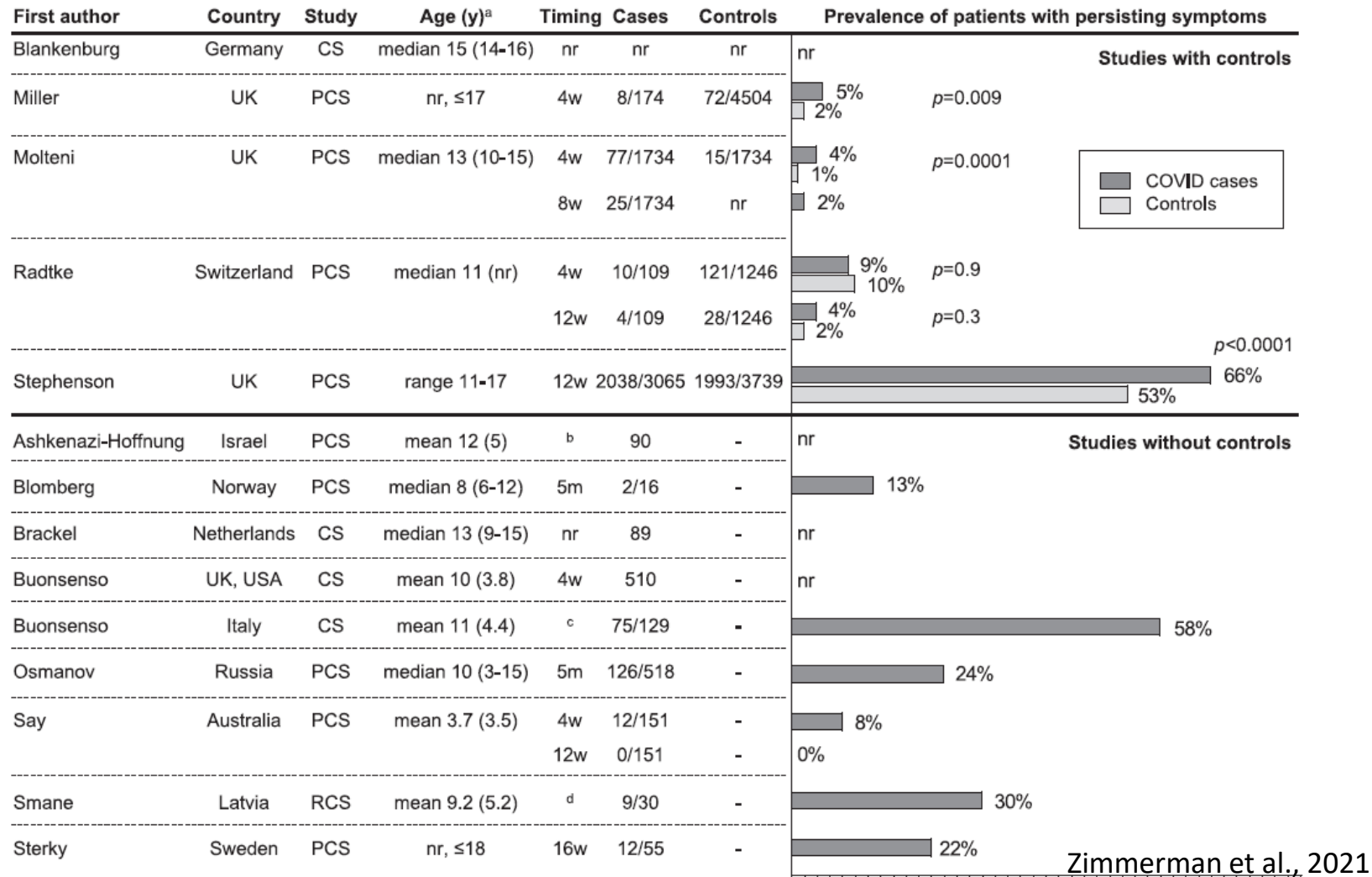
Kennedy Krieger Institute
UNLOCKING POTENTIAL

COVID-19 in children and adolescents

- As of **March 10, 2022** (aap.org):
- ~12.8 million pediatric cases of COVID-19 in the United States
 - ~19% of the total cases
 - 0.1-1.5% resulted in hospitalization
 - 0.0-0.01% resulted in death



Prevalence of long-COVID in children



- Prevalence estimates in review of 14 studies: **4-66%**

- Major study limitations

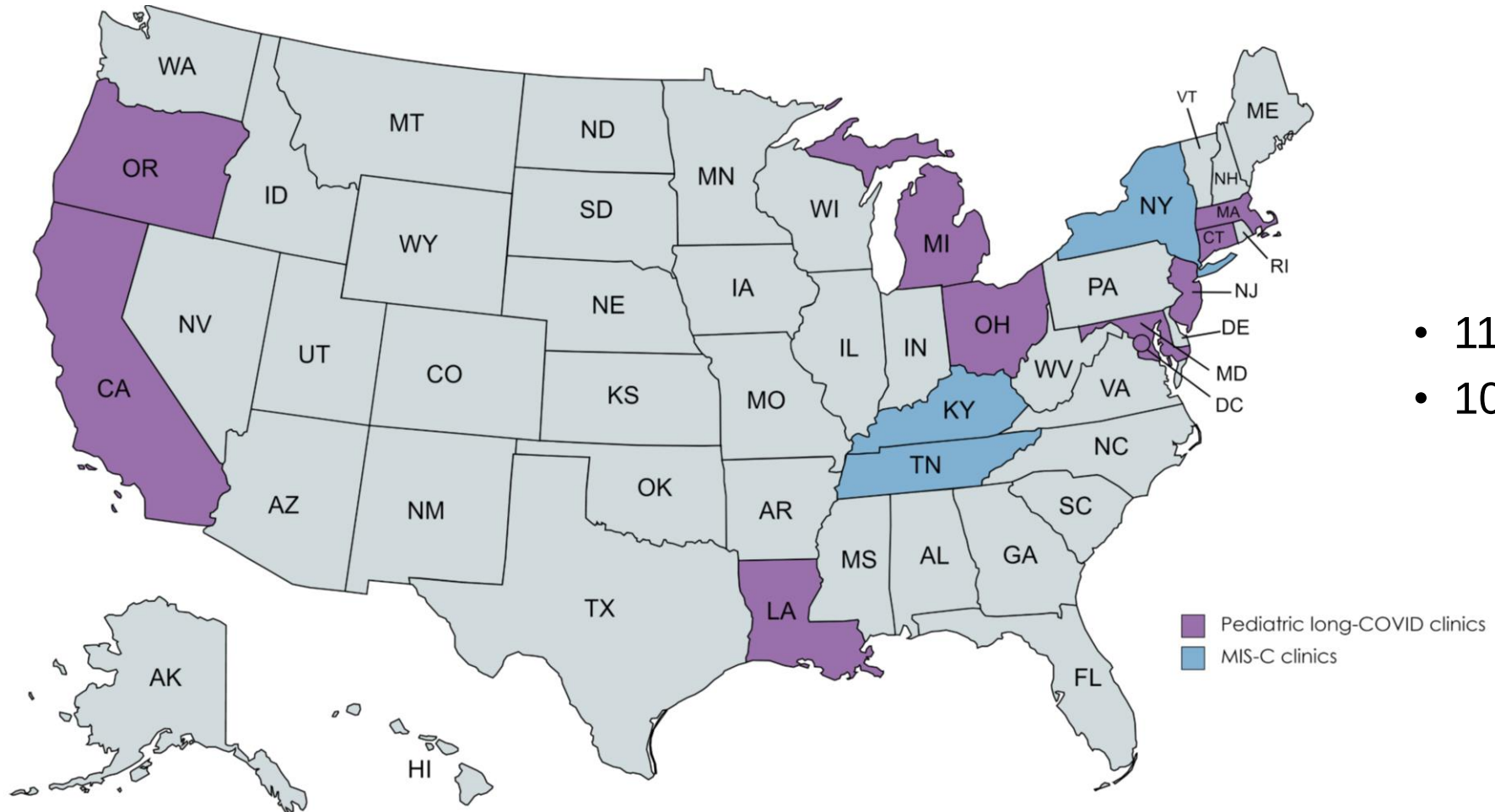
Multiple symptoms across different organ systems

Most common reported symptoms in children and adolescents (Zimmerman et al 2021):

- headache (3 to 80%)
- fatigue (3 to 87%)
- sleep disturbance (2 to 63%)
- concentration difficulties (2 to 81%)
- abdominal pain (1 to 76%)
- myalgia or arthralgia (1 to 61%)
- congested or runny nose (1 to 12%)
- cough (1 to 30%)
- chest tightness or pain (1 to 31%)
- loss of appetite or weight (2 to 50%)
- disturbed smell or anosmia (3 to 26%)
- rash (2 to 52%)

Most common symptoms in patient seeking care at KKI Pediatric Post COVID Clinic	Percentage of patients
Fatigue	90%
Concentration difficulties/memory problems/brain fog	86%
Changes to mood (e.g., anxiety/depression)	76%
Headaches	74%
Sleep disturbances	64%
Dizziness/Lightheadedness	62%
Shortness of breath/Cough	57%
Abdominal pain	48%
Chest/Thoracic pain	36%
Joint pain	33%
Loss/altered taste or smell	21%

Pediatric long-COVID clinics in the US



Pediatric long-COVID clinics in the US

- Kennedy Krieger Institute
Baltimore, MD
- Boston Children's Hospital
Boston, MA
- Yale New Haven Children's Hospital
New Haven, CT
- Children's Hospital New Orleans
New Orleans, LA
- Children's National Hospital
Washington DC
- C.S. Mott Children's Hospital
Ann Arbor, MI
- University Hospitals Rainbow Babies and Children's Hospital
Cleveland, OH
- Children's Hospital Los Angeles
Los Angeles, CA
- Oregon Health & Science University Doernbecher Children's Hospital
Portland, OR
- Joseph M. Sanzari Children's Hospital at Hackensack University Medical Center
Hackensack, NJ
- Cooperman Barnabas Medical Center and Children's Hospital of New Jersey at Newark Beth Israel Medical Center
Livingston, NJ

MIS-C Specific Clinics:

- Norton Children's Hospital, Louisville, KY
- Children's Hospital at Montefiore, Bronx NY
- Monroe Carell Jr. Children's Hospital at Vanderbilt, Nashville, TN

Multidisciplinary care in other complex chronic illnesses

The Multidisciplinary Team



- Cystic fibrosis
- Metabolic disorders
- Congenital heart disease
- Hemophilia
- Sickle cell disease
- Celiac Disease
- Chronic kidney disease
- Traumatic brain injury
- Concussion
- Leukodystrophy
- Spina bifida
- Muscular dystrophy
- Pain
- Limb Differences
- Pediatric cancers
- Palliative Care



<https://www.cff.org/your-cf-care-team>

Multidisciplinary specialty clinics

Benefits

- Holistic approach to care
- Increases communication and coordination
- Decreases appointment burden
 - Helpful for disorders with multiple organ system involvement

Challenges

- Institutional infrastructure needed for support
 - Increased space, lower patient volumes
- Insurance limitations
 - Multiple providers, out of network, variable coverage
- Access to clinics and subspecialists vary geographically

Does NOT take the place of PCP for routine health screening and preventative services

Grosse et al 2009

Clinical Approach at Kennedy Krieger Institute

- Multidisciplinary team-based approach
 - Medical
 - Psychosocial
 - Cognitive
 - Physical
- Goal to improve patients' overall functioning
 - Day to day tasks
 - Physical activity
 - School
 - Extracurricular activities & social engagement



ANALYSIS & PERSPECTIVE: PDF ONLY

Post-Acute/Long-COVID in pediatrics

development of a multi-disciplinary rehabilitation clinic and preliminary case series

Morrow, Amanda K. MD^{1,2}; Ng, Rowena PhD^{1,3}; Vargas, Gray PhD¹; Jashar, Dasal Tenzin PhD¹; Henning, Ellen PhD¹; Stinson, Nika PT, DPT¹; Malone, Laura A. MD, PhD^{1,2,4}

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Clinic Structure

Initial Visit:

- Neurology
- Pediatric PM&R
- Physical Therapy
- Behavioral Psychology
- Social Work



Close follow-up (1-2 weeks):

- Neuropsychology evaluation
- Education specialist



Referrals (as needed):

- POTS (postural orthostatic tachycardia syndrome)
- Pulmonology
- Cardiology
- Rheumatology
- Psychiatry
- Otolaryngology/ENT



Special considerations in children & adolescents

- Educational considerations
 - School accommodations
 - Academic
 - Increased time for testing, limited assignments
 - Environmental
 - Planned rest breaks, access to water
 - Staff education
- Transitions of care: child to adult based care
 - College age young adults

Upcoming Pediatric Guidance Statement: AAPM&R PASC collaborative

Disciplines:

- Cardiology
- Gastroenterology
- Infectious disease
- Neurology
- Neurocritical care
- Neuropsychology
- Otolaryngology (ENT)
- Pediatrics
- Physical medicine & rehabilitation (PM&R)
- Pulmonology
- Psychiatry
- Psychology

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Multidisciplinary Quality Improvement Initiative

Centers:

- Kennedy Krieger Institute
- Oregon Health & Science University
- Boston Children's Hospital
- Children's Hospital of Philadelphia
- Children's Hospital Colorado
- Montefiore Medical Center
- Texas Children's Hospital/Baylor College of Medicine
- Johns Hopkins Children's Center

Future directions: International collaborative

- **International Pediatric Post-Covid Condition in Children Collaboration (IP4C)**
 - Lead: Dr. Caroline L.H. Brackel, Amsterdam UMC
 - Netherlands, Germany, Hungary, Israel, Italy, Lithuania, Sweden, United States, Australia, Brazil, Croatia, Russia, England, Indonesia
- Current research exploring:
 - Programs/clinic models
 - Definitions used
 - Patient characteristics
 - Diagnostics
 - Therapeutic interventions
- Goals:
 - Create standardized definitions and data harmonization tools to better understand pathophysiology and treatment
 - Guideline development



Conclusions

- Similar to integrated care models in other complex pediatric illnesses, children with long-COVID may also benefit from multidisciplinary team based approaches to care
- Special consideration should be made to educational needs as well as ensuring appropriate transitions of care when reaching adulthood
- Further work is needed to determine optimal models of clinical care in pediatric long-COVID

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 - Dasal Jashar, PhD
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- Clinic coordinators: La'Kendra Davis, Fred Finkenbinder

