

Impact of disrupted access to rehabilitation services during COVID-19 on children with disabilities and their caregivers

Ellen N. Sutter¹, Linda Smith Francis², Sunday M. Francis³, Daniel H. Lench⁴, Samuel T. Nemanich⁵, Linda E. Krach^{1,6}, Bernadette T. Gillick¹
 Contact: sutte051@umn.edu

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:
 - To determine the impact of the COVID-19 pandemic on access to rehabilitation services for children with motor impairment
 - To assess the impact of disruptions to services on physical and mental well-being of children and their families

METHODS

- Participants: caregivers of children (child 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:
 - Demographics
 - Current and prior therapies received (types, hours per week)
 - Satisfaction with therapies
 - Physical and mental/emotional health effects experienced by the child
 - Caregiver burden
- Data were analyzed with descriptive statistics and non-parametric statistical tests

1. Department of Rehabilitation Medicine, University of Minnesota
 2. Warner School of Education, University of Rochester
 3. Department of Psychiatry & Behavioral Sciences, University of Minnesota
 4. Department of Psychiatry, Medical University of South Carolina
 5. Department of Occupational Therapy, Marquette University
 6. Gillette Children's Specialty Healthcare

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.

Percentage of children receiving therapies prior to and during COVID-19

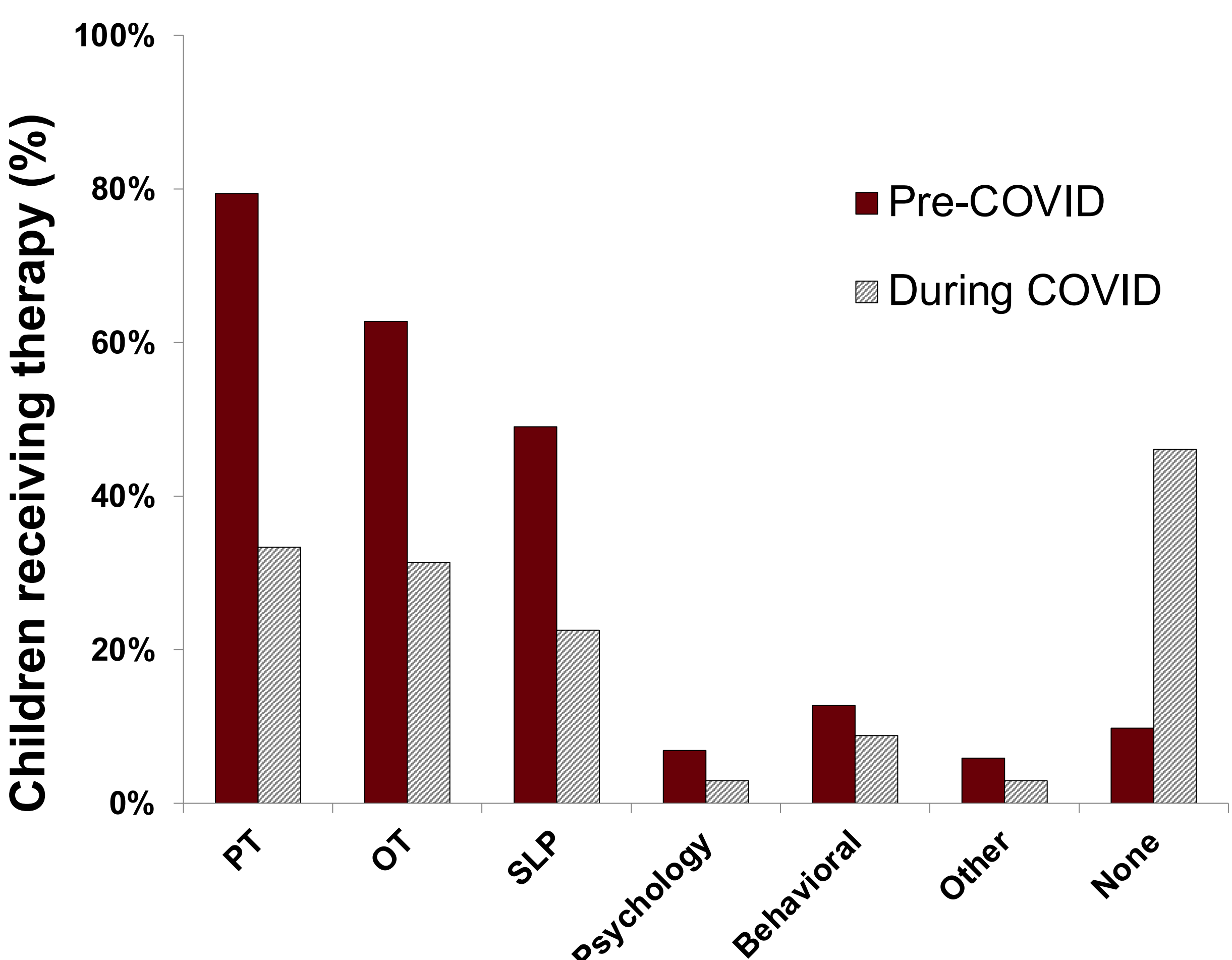


Figure 1. Percentage of children receiving different therapies (via any modality) before the pandemic compared to during the pandemic. PT = Physical Therapy, OT = Occupational Therapy, SLP = Speech/Language Pathology. "None" indicates participant was receiving no therapies at that time point.

Change in total hours of therapies received during COVID-19

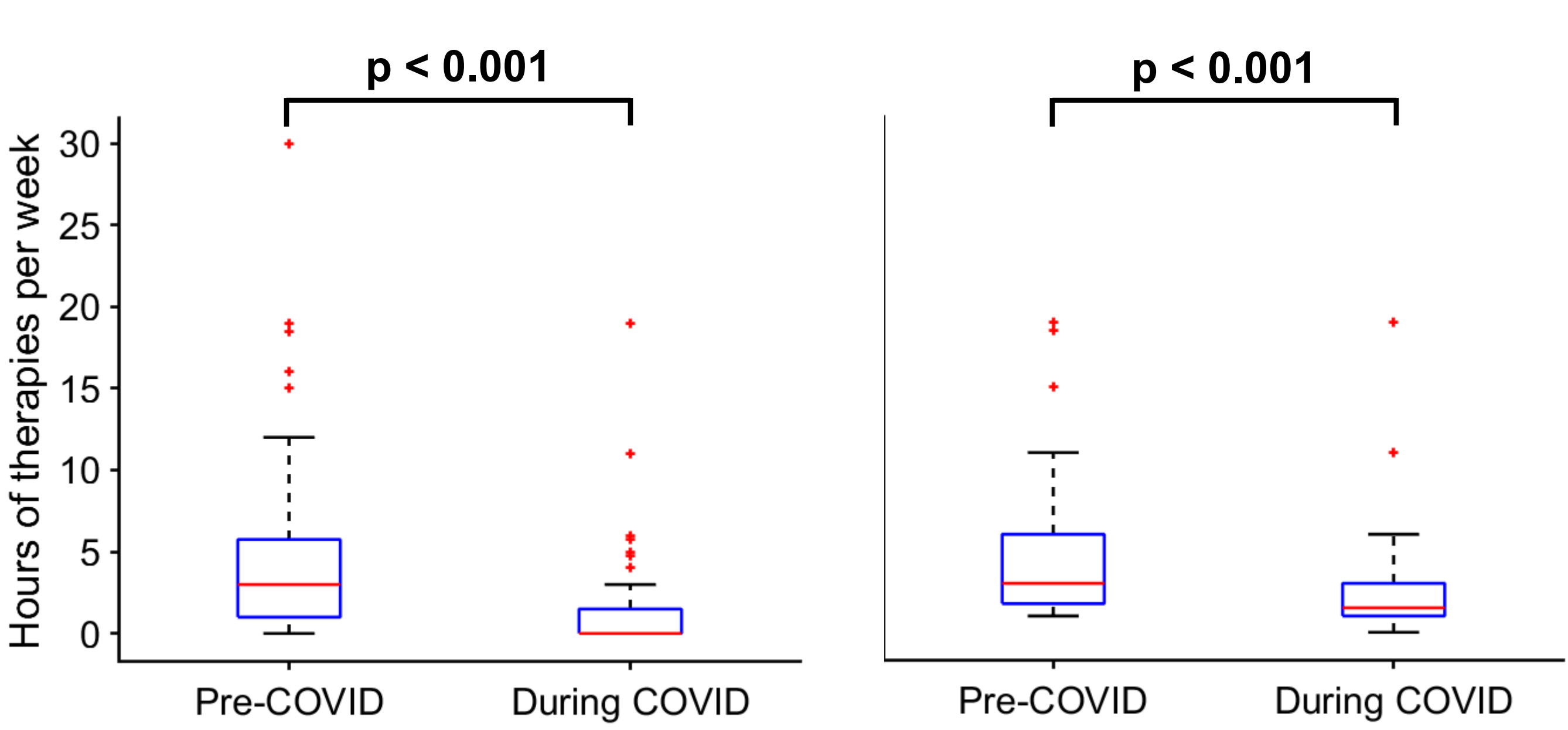


Figure 2. Total hours of therapies per week reported prior to and during the pandemic. Red center line indicates median, blue lines (box) indicates interquartile range, red dots indicate outliers. A: Hours reported across the total sample (n = 99 participants) B: Hours reported by a subset who received at least one therapy both prior to and during the pandemic (n = 52 participants). P-values represent results of a related-samples Wilcoxon Signed Rank test.

Satisfaction	% of participants (n=55)
Somewhat or very unsatisfied	36%
Neutral	15%
Somewhat or very satisfied	49%
No response	0%

Table 1. Satisfaction with therapies delivered at the time surveyed, in a subset of 55 participants who reported participating in at least one therapy during the pandemic.

Physical health impact	Decrease in number of therapies		P-Value
	No	Yes	
Decline in mobility	23%	57%	0.001*
Improvement in mobility	8%	8%	0.918
Reported increase in pain	10%	23%	0.104
New onset physical symptoms that have NOT been treated	3%	11%	0.107
Outgrown or unusable assistive equipment that has NOT been replaced/adjusted	18%	29%	0.186
Adjustment to medication	23%	36%	0.164

Table 2. Selected physical health impacts. P-values represent results of Chi Square tests comparing participants who reported a decrease in therapies received and those who did not. *indicates significance at p < 0.05

Well-being impact	Somewhat/ a lot higher About the same Somewhat/ a lot lower than usual			P value
	than usual		than usual	
Caregiver burden	85%	13%	2%	.015*
Child stress/anxiety	61%	33%	6%	.037*
Child sad/down	34%	59%	6%	.285
Child behavioral issues	41%	53%	4%	.080
Caregiver stress/anxiety	84%	13%	3%	.004*
Child physical activity	17%	21%	61%	.102

Table 3. Impact on child and caregiver well-being. Participants responded via a 5-point Likert-type scale, analyzed in three categories. P-values represent results of Mann Whitney U tests comparing participants who reported a decrease in therapies received and those who did not. *indicates significance at p < 0.05

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 (n = 55), method of therapy delivery included video call (76%), at the therapy centers (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 world-wide^{1,2,3}
- 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

1. Bertamino M, Cornaglia S, Zanetti A, Di Rocco A, Ronchetti A, Signa S et al. Impact on rehabilitation programs during Covid-19 containment for children with pediatric and perinatal stroke. Eur J Phys Rehabil Med 2020.
 2. Dickinson H, Yates, S. More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic
 3. European Academy of Childhood Disability. EACD COVID-19 Surveys Initial Report: The impact of COVID-19 and accompanied restrictions and regulations on the area of childhood disability during March-May 2020. 2020 August.

