Pediatric Long-COVID: Multidisciplinary Approach to Care

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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

Percentage of COVID-19 infections by age group
United States, February 2020-September 2021

- 0-17 years
- 18-49 years
- 50-64 years
- 65 and older

(Images: CDC.gov)
Prevalence of long-COVID in children

<table>
<thead>
<tr>
<th>First author</th>
<th>Country</th>
<th>Study</th>
<th>Age (y)</th>
<th>Timing</th>
<th>Cases</th>
<th>Controls</th>
<th>Prevalence of patients with persisting symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blankenburg</td>
<td>Germany</td>
<td>CS</td>
<td>median 15 (14-16)</td>
<td>nr</td>
<td>nr</td>
<td>nr</td>
<td>5% [p=0.009]</td>
</tr>
<tr>
<td>Miller</td>
<td>UK</td>
<td>PCS</td>
<td>nr</td>
<td>4w</td>
<td>8/174</td>
<td>72/4504</td>
<td></td>
</tr>
<tr>
<td>Moirani</td>
<td>UK</td>
<td>PCS</td>
<td>median 13 (10-15)</td>
<td>4w</td>
<td>77/1734</td>
<td>15/1734</td>
<td>4% [p=0.0001]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8w</td>
<td>25/1734</td>
<td>nr</td>
<td></td>
</tr>
<tr>
<td>Radlke</td>
<td>Switzerland</td>
<td>PCS</td>
<td>median 11 (nr)</td>
<td>4w</td>
<td>10/109</td>
<td>121/1246</td>
<td>9% [p&lt;0.001]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12w</td>
<td>4/109</td>
<td>28/1246</td>
<td></td>
</tr>
<tr>
<td>Stephenson</td>
<td>UK</td>
<td>PCS</td>
<td>range 11-17</td>
<td>12w</td>
<td>2038/3065</td>
<td>1993/3739</td>
<td>66%</td>
</tr>
<tr>
<td>Ashkenazi-Hoffnung</td>
<td>Israel</td>
<td>PCS</td>
<td>mean 12 (5)</td>
<td>b</td>
<td>90</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Blomberg</td>
<td>Norway</td>
<td>PCS</td>
<td>median 8 (6-12)</td>
<td>5m</td>
<td>2/16</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Brackel</td>
<td>Netherlands</td>
<td>CS</td>
<td>median 13 (9-15)</td>
<td>nr</td>
<td>89</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Buorsenso</td>
<td>UK, USA</td>
<td>CS</td>
<td>mean 10 (3.8)</td>
<td>4w</td>
<td>510</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Buorsensse</td>
<td>Italy</td>
<td>CS</td>
<td>mean 11 (4.4)</td>
<td>c</td>
<td>75/129</td>
<td>-</td>
<td>55%</td>
</tr>
<tr>
<td>Osmanov</td>
<td>Russia</td>
<td>PCS</td>
<td>median 10 (3-15)</td>
<td>5m</td>
<td>126/518</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Say</td>
<td>Australia</td>
<td>PCS</td>
<td>mean 3.7 (3.5)</td>
<td>4w</td>
<td>12/151</td>
<td>-</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12w</td>
<td>0/151</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Smaje</td>
<td>Latvia</td>
<td>RCS</td>
<td>mean 9.2 (5.2)</td>
<td>d</td>
<td>9/30</td>
<td>-</td>
<td>8%</td>
</tr>
<tr>
<td>Sterky</td>
<td>Sweden</td>
<td>PCS</td>
<td>nr ≤18</td>
<td>16w</td>
<td>12/55</td>
<td>-</td>
<td>30%</td>
</tr>
</tbody>
</table>

- 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

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>90%</td>
</tr>
<tr>
<td>Concentration difficulties/memory problems/brain fog</td>
<td>86%</td>
</tr>
<tr>
<td>Changes to mood (e.g., anxiety/depression)</td>
<td>76%</td>
</tr>
<tr>
<td>Headaches</td>
<td>74%</td>
</tr>
<tr>
<td>Sleep disturbances</td>
<td>64%</td>
</tr>
<tr>
<td>Dizziness/Lightheadedness</td>
<td>62%</td>
</tr>
<tr>
<td>Shortness of breath/Cough</td>
<td>57%</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>48%</td>
</tr>
<tr>
<td>Chest/Thoracic pain</td>
<td>36%</td>
</tr>
<tr>
<td>Joint pain</td>
<td>33%</td>
</tr>
<tr>
<td>Loss/altered taste or smell</td>
<td>21%</td>
</tr>
</tbody>
</table>
Pediatric long-COVID clinics in the US

- 11 clinics
- 10 states
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

- 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

Pediatric Long-COVID
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

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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  - Gray Vargas, PhD
  - Dasal Jashar, PhD
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