Caregivers of children with motor impairment reported via survey that the COVID-19 pandemic disrupted access to rehabilitation therapies, impacting child physical and mental health and caregiver well-being.

INTRODUCTION

- The COVID-19 pandemic has disrupted many aspects of daily life worldwide, including employment, education, and healthcare.
- Many rehabilitation clinics transitioned to telehealth therapies in compliance with government mandates and recommendations.
- The extent to which access to rehabilitation therapies was impacted by the pandemic in the United States for children with motor impairment is unknown.
- The pandemic may have implications on child physical and mental well-being, as well as create new sources of caregiver burden.
- The objectives of this study were:
  1. To determine the impact of the COVID-19 pandemic on access to rehabilitation services for children with motor impairment.
  2. To assess the impact of disruptions to services on physical and mental well-being of children and their families.

METHODS

- Participants: caregivers of children (age <18 years) with childhood-onset motor disabilities, primarily cerebral palsy.
- Participants were recruited by email through nationwide contact lists from the Gillick Pediatric Research Lab, the Cerebral Palsy Research Registry, and Gillette Children’s Specialty Healthcare.
- An anonymous survey was completed through the online platform REDCap between May 5 and July 13, 2020.
- Study was determined exempt by UMN IRB.
- Survey questions included:
  1. Demographics
  2. Current and prior therapies received (types, hours per week)
  3. Satisfaction with therapies
  4. Physical and mental/emotional health effects experienced by the child
  5. Caregiver burden
- Data were analyzed with descriptive statistics and non-parametric statistical tests.

RESULTS

- Age (mean±SD, range): 9.95 ± 4.66 years, 1.3-18 years.
- 0-4 years: 19%
- 5-10 years: 30%
- 11-18 years: 51%
- Sex: Male 72%
- Female 28%
- Location: Urban 14%
- Suburban 64%
- Rural 21%
- "Stay At Home" order at time of survey completion:
  - Yes: 71%
  - No: 29%

- 92% of participants reported receiving at least one therapy prior to the pandemic, while only 54% reported receiving any therapies during the pandemic (p<0.001).
- Of those receiving one or more therapies during the pandemic, method of therapy delivery included video call (76%), at the therapy center (22%), phone (16%), email (7%), and home visit (5%).
- Change in number of therapies and satisfaction with therapies did not differ with presence of a "stay at home" order at the time of survey completion (p=.745, p=.862).

DISCUSSION

- Access to rehabilitation therapies was disrupted during COVID-19 in the sample surveyed between May and July 2020, and did not depend on the presence of a "Stay At Home" order.
- Satisfaction with therapy delivery was mixed.
- Disrupted access may be related to physical and mental health impacts.
- Caregivers reported increased burden and stress.
- Findings are similar to other surveys of families of children with disabilities worldwide.
- Responses to this survey suggest that available resources, though often helpful, were not sufficient to mitigate the detrimental impact of the COVID-19 pandemic on children with disabilities and their caregivers.
- Future research should expand upon caregiver and child input and feedback related to telehealth, to optimize care for families with limited access to in-person therapies and for future health care access crises.