

# Disrupted Access to Therapies and Impact on Well-Being During the COVID-19 Pandemic for Children With Motor Impairment and Their Caregivers

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**Objectives:** The aim of this study was to determine the impact of the COVID-19 pandemic on access to rehabilitation therapies and the impact of changes in therapy access on the physical and mental well-being of children with motor impairment and their caregivers.

**Design:** Caregivers of children younger than 18 yrs with childhood-onset motor impairment (primarily cerebral palsy) completed an anonymous survey through the online platform REDCap between May 5 and July 13, 2020.

**Results:** The survey was completed by 102 participants. Before the pandemic, 92 of 102 children (90%) were receiving one or more therapies; at the time surveyed, 55 children (54%) were receiving any therapies ( $P < 0.001$ ). More than 40% of the sample reported increased child stress, decreased physical activity, and/or decline in mobility/movement. Participants who reported a decrease in number of therapies at the time surveyed more frequently reported lower satisfaction with treatment delivery ( $P < 0.001$ ), a decline in child's mobility ( $P = 0.001$ ), and increased caregiver stress ( $P = 0.004$ ). Five qualitative themes were identified from open-ended question responses related to therapies and well-being.

**Conclusions:** Access to pediatric rehabilitation therapies was disrupted during COVID-19. Disrupted access may be related to impact on physical and mental health. With the expansion of telehealth, caregiver and child feedback should be incorporated to optimize benefit.

**Key Words:** Telemedicine, Cerebral Palsy, Rehabilitation, COVID-19

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The novel coronavirus disease 2019 (COVID-19) was declared a pandemic on March 11, 2020, by the World Health Organization.<sup>1</sup> The impact of subsequent local and national health and safety mandates on children with childhood-onset motor disabilities and their families in the United States, particularly regarding healthcare access and well-being, is not fully understood.<sup>2–4</sup>

## What Is Known

- The COVID-19 pandemic has impacted many facets of healthcare access across the United States. Consistent access to therapies and other support services is important for children with motor impairment and their caregivers.

## What Is New

- Access to rehabilitation therapies was disrupted during the first few months of the COVID-19 pandemic in the United States, as reported by caregivers of children with motor impairment. Therapy was most frequently delivered via telehealth, and satisfaction was mixed. The pandemic and subsequent disruptions in access to therapies may be related to child physical and mental health impacts and increased caregiver burden.

Infants and children with motor impairments, including cerebral palsy, often participate regularly in multiple therapies at home, school, and/or clinic locations from an early age to optimize function.<sup>5</sup> Additional healthcare needs may include spasticity management, assistive equipment, surgery, or follow-up with healthcare specialists.<sup>6</sup> In response to the COVID-19 pandemic, many states mandated temporary holds on “nonessential” medical procedures and appointments from early March until May,<sup>7</sup> with continued limitations in some clinical settings thereafter. This produced a rapid expansion of telehealth utilization across health care, including in pediatrics,<sup>8–10</sup> often with little underlying infrastructure.<sup>11</sup> Although telehealth presents an alternative healthcare option during the pandemic, limitations exist for certain evaluation and treatment procedures, with additional concerns surrounding inequity of access to the Internet and other necessary technologies.<sup>4,9,10,12</sup> School systems,

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Ellen N. Sutter is in training.

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providing education, therapies, and support services for children with motor impairment, also faced challenges in quickly adapting quality in-person services to be delivered remotely.<sup>13</sup>

In addition to physical health concerns, children with motor impairment have higher incidence of mental health disorders in general than their typically developing peers, because of both social factors and physical factors (i.e., pain, decreased physical activity, poor sleep quality).<sup>14,15</sup> Pandemic-related stress associated with reorganization of family life, fear and grief, financial insecurity, limited access to health services, or lack of social interaction may directly impact mental health or exacerbate preexisting mental health concerns.<sup>16</sup> Regarding caregivers, disruptions to routines and access to supports during COVID-19 may result in additional burden and stress.<sup>17,18</sup>

The extent of the impact of COVID-19 on access to rehabilitation therapies for children with motor impairment, and the subsequent impact on child and caregiver physical and mental health, has not yet been explored in the United States. In this study, an online survey was constructed to query caregivers of children with motor impairment during the first several months of the pandemic. The primary aims were to assess caregiver perceptions of (1) the impact of the pandemic on access to pediatric rehabilitation therapies, (2) caregiver satisfaction with therapies received during the pandemic, and (3) the impact on mental and physical well-being of children with motor impairment and their caregivers.

## METHODS

### Study Design

This study was conducted using a mixed-methods approach; quantitative and qualitative data were collected within one survey and analyzed simultaneously. Quantitative data provided insight into changes in therapy access and health impact during the first few months of the pandemic on a sample of children with motor impairment and their caregivers. Qualitative data expanded upon the caregivers' lived experiences and perceptions of their caregiving during the pandemic. Quantitative data were prioritized and collected in greater detail than the qualitative data.

### Participants

Participants were recruited between May 5 and July 13, 2020. At the start of recruitment, most US states had implemented a Stay-at-Home order; however, mandates and restrictions were frequently adjusted during the time period of recruitment. Adults who self-identified as parents/caregivers of children (birth–18 yrs) with a motor disability were included. Participants were recruited by email invitation from three sources, all based in the Midwest with nationwide reach:

1. The Gillick Pediatric Neuromodulation Laboratory database of families interested in research, based in Minneapolis, MN (204 families contacted).
2. The Cerebral Palsy Research Registry, a multi-institutional effort based in Chicago, IL (550 families contacted).
3. Gillette Children's Specialty Healthcare, a hospital based in St. Paul, MN. Invitations were sent to families of children with a cerebral palsy diagnosis who had expressed interest in research (982 families contacted).

### Survey Design

Eligible participants completed an anonymous online survey through the secure Web platform REDCap<sup>19</sup> that was sent via email link. Most (24/27) of the survey questions utilized checkboxes, radio buttons, or short answer response fields to address demographics, current and previous therapies received, modalities of therapy delivery, satisfaction with therapies, physical and mental/emotional health effects experienced by the child, and caregiver stress and burden. Three open-response questions elicited narrative comments describing the participants' caregiving experience. Specific location data were not collected to protect anonymity; however, to provide general information on the types of communities in which they lived, participants indicated whether their home location was urban, suburban, or rural. Similarly, participants self-selected whether their state was under a Stay-at-Home/Shelter-in-Place or similar order at the time of the survey. Because of the nonuniform regulatory response in the United States, these terms are expected to reflect varying local regulations. Some survey questions were adapted from a similar survey designed by the European Academy of Childhood Disability.<sup>20</sup> Survey questions were reviewed by the research team and a mock REDCap survey was sent to 16 adults who were parents to pilot (results not included in analysis). Feedback provided on survey content and construction was incorporated before survey dissemination. The complete survey is provided in Supplemental Material 1 (Supplemental Digital Content 1, <http://links.lww.com/PHM/B320>).

The study and electronic consent were approved by the University of Minnesota Institutional Review Board, and participants indicated their informed consent to participate electronically before completing the survey. This study conforms to STROBE guidelines and reports the required information accordingly (see Supplemental Checklist, Supplemental Digital Content 2, <http://links.lww.com/PHM/B321>).

### Data Analysis

A concurrent data analysis procedure was conducted in which quantitative and qualitative data were analyzed separately: Quantitative data were analyzed in SPSS version 26.0 (IBM, Armonk, NY) and qualitative data were analyzed using a thematic analysis method.<sup>21</sup> The datasets were merged to provide a more complete analysis, supplementing the quantitative findings with qualitative data.

### Quantitative Data

Data were assessed for normality and nonparametric statistics were used when appropriate. Data were analyzed from all participants who submitted both the initial consent page and the survey questionnaire. Skipped questions were excluded from analysis. Data were reviewed and modifications were made in the following scenarios: if the participant did not specify whether their child's age was in months or years, years was assumed. If time in one therapy exceeded 15 hours per week, that data point was removed, and all calculations of hours were excluded for that participant (three participants). Data entered in "Other" categories were recoded and, if possible, added to a preexisting category within the question.

Descriptive statistics were used to examine the distributions of demographic variables across the three sources. Kruskal-Wallis

*H* tests compared demographic variables (age, sex, home location, Stay-at-Home order) and hours of therapies before and during the pandemic for the three data sources. For all subsequent analyses, the data sources were grouped. A categorical age variable was also created, with age categories of 0 to 4 yrs (preschool), 5 to 10 yrs (elementary), and 11 to 18 yrs (adolescence).

### Impact on Access to Therapies

A change variable was created to quantify the difference in number of therapy hours received by the child before the pandemic and at the time surveyed ( $\Delta_{\text{hours}} = \text{hours}_{\text{pre}} - \text{hours}_{\text{during}}$ ). A related-samples Wilcoxon signed rank test compared overall hours of therapies received before and during the pandemic. Potential relationships between participant factors and the change in number of therapy hours were analyzed by (a) Kruskal-Wallis *H* Test (participant home location, child age category); (b) Mann-Whitney *U* test (presence or absence of a reported Stay-at-Home order, recent changes in child medical status); and (c) Spearman correlation (survey completion date).

### Satisfaction with Therapies Received

All participants who were receiving at least one therapy at the time surveyed ( $n = 55$ ) were included in the analysis of satisfaction with therapies. Satisfaction with therapies was compared by (a) Kruskal-Wallis *H* Test (participant home location and child's age category); (b) Mann-Whitney *U* Test (sex of the child, recent change in medical status, and presence/absence of a reported Stay-at-Home order); and (c) Spearman correlation ( $\Delta_{\text{hours}}$ ).

### Impact on Child and Caregiver Well-Being

For some questions, participants were asked to compare the situation at the time surveyed ("during the pandemic") to a "usual" time before the pandemic. Descriptive statistics explored yes/no and Likert-type responses to questions regarding changes in physical and mental health.

Participants were grouped by (1) those who reported receiving a decrease in number of different therapies during the pandemic or (2) those who reported receiving the same or greater number of therapies. Analyses compared the two groups using (a) Mann-Whitney *U* tests to analyze Likert-type scale questions about child and caregiver mental health and (b)  $\chi^2$  tests to analyze "yes/no" responses to questions regarding physical and mental health.

### Qualitative Data

Qualitative data were compiled from the participants' answers to three open-response questions. The data were analyzed using a process based on Braun and Clarke's six-phase approach to thematic analysis<sup>21</sup>: (1) Became familiar with content of the dataset; (2) Generated initial codes with associated quotations; (3) Searched for potential themes within coded data; (4) Identified preliminary themes. Reviewed themes in relationship to data extracts; (5) Defined and named each unique theme. Selected quotations that captured core aspects of each theme; and (6) Produced fully developed themes with vivid quotations that provided a coherent account of data. After the thematic analysis, the qualitative and quantitative data were

integrated to provide a holistic and more complex understanding of the caregivers' experiences.

## RESULTS

### Overview

A total of 124 caregivers consented to participate in the survey, and 102 caregivers (89% mothers, 9% fathers, 1% grandmothers, 1% other) submitted a completed survey questionnaire. The overall response rate was 7%. Quantitative questions were each answered by more than 96% of participants. Demographics of participants from each recruitment source and across the overall sample are shown in Table 1. The significant difference observed in the presence/absence of a Stay-at-Home order among recruitment sources is attributable to different dates of survey completion.

Ninety-two percent of the participants answered at least one of the open-ended questions. Five themes were identified from the qualitative data, which described the lived experiences of the caregivers who participated in the survey and explored their perceptions of the pandemic's impact on themselves and their children. Quantitative and qualitative results were grouped in response to three overarching research topics: (1) Impact on access to therapies, (2) Satisfaction with therapies, and (3) Impact on child/caregiver well-being. The qualitative findings embellished, validated, and substantiated selected quantitative findings (Table 2).<sup>22</sup> An expanded write-up of themes, including additional participant quotations, is included in Supplemental Material 2 (Supplemental Digital Content 3, <http://links.lww.com/PHM/B322>).

### Impact on Access to Therapies

There was a significant difference in total therapy hours received during compared with before the pandemic for all participants ( $P < 0.001$ ) and for a subset of participants ( $n = 55$ ) who reported receiving one or more therapies both before and during the pandemic ( $P < 0.001$ ; Fig. 1A and B). There was no difference in  $\Delta_{\text{hours}}$  with child age ( $P = 0.851$ ), reported presence of a Stay-at-Home order ( $P = 0.301$ ), or recent change in the child's medical status ( $P = 0.283$ ), and  $\Delta_{\text{hours}}$  was not correlated with the date of survey completion ( $\rho = -0.077$ ,  $P = 0.450$ ). Participant home location (urban/suburban/rural) had a statistically significant association with  $\Delta_{\text{hours}}$  ( $P = 0.049$ ); however, home location was unequally distributed, with 64% of participants residing in the suburbs (see Table 1).

The percentage of children receiving each type of therapy before and during the pandemic is shown in Fig. 1C. Of participants receiving any therapies during the pandemic, methods of therapy delivery included video call (76%), in-person at therapy centers (22%), phone (16%), email (7%), and in-home visits (5%). Twenty-seven percent reported receiving therapies via multiple delivery methods.

Responses to open-ended questions supported the quantitative findings regarding access impact. Caregivers, *unable to access needed care* (theme 1) for their child, recognized the negative impact of postponed or canceled therapies and services (participant quotations are unedited):

"He was supposed to have a botox and casting when we moved to shelter in place and it was postponed. He started to experience an increase in pain after activities...."

**TABLE 1.** Caregiver-reported child demographics for the three recruitment sources and for the overall sample

	Gillick Lab (n = 30)	CPRR (n = 33)	Gillette Children's (n = 39)	Total (n = 102)
Age, mean ± SD, y	10.8 ± 5.6	10.6 ± 3.6	8.7 ± 4.5	10.0 ± 4.7
0–4	7	2	10	19 (19%)
5–10	5	12	14	31 (30%)
11–18	18	19	15	52 (51%)
Sex				
Male	19	28	26	73 (72%)
Female	10	5	13	28 (27%)
Ethnicity				
Hispanic/Latino	4	5	4	13 (13%)
Not Hispanic/Latino	26	28	35	89 (87%)
Race				
Native American/Alaska Native	1	0	2	3 (3%)
Asian	3	0	4	7 (7%)
Black/African American	0	1	0	1 (1%)
Native Hawaiian/Pacific Islander	0	0	1	1 (1%)
White	25	29	36	90 (88%)
Other	0	2	2	4 (4%)
Reported home location <sup>a</sup>				
Urban	2	8	4	14 (14%)
Suburban	21	22	22	65 (64%)
Rural	7	3	11	21 (21%)
Reported Stay-at-Home order <sup>a</sup>				
Yes	27	32	13	72 (71%)
No	3	1	26	30 (30%)
Caregiver type				
Mother	27	29	35	91 (89%)
Father	2	4	3	9 (9%)
Other	1	0	1	2 (2%)
Number of adults in home, median (range)	2 (1–4)	2 (1–5)	2 (1–4)	2 (1–5)
Number of children in home, median (range)	2 (1–7)	2 (1–3)	2 (1–10)	2 (1–10)
Total hours of therapy prepandemic, median (range) <sup>a</sup>	1.9 (0–18.5)	5 (0–30)	3 (0–19)	3 (0–30)
Total hours of therapy during the pandemic, median (range)	0 (0–5.75)	0.5 (0–5)	0.125 (0–19)	0 (0–19)

CPRR indicates Cerebral Palsy Research Registry.

<sup>a</sup>Significant difference among recruitment sources ( $P < 0.05$ ).

“Before the pandemic we had 5 appointments that were scheduled to be done by now. Instead we are repeatedly rescheduling those appointments and have not had any of them yet.”

“Getting online access to mental health professionals has not been possible.”

Caregivers also specifically identified the impact of school closures on access to therapies and support services for their children:

“He was getting many school-based support services that disappeared overnight.”

### Satisfaction with Therapies Received

In the subset receiving one or more therapies at the time surveyed, satisfaction with therapies received during the pandemic was mixed: 36% were “somewhat or very unsatisfied,” 15% were

“neutral,” and 49% were “somewhat or very satisfied.” There was a significant difference in satisfaction between caregivers whose children had a recent change in medical status (median = 2, “Somewhat unsatisfied”) and those who had not (median = 4, “Somewhat satisfied”) ( $P = 0.019$ ). There was a weak, negative correlation between  $\Delta_{\text{hours}}$  and satisfaction ( $\rho = -0.281$ ,  $P = 0.044$ ). Satisfaction did not differ with child age ( $P = 0.096$ ), sex ( $P = 0.204$ ), home location ( $P = 0.081$ ), or reported presence of a Stay-at-Home order ( $P = 0.759$ ).

Participants described *benefits and limitations of telehealth* (theme 2) in open-ended responses. Several caregivers expressed appreciation for telehealth and the therapists’ efforts:

“We also have access to therapists and a clinic that has done an exceptional job of transitioning over to telehealth.”  
 “Our physical therapist is AMAZING and has been doing the best she can given the circumstances. She even let us take home an E-stim machine to work with our son.”

**TABLE 2.** Qualitative extracts provide depth to quantitative results from survey questions

<b>2A. Theme 1: Unable to Access Needed Care</b>			
<b>Related Survey Questions/Items</b>	<b>Responses to Survey Item</b>		<b>Related Qualitative Responses</b>
	<b>Yes</b>	<b>No</b>	
Receiving one or more therapies at the time surveyed	54%	46%	<ul style="list-style-type: none"> <li>• “We have been fortunate as we have been able to receive services as needed although the delivery of them has changed.”</li> <li>• “Medical needs have been taken care of as best as possible including (virtual, telephone, and in-person), but therapies have fallen to the wayside.”</li> </ul>
Recent (within the 6 mos before the pandemic) surgical treatment or change in medical status	28%	72%	<ul style="list-style-type: none"> <li>• “Physical therapy is not the same over video calls. My son needs measurements taken, and specific gait analysis and exercises after a surgical procedure in January 2020.”</li> <li>• “My son did not require a lot of services before the safer-at-home order, so we were not significantly impacted.”</li> </ul>

<b>2B. Theme 2: Benefits and Limitations of Telehealth</b>				
<b>Related Survey Questions/Items</b>	<b>Responses to Survey Item</b>			<b>Related Qualitative Responses</b>
	<b>Somewhat/Very Unsatisfied</b>	<b>Neutral</b>	<b>Somewhat/Very Satisfied</b>	
Satisfaction with current therapy delivery (n = 55)	36%	15%	49%	<ul style="list-style-type: none"> <li>• “I appreciate the effort but just know this would not be beneficial for my child as she cannot learn from a screen.”</li> <li>• “Access to telehealth therapy and medical visits sessions are ok, but not an acceptable solution in the long term.”</li> <li>• “We also have access to therapists and a clinic that has done an exceptional job of transitioning over to telehealth. The therapists have still managed to make therapy motivating.”</li> </ul>

<b>2C. Theme 3: Child’s Physical and Mental Well-Being</b>			
<b>Related Survey Questions/Items</b>	<b>Responses to Survey Item</b>		<b>Related Qualitative Responses</b>
	<b>Yes</b>	<b>No</b>	
Experienced a decline in mobility/movement-related skills	43%	57%	<ul style="list-style-type: none"> <li>• “Access to regular therapies has been disrupted, which has led to functional declines in my son’s gross and fine motor skills. These changes may have brought on the pain he is now experiencing.”</li> <li>• “We are doing telehealth PT which has helped with ADL’s but he’s missing out in electrical stimulation to help with his gait.”</li> </ul>
Outgrown or unusable assistive equipment that has not been replaced	25%	75%	<ul style="list-style-type: none"> <li>• “He has outgrown his wheelchair that was supposed to be replaced in March. This had caused muscle pain/fatigue from the incorrect seating.”</li> <li>• “Trying to find time to get her leg AFO brace adjusted with their appointment times, my work schedule and the high demand of 7th grade schoolwork.”</li> </ul>

<b>2C. Theme 3: Child’s Physical and Mental Well-Being</b>				
<b>Related Survey Questions/Items</b>	<b>Responses to Survey Item</b>			<b>Related Qualitative Responses</b>
	<b>Somewhat/a Lot Higher Than Usual</b>	<b>About the Same</b>	<b>Somewhat/a Lot Lower Than Usual</b>	
Child experiencing stress/anxiety	61%	33%	6%	<ul style="list-style-type: none"> <li>• “His mental health has definitely suffered. This has caused meltdowns, decreased desire to work his muscles, and been stressful for our family of 5.”</li> <li>• “High anxiety with change in routine and therapy which is inconsistent.”</li> </ul>
Child engagement in physical activity (n = 100)	17%	21%	61%	<ul style="list-style-type: none"> <li>• “It’s concerning to me that he has much less therapy and much less access to physical activity and recreation. We are only a couple of months into this but I wonder how this will affect his mobility, posture, pain, and mood over time.”</li> <li>• “We found an adaptive virtual group work out that has been life giving to my son. He participates 2x a week and it has been great for him.”</li> </ul>

*(Continued on next page)*

TABLE 2. (Continued)

Related Survey Questions/Items	Responses to Survey Item			Related Qualitative Responses
	Somewhat/a Lot Higher Than Usual	About the Same	Somewhat/a Lot Lower Than Usual	
Current burden being placed upon family caregivers	85%	13%	2%	<ul style="list-style-type: none"> <li>• “Another burden put upon us is, both parents have committed hours per day to doing the PT, OT and home school work. It is a lot of extra work but what is the alternative, look back years from now and realize we should have done more?”</li> <li>• “I feel like this has decreased the pressure and busyness of our everyday life. We needed a break, overall it has been good for us.”</li> </ul>
Parent experiencing stress/ anxiety	84%	13%	3%	<ul style="list-style-type: none"> <li>• “Financial stress and not being able to get support from extended family has been challenging.”</li> <li>• “We also have great technology and my husband is present to help as well. I cannot imagine doing this if we did not have such support and access.”</li> </ul>

*N* = 102 participants for all quantitative data except where noted. Summarized responses to specific survey items are presented alongside related quotations from qualitative data. Unedited quotations were selected to reflect the variability of responses received.

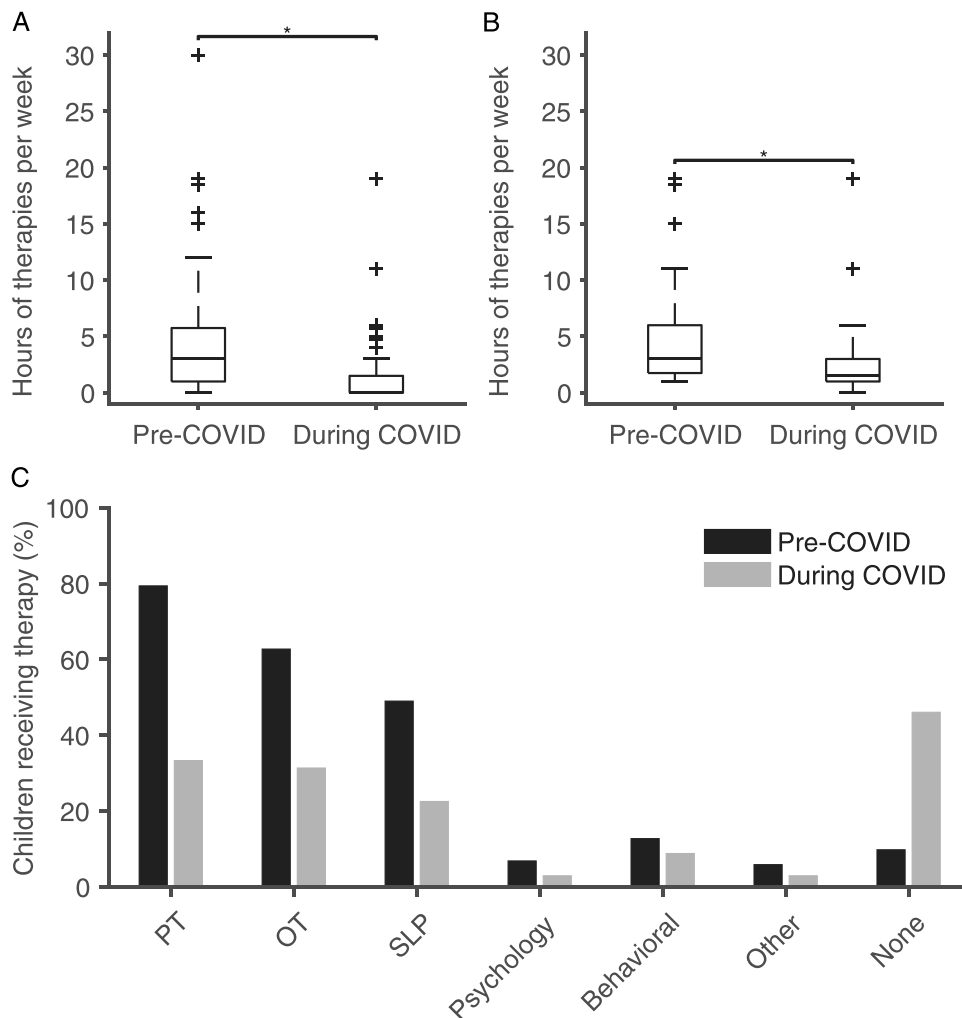


FIGURE 1. Change in amount and types of therapy received. A, Boxplot displaying the total hours of therapies received before and during the COVID-19 pandemic (*n* = 99, *P* < 0.001). B, Boxplot displaying the total hours of therapies received before and during the COVID-19 pandemic for participants who received at least one therapy (in any format) both before and during the pandemic (*n* = 52, *P* < 0.001). C, Percentage of children in the total sample (*n* = 102) receiving each type of therapy before (black bars) and during (gray bars) the COVID-19 pandemic.

**TABLE 3.** Responses to yes/no questions regarding child physical and mental well-being

	Did Not Experience a Decrease in Therapies	Experienced a Decrease in Therapies	<i>P</i>
<b>Physical health impacts</b>			
Decline in mobility/movement-related skills	23%	57%	0.001 <sup>a</sup>
Improvement in mobility/movement-related skills	8%	8%	0.918
Decrease in pain	3%	3%	0.832
Increase in pain	10%	23%	0.104
New-onset physical symptoms that have been treated	5%	8%	0.550
New-onset physical symptoms that have <i>not</i> been treated	3%	11%	0.107
Outgrown or unusable assistive equipment that has been replaced/adjusted	15%	13%	0.764
Outgrown or unusable assistive equipment that has <i>not</i> been replaced/adjusted	18%	29%	0.186
Adjustment to medication	23%	36%	0.164
Other	10%	2%	0.055
<b>Mental/emotional health impacts</b>			
Decrease in sleep quality	25%	31%	0.539
Increase in fatigue/tiredness	28%	29%	0.868
Change in appetite	2%	20%	0.013 <sup>a</sup>
Decreased interaction with family/friends	23%	29%	0.468
None of the above	48%	37%	0.300

Percentage of children experiencing physical or mental health impacts (responded “yes” via yes/no checkboxes), grouped by participants who received fewer therapies compared with those who received the same or increased amount of therapies during the pandemic as before the pandemic. *P* represents the outcome of the  $\chi^2$  test comparing whether the child decreased number of therapy services received during the pandemic (yes/no) and whether they experienced that physical/mental health impact.

<sup>a</sup>Indicates significant  $P < 0.05$ .

Some participants living in rural communities responded positively to the access provided by telehealth:

“Since we live in a rural community and are a 5 hr drive from the closest children’s hospital, we are LOVING the increased availability of telemedicine. We have been able to save a substantial amount of money in gas, accommodation and food expenses that would normally have been spent to travel to my daughter’s pediatric specialists.”

Caregivers expressed concerns about the technological limitations of online delivery of therapies and that services would not meet their children’s needs:

“With the tele videoing, it is hard having a child with special needs as you do therapy. You have to hold the computer, help (assist) the child at the same time. As a parent I am not specialized in these therapy techniques.”

### Impact on Child and Caregiver Well-Being

Participants who experienced a decrease in the number of therapies received during the pandemic reported greater negative impact on some aspects of well-being compared with those who continued to receive the same number of therapies (regardless of delivery method). Participants who experienced a decrease in therapies more frequently reported a decline in their child’s mobility/movement-related skills (Table 3;  $P = 0.001$ ). Participants who experienced a decrease in therapies also reported a greater negative impact on burden being placed upon

family caregivers ( $P = 0.015$ ), child stress and anxiety ( $P = 0.037$ ), and caregiver stress and anxiety ( $P = 0.004$ ) (Table 4).

Caregivers expressed concern in open-ended responses that ongoing reduced access to care would negatively impact their child’s physical and mental well-being (theme 3):

“My child has had increased tone and spasticity making daily things and sleep harder on him.”

“My son is very social, and has suffered significantly from not seeing classmates, paras, teachers, caregivers, and family. His mental health has definitely suffered. This has caused meltdowns, decreased desire to work his muscles, and been stressful for our family.”

Caregivers additionally described their perceptions of caregiving demands/burden-related stressors (theme 4) associated with satisfying their children’s needs, balancing work and family responsibilities, and meeting financial obligations:

“Both parents have committed hours per day to doing PT, OT and home school work. It is a lot of extra work but what is the alternative, look back years from now and realize we should have done more?”

“As caregivers, we are too worn out to do all therapies in addition to providing around the clock care.”

“We’ve had to pay out of pocket to have our son have care.”

However, the negative impact of stressors associated with caregiver burden was often mitigated by caregivers acknowledging the positive aspects of their caregiving experience (theme 5).

**TABLE 4.** Responses to Likert-type scale questions about child and caregiver physical and mental well-being

	Somewhat/a Lot Higher Than Usual	About the Same	Somewhat/a Lot Lower Than Usual	P
Current burden being placed upon family caregivers	85%	13%	2%	0.015 <sup>a</sup>
Child stress/anxiety	61%	33%	6%	0.037 <sup>a</sup>
Child sad, down, or disinterested in usual activities	34%	59%	6%	0.285
Child behavioral issues/problems	41%	53%	4%	0.080
Parent stress/anxiety	84%	13%	3%	0.004 <sup>a</sup>

	Somewhat/a Lot Lower Than Usual	About the Same	Somewhat/a Lot Higher Than Usual	P
Child physical activity	61%	21%	17%	0.102

Responses to Likert-type scale questions have been grouped into three categories from the original five possible responses. *P* represents the relationship between whether the child decreased number of therapy services received during the pandemic (yes/no) and ordinal response to Likert-type questions (based on original five categories).

<sup>a</sup>Significant *P* < 0.05.

Seventeen percent of caregivers noted positive aspects of caregiving during the pandemic in their open-ended responses:

“We have the help of family members, and we observed enough of his therapies to do many of them ourselves.”  
 “My child has been receiving services since she was an infant. If she had not had years of services in place, I would be more stressed and unable to manage her behavior.”

### DISCUSSION

This study, completed in rapid response to the COVID-19 pandemic, used caregiver report to determine impact on access to therapies for children with motor impairment as well as the physical and mental health of children and their caregivers. Quantitative findings indicated the extent of the pandemic’s impact among this sample of children with motor impairment and their caregivers. Responses to open-ended survey questions allowed for qualitative analysis of the lived experiences and perspectives of caregivers.

The percentage of children receiving no therapies increased by 4.8 times during the pandemic; among those continuing to receive therapies, hours per week decreased. Furthermore, caregivers frequently reported an impact on their child’s physical activity and health. Thematic analysis confirmed that caregivers perceived a negative impact of the pandemic on access to needed health care, and subsequently on their children’s well-being. Although no other therapy access data in children with motor impairment have been reported in the United States, a survey of 1790 families of children with disabilities by the European Academy of Childhood Disability found that 70% of families reported decreased access to treatment, and 49% reported not receiving any treatment from March to May 2020.<sup>20</sup> A survey completed by Bertamino et al.<sup>23</sup> specific to children with stroke in Italy found that 27.9% discontinued rehabilitation services without any alternative program. Reduced physical activity during the pandemic has been reported in other pediatric populations,<sup>24</sup> and health impacts are also consistent with the results of European surveys, where 32% to 38% of parents noted a physical health impact or worsening of their child’s clinical course.<sup>20,23</sup>

Opportunities have emerged in response to the reduced availability of traditional care. Many successful virtual therapy

experiences were described in the open-ended responses. Several caregivers reported feeling equipped to manage virtual therapies at home by their history of witnessing and participating in-person, which may have contributed to resiliency during a period of decreased or changed access to care. Bertamino et al.<sup>23</sup> reported that when parents were empowered to maintain or increase therapeutic activity hours per week at home, they perceived a stabilization or improvement in their child’s well-being, regardless of the modality or length of therapist supervision. This points to a key role for patient and caregiver involvement in therapies.

Caregivers often expressed concern that changing to on-line delivery of needed services and treatments would negatively impact their children’s physical condition and mental well-being, as well as their own ability to balance family responsibilities with the child’s needs while meeting financial obligations. These concerns have been echoed in other surveys of the impact of the COVID-19 pandemic on caregivers.<sup>18</sup> Many caregivers in this study perceived adverse mental health impacts on themselves and their children and shared their experiences of increased burden and stress. Some of these mental health impacts were associated with reduced access to therapies. An Australian survey of families of children with disabilities found that 50% reported mental health declines in either themselves (the family member) or the child with disability, with similar numbers (49%) reported in the European Academy of Childhood Disability survey relating specifically to the child.<sup>20,25</sup> In the European Academy of Childhood Disability survey, 69% reported very high family burden, similar to this study.<sup>20</sup> As children with disabilities and their caregivers are found to have higher incidence of mental health concerns in general,<sup>14,15,26</sup> increased support will be needed both during and after the pandemic to mitigate this effect.

However, many caregivers also expressed positive aspects of their caregiving experience, including supportive family members, reliable access to telehealth therapies, and personal skills to manage therapy at home. These positive experiences and perceptions may have enhanced caregiver and/or child resiliency and lessened negative outcomes during disruptions in care. Past studies that explored quality of life of caregivers suggest that quality of life and coping are enhanced by support



received from family, community, and providers, as well as general family function and stress management strategies.<sup>27,28</sup>

Responses to this survey and similar surveys globally suggest that available resources (e.g., telehealth, virtual support, governmental guidance, etc.), although helpful, were not sufficient to mitigate the detrimental impact of the first few months of the COVID-19 pandemic on children with motor impairment and their caregivers.<sup>20,23,25</sup> There was mixed satisfaction regarding alternative treatment delivery, with lower satisfaction when a recent change in health status or a decrease in hours of treatments occurred. Qualitative responses expanded on the challenges and limitations of telehealth services, including developmental challenges, limits to types of treatment available virtually, and the need for increased caregiver involvement. Although many caregivers expressed interest to quickly return to in-person care, others appreciated aspects of telehealth and hoped for its continuation. It is likely that telehealth, spurred into growth by the pandemic, will continue to expand.<sup>10</sup> Future studies should specifically investigate caregiver and child preferences for telehealth in all types of rehabilitation therapies, to design and implement telehealth systems and interventions that maximize satisfaction and effectiveness.

## Study Limitations

This survey was created and distributed in rapid response to the COVID-19 pandemic. As such, detailed information regarding participant demographics and treatment characteristics were not included in the survey to obtain a greater number of responses and minimize time burden on participants. Data were obtained at only one time point and any comparisons to status before the pandemic may have been subject to recall bias. As this was a cross-sectional study, changes to the children's well-being were based on the caregiver's perceptions and were not validated by examination. Without a comparison group, it is unknown whether some functional losses may have occurred in the absence of the pandemic. This survey had a limited response rate and cannot be assumed to represent all children and families' experiences in the Midwest United States but does importantly reflect a variety of family experiences and various approaches to rehabilitation during the first few months of the pandemic. As evidenced by the quantitative survey results and themes, caregivers were experiencing high burden and expansion of caregiving roles during this time period, which may have contributed to a lower response rate. This survey captures only the caregiver's perspective of the impact of the pandemic on their child; future work should also assess the child's perception of the impact of the pandemic. In addition, this survey reflects primarily outpatient, home care, and school-based services; acute and inpatient rehabilitation services are likely to be differently impacted by COVID-19.<sup>29</sup> Because of the timing of this survey, it is possible that some children would have experienced a reduction in therapies in a nonpandemic year as well, with some school-based services ending for the summer. However, the open-ended responses confirm that many families experienced a marked and unexpected disruption to therapies, which would not be explained by the ending of the school year. Finally, although survey participants reported varied races and ethnicities, Black children/caregivers in particular were underrepresented in the survey responses and there was not sufficient

representation of all racial/ethnic groups to assess potential disparities in impact. Black, Latinx, and Native American children are more likely to have reduced access to health care in the United States, and these groups are also disproportionately impacted by COVID-19.<sup>30</sup> The specific impact of the pandemic on access to therapies in underrepresented racial and ethnic groups should be a topic for future studies.

## CONCLUSION

Caregivers of children with motor impairment reported significant disruptions to their child's therapy services owing to the COVID-19 pandemic, with impact on child and caregiver well-being. The long-term consequences of decreased access to rehabilitation therapies are unknown, but it is clear that rehabilitation providers must act, with the input and feedback of children and caregivers, to be responsive to the experience of families during the COVID-19 pandemic and to optimize healthcare systems for future access challenges. Despite the challenges presented during the pandemic, the study findings affirm the value of rehabilitation therapies to children and their families and present an opportunity to improve delivery of remote care and support.

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