How Did the Lockdown Imposed Due to COVID-19 Affect Patients With Cerebral Palsy?

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Background: The novel coronavirus infection (SARS-CoV-2) caused disruption of the treatment and follow-up evaluations of children with cerebral palsy.

Aim: The change in mobility, pain, functional status, and spasticity was investigated who were followed in a pediatric rehabilitation unit after the lockdown.

Methods: One hundred ten children were evaluated. Pain, severity of spasticity, botulinum toxin administration dates, and continuity of home exercises were recorded. The functional status was evaluated with the Functional Independence Measure for Children (WeeFIM).

Results: The WeeFIM self-care and mobility subscale scores and total scores were significantly worse. Only 5 of the participants had pain in the previous evaluations; in the last evaluation, 29 had pain complaints. The pain and spasticity severity of the participants whose botulinum toxin administration was delayed were significantly increased.

Conclusions: The children with cerebral palsy should be followed with telemedicine at short intervals, and when necessary, in the hospital. (Pediatr Phys Ther 2021;33:246–249)

Key words: cerebral palsy, COVID-19, function, lockdown, pain, spasticity

INTRODUCTION

Cerebral palsy (CP) is the most common motor disability of childhood.1 Most individuals with CP continue lifelong physical therapy and routine follow-up evaluations.2 In addition, some need botulinum toxin injections at intervals of 3 to 6 months due to spasticity.3

The novel coronavirus (SARS-CoV-2) infection affected health systems throughout the world, making it difficult for children to access health care services. The collateral damage of this lack of access is not yet known. In Turkey, a lockdown was imposed for people older than 65 years and younger than 18 years between April and June 2020. During the lockdown, children in these age groups faced an interruption of their ongoing care. Although community-dwelling individuals with disability were given special permission to go out, physical therapy and rehabilitation services were disrupted because of the fact that individuals with disability and their caregivers did not want to go to hospitals, and because physiatrists, physical therapists, and technicians were shifted to pandemic duties.4 Some who required botulinum toxin could not receive their injections, and those who required surgery had their operations postponed. In addition, the closure of schools and physical therapy centers during the lockdown prevented children with CP from engaging in social interactions.

The current study determined changes in mobility, pain intensity, functional status, and spasticity of children with CP who were followed at a pediatric rehabilitation unit in a tertiary university hospital from April to June 2020, during the lockdown.

MATERIALS AND METHODS

One hundred ten children with CP who have been followed at our university hospital pediatric rehabilitation unit from July to September 2020 were included in the study. Children who attended a first-time appointment during this period were excluded. All assessments of the children recorded in the prepandemic period were retrieved from the hospital’s electronic database. Detailed physical examinations were performed by one experienced physical medicine and rehabilitation specialist and all children were examined by the same examiner.
The participants Gross Motor Function Classification System (GMFCS) of the children were recorded. The date of the most recent injection were recorded for children with spastic CP who required regular botulinum toxin administration, and spasticity was assessed using the Modified Ashworth Scale (MAS). The MAS is a valid and reliable tool to measure the increase of muscle tone. In this scale, spasticity is graded by scores ranging from “0” to “4” according to the amount of resistance the muscle shows during passive stretching. Whether the children had pain was questioned, and the severity of pain was evaluated using the visual analog scale (VAS) in children with pain. Children were asked about the presence of pain and its severity. For the participants who were unable to respond or had intellectual disability, the caregiver’s response was recorded. The Functional Independence Measure for Children (WeeFIM) was used for functionality assessment. The WeeFIM is an adaptation of the Functional Independence Measure (FIM) developed for adults. It is a useful, short, comprehensive measurement tool that detects developmental, educational, and social functional limitations of children with CP and other developmental disorders. The WeeFIM consists of 18 items in 6 domains: self-care, sphincter control, transfers, mobility, communication, and social cognition. The child’s functional independence in these areas is scored from 1 to 7 points according to the level of assistance received; 1 point indicates that the child performs a specific task with help and 7 points denote complete independence doing the task at the appropriate time and safely. A child can receive a minimum of 18 points (fully dependent) and a maximum of 126 points (fully independent). Reliability, validity, and responsiveness to change of the WeeFIM have been shown. In addition, the caregivers were asked whether there were hospital admissions during that period and about their child’s adherence to the home exercise program.

The study protocol was approved by the Ethics Committee of Istanbul Medeniyet University Health Sciences (2020/0548). Written consent was obtained from the caregivers before the study.

Statistical Analysis
Statistical analyses were conducted using the Statistical Package for the Social Sciences Version 22.0 (IBM Corp, Chicago, Illinois). Pre-/postlockdown demographic and clinical data were compared and descriptive statistics were summarized as mean ± standard deviation or minimum-maximum values for continuous variables and frequency values (number of cases) and percentages for categorical variables. For a continuous variable, statistically significant differences between measurements from 2 different periods in the group were determined using the Student t test for the relevant sample. Wilcoxon signed rank test was used in cases in which the assumptions of normality were violated. Student t test and Wilcoxon signed rank test results were analyzed with statistical significance set at \( \alpha \) value of less than 0.05 at 95% confidence interval.

RESULTS
The mean age of participants was 6.9 years (SD: 3.88 minimum: 1, maximum: 18). Demographic data are shown in Table 1. Adherence to home exercise programs during 2 months of lockdown is shown in the Figure. The functional status of the children before and after the lockdown was compared using the WeeFIM Scale. The comparison results are shown in Table 2. While only 5 (4.5%) of the children had pain in prelockdown assessment, 29 (26.4%) had pain complaint after lockdown. Among 29 children in whom pain was reported after the lockdown, 20 (82.8%) were pain-free before the lockdown. The average VAS score of children with pain was 4.27. The mean MAS score was 2.79 (SD: 0.61). Nine children (31%) reported that they could not continue their exercises at home and 13 (44.8%) could continue only partially due to pain. Fifty-five children (50%) were those who were administered regular botulinum toxin injections. Among them, 23 were scheduled to have botulinum toxin injections but their appointments were postponed because of the pandemic. Table 3 shows the changes in the severity of spasticity, pain, and functional status before and after the lockdown in children who could not receive botulinum toxin injections on time due to the pandemic.

Table 1: Demographic Characteristics

| CP subtype         | n | %    |
|--------------------|---|------|
| Spastic unilateral | 16| 14.5 |
| Spastic bilateral  | 80| 72.7 |
| Dyskinetic         | 8 | 7.3  |
| Ataxic/hypotonic   | 6 | 5.5  |

Gender

|    | n | %    |
|----|---|------|
| Female | 40 | 36.4 |
| Male   | 70 | 63.6 |

GMFCS

|    | n | %    |
|----|---|------|
| I   | 1 | 0.9  |
| II  | 29| 26.4 |
| III | 31| 28.2 |
| IV  | 15| 13.6 |
| V   | 24| 21.8 |

Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

TABLE 1
Demographic Characteristics

Table 1. Adherence to home exercise programs during 2 months of lockdown is shown in the Figure. The functional status of the children before and after the lockdown was compared using the WeeFIM Scale. The comparison results are shown in Table 2. While only 5 (4.5%) of the children had pain in prelockdown assessment, 29 (26.4%) had pain complaint after lockdown. Among 29 children in whom pain was reported after the lockdown, 20 (82.8%) were pain-free before the lockdown. The average VAS score of children with pain was 4.27. The mean MAS score was 2.79 (SD: 0.61). Nine children (31%) reported that they could not continue their exercises at home and 13 (44.8%) could continue only partially due to pain. Fifty-five children (50%) were those who were administered regular botulinum toxin injections. Among them, 23 were scheduled to have botulinum toxin injections but their appointments were postponed because of the pandemic. Table 3 shows the changes in the severity of spasticity, pain, and functional status before and after the lockdown in children who could not receive botulinum toxin injections on time due to the pandemic.

Fig. Home exercise program compliance among the study participants. This figure is available in color online (www.pedpt.com).
TABLE 2
WeeFIM Scores Before and After the Lockdown

| Tests          | Before | After | Z     | P     |
|----------------|--------|-------|-------|-------|
|                | Mean   | SD    | Mean  | SD    |       |
| WeeFIM self-care | 22.91  | 15.69 | 22.76 | 15.73 | 3.17a | <.01  |
| WeeFIM mobility  | 15.25  | 10.31 | 14.60 | 10.38 | 6.76b | <.001 |
| WeeFIM cognition | 22.37  | 11.35 | 22.35 | 11.34 | 1.00  | >.05  |
| WeeFIM total    | 60.45  | 33.43 | 59.63 | 33.48 | 6.23b | <.001 |

Abbreviation: WeeFIM, The Functional Independence Measure for Children.

aStatistically significant at the level of P < .01.
bStatistically significant at the level of P < .001.

DISCUSSION

The COVID-19 pandemic affected health care systems worldwide including physical medicine and rehabilitation practice. In response to pandemic, pediatric rehabilitation is challenged to put in practice new, innovative ways to assist the child and the family in their adjustment to the child’s disability. During the lockdown period in Turkey, children were able to access hospitals in emergency situations but hesitated to be admitted to health centers due to their fear of contracting COVID-19 even if they had functional deterioration. Thus, treatment and routine follow-up evaluations of children with CP were interrupted. Although efforts were made to continue physical therapy and rehabilitation of the children with home exercise programs, 1 of 4 children did not even partially comply with prescribed exercise. Children are less active, their sleep patterns are disrupted, they eat unhealthy foods, and the time they spend in front of TV increases in a pandemic. This indicates the need to implement a monitoring mechanism for tracking adherence to the exercise programs. Telerehabilitation programs may be useful in this regard.

Significant worsening was found in the functional and pain status of the children who stayed at home during the lockdown period (except for cognitive function) as evidenced by VAS, WeeFIM, and MAS scores. Most of the children with pain had increased spasticity, and this may have contributed to the deterioration of their overall functional status. As with all participants, a significant deterioration was also observed in their functional status. This finding may indicate that continuous active stimulation is crucial and, to ensure the continuity of the care, is equally important to avoid worsening of the child’s condition.

Half of the participants had spastic CP and needed regular botulinum toxin injections. When left untreated, spasticity gives rise to many problems such as contracture, spasms, deformity, and pressure sores on the skin, which are very painful, all associated with impaired quality of life and functional deterioration. Children with spastic CP require periodic access to health care facilities. To maintain the clinical effect of the botulinum toxin, it should be applied regularly, every 3 to 6 months. During the COVID-19 pandemic, various guidelines were published for the treatment of spasticity. It was suggested that the outpatient care should be delayed as much as possible, and only those individuals who require very urgent intervention such as intrathecal baclofen refill should be referred to health centers. Some children were recommended to be evaluated in the hospital. These children had severe pain, hypertonicity, or spasticity that may impair their function or autonomy, or prevent the use of orthoses, a high risk for potential functional deterioration, and the last botulinum toxin injection administered more than 3 months previously. According to a Canadian task force, spasticity clinics should not be canceled, and telemedicine can be used only for short term in the assessment.

A recent study highlighted the key role of caregivers who encouraged their child to be more active. The pediatric population and their caregivers may have greater anxiety than adults. As pediatric practitioners, we need to communicate more frequently with children and their families and provide reassurance during this period.

Limitations of this study are the small sample size and the lack of reported data on other spasticity interventions such as systemic antispasticity agents or intrathecal baclofen.

TABLE 3
Comparison of Assessment in Children With Delayed Botulinum Toxin Administration Before and After the Lockdown

| Tests          | Before | After | Z     | P     |
|----------------|--------|-------|-------|-------|
|                | Mean   | SD    | Mean  | SD    |       |
| Pain           | 0.09   | 0.29  | 0.45  | 0.50  | −3.46a| <.01  |
| MAS            | 1.72   | 0.55  | 2.50  | 0.59  | −5.92b| <.001 |
| WeeFIM self-care | 23.81  | 16.65 | 23.59 | 16.68 | 2.01  | >.05  |
| WeeFIM mobility | 15.09  | 11.10 | 14.79 | 10.94 | 3.52a | <.01  |
| WeeFIM cognition | 24.09  | 10.06 | 24.09 | 10.94 | …     | …     |
| WeeFIM total   | 63.00  | 34.62 | 62.13 | 34.64 | 3.60a | <.01  |

Abbreviations: MAS, Modified Ashworth Scale; WeeFIM, The Functional Independence Measure for Children.

aStatistically significant at the level of P < .01.
bStatistically significant at the level of P < .001.
Considering the deterioration of function and increased spasticity and pain in our participants with CP, it seems clear that in this period of uncertainty, children need more reassurance than ever before and we should follow them remotely as often as possible or, when necessary, see them at the hospital.

CONCLUSION

The home exercise program compliance during the pandemic among the study participants was not at the desired level. Isolation at home contributed to the deterioration of their functional status and an increase in spasticity and pain. During a lockdown, children with CP should be followed via telemedicine more frequently, whenever possible.

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