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MEDICAL SCIENCES / DAHİLİ TIP BİLİMLERİ

Access of Children with Cerebral Palsy to Rehabilitation and Special Education Services During the COVID-19 Pandemic

COVID-19 Pandemi Sürecinde Serebral Palsili Çocukların Rehabilitasyon ve Tedavi Hizmetlerine Ulaşımlarının Değerlendirilmesi

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Abstract

Objectives: Prohibitions and precautions implemented due to the coronavirus disease-2019 (COVID-19) pandemic have disrupted children with cerebral palsy (CP) from accessing special education, rehabilitation and medical care. This study aimed to determine the changes and problems of children with CP regarding health and special education due to the COVID-19 pandemic.

Materials and Methods: Hundred children were included with CP who were followed up with a diagnosis of CP in the Ankara University Faculty of Medicine, Department of Physical Medicine and Rehabilitation, Pediatric Rehabilitation Unit. Hundred patients aged 0-18 years, who accepted to participate, were included between January 1, 2021 and January 31, 2022. Afterwards, questions were asked to the parents within the scope of the questionnaire consisting of 25 open- and close-ended questions.

Results: Hundred children with CP [47 female, 53 male; mean age 7.4 (2-16 years)] were included. It was determined that 19% of children had COVID-19 infection and only 2 children had impaired functional status. It was determined that 38% of children could not continue special education, but 81% could go to regular outpatient clinic control. It was observed that 31 (31%) children needed botulinum toxin injection and only 17 children were injected. It was noted that 92% of the participants had internet access at home, but only 2 (2%) had knowledge about telemedicine or telerehabilitation. In this process, it was seen that 44% of the participants continued their home exercises every day and 30% of them performed more than 3 days a week.

Conclusion: It was determined that, pediatric patients with CP who needed special education and rehabilitation were affected due to the COVID-19 pandemic. Difficulty in accessing interventional procedures such as botulinum toxin injection, special education services and the use of telerehabilitation were identified as the most affected areas. This pandemic has taught us that we should include alternative approaches such as telemedicine and telerehabilitation in the rehabilitation program to minimize these effects.

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

Öz

Amaç: Koronavirüs hastalığı-2019 (COVID-19) pandemisi nedeniyle uygulanan önlemler serebral palsili (SP) çocukların özel eğitim, rehabilitasyon ve tıbbi tedavilere erişimlerinde kesintilere neden olmuştur. Bu çalışmada, COVID-19 pandemisi nedeniyle SP'li çocukların ve ailelerinin, sağlık ve eğitim ile ilgili yaşadıkları değişimleri ve sorunları belirlemek amaçlanmıştır.

Gereç ve Yöntem: Ankara Üniversitesi Tıp Fakültesi Fiziksel Tıp ve Rehabilitasyon Anabilim Dalı Pediyatrik Rehabilitasyon Ünitesi'nde SP tanısı ile izlenen 100 SP'li çocuk dahil edilmiştir. Açık ve kapalı 25 sorudan oluşan anket formu ile 1 Ocak 2021-31 Ocak 2022 arasında değerlendirme yapılmıştır.

Bulgular: Çocukların 47'si kız, 53'ü erkek olup ortalama yaş 7,4'tür (2-16 yaş). SP tiplerine göre dağılımları ise; %30'u hemiplejik, %49'u diplejik ve %21'i tüm vücut tutulumlu şeklindeydi. SP'li çocukların %19'unun COVID-19 enfeksiyonu geçirdiği ve sadece 2 tanesinin fonksiyonel durumunda bozulma olduğu görüldü. SP'li çocukların %38'i pandemi sürecinde özel eğitime devam edememiştir, buna karşılık %81'inin düzenli fiziksel tıp ve rehabilitasyon polikliniği kontrolüne gidebildiği saptanmıştır. Otuz bir hastanın pandemi sürecinde botulinum toksin enjeksiyonu ihtiyacının

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Öz

olduğu ve yalnızca 17 hastaya botulinum toksin enjeksiyonu yapıldığı görülmüştür. Katılımcıların %92'si evinde internet erişimi olduğunu, ancak katılımcılardan sadece 2 tanesinin (%2) teletıp veya telerehabilitasyon konusunda bilgi sahibi olduğu dikkat çekmiştir. Bu süreçte %68 hastanın evde egzersizlerinin yaptırıldığı ve bu hastaların %44'ünün her gün, %30'unun ise haftada 3 günden fazla ev egzersizlerine devamlılık sağladığı görülmüştür.

Sonuç: COVID-19 pandemisi nedeniyle tüm hasta grupları gibi özel eğitim ve rehabilitasyon ihtiyacı duyan SP'li çocuk yaş grubu hastaların da etkilendiği saptanmıştır. En sık etkilenen alanlar olarak; özel eğitim hizmetleri, botulinum toksin enjeksiyonu gibi girişimsel işlemlere ulaşımda güçlük ve telerehabilitasyon uygulamalarının yaygın olarak kullanılmadığı saptanmıştır. Günümüzde teknolojideki gelişimler, birçok medikal alanda kullanılmaktadır, bu pandemi nedeniyle görüyoruz ki teknolojideki bu gelişimleri teletıp ve telerehabilitasyon alanlarına uyarlayarak rehabilitasyon programlarına daha sık dahil etmeliyiz.

Anahtar Kelimeler: Serebral Palsi, COVID-19, Rehabilitasyon, Telerehabilitasyon, Teletıp

Introduction

Cerebral palsy (CP) is a group of disorders affecting the development of movement and posture, causing activity limitation (1). It is the most common cause of childhood disability. In Türkiye the prevalence was reported to be 4.4 per 1000 live births (2). The aim of the clinical management of children with CP is to maximize functions and participation in activities and community and prevent or minimize the occurrence of CP complications such as joint contracture, delay surgical interventions as much as possible, and provide new skills appropriate for the child's age and functional status. In our country, rehabilitation services for children with CP are carried out in hospitals and private physical therapy centers special education institutions.

The novel coronavirus disease-2019 (COVID-19) outbroke in December 2019 in Wuhan, China. It was declared a pandemic by the World Health Organization on March 11, 2020, with its rapid spread all over the world. COVID-19 is less severe among children compared to adults, and most of children are diagnosed with asymptomatic or mild disease (3,4). However, 6.7% patients may show severe disease, especially the ones with comorbidities such as neurological disorders (5). Due to the lack of effective vaccination protocols or effective antiviral therapies, strict public health precautions such as social isolation are the most effective means of reducing cases and deaths in most countries (6).

The importance of rehabilitation for patients with chronic neurological disease has been emphasized in many articles (7,8). However, due to the pandemic, these activities had to be suspended. The CP rehabilitation team is also at risk of contamination, as other health care professionals. During this period, disruptions occurred in the routine rehabilitation services of the patients. It is thought that there may be problems such as lack of access to rehabilitation, inability to renew existing assistive devices or prescribe a new device, inability to perform botulinum toxin A injection or prescribe oral anti-spasticity medicines. Because most of the physical medicine and rehabilitation clinics were closed and turned into COVID-19 clinics, the teams are also involved in the filiation groups or in the direct follow-up of COVID-19 patients. In addition, special education institutions were closed during this period. Both the changes in rehabilitation services and the problems experienced by the patients and their families during the pandemic period (not being able to leave the house, etc.) can cause complications such as soft tissue problems and bone deformities, and regression in motor skills. Suggested model of rehabilitation approach during social isolation period is telerehabilitation; where rehabilitation professionals interact with patients remotely via telecommunication devices to provide rehabilitation assistance (9).

Telemedicine or telerehabilitation is an new and challenging method for many healthcare professionals around the world. In our country, telerehabilitation applications have started to be implemented, albeit limited, in this period.

Despite the importance of social isolation in both control strategies for pandemic and protection of at-risk groups, it negatively affects the biopsychosocial life of the pediatric population with chronic neurological disease. Due to isolation, these patients may have problems in accessing special education, rehabilitation or medical treatments.

There is few studies examining the rehabilitation process during the COVID-19 pandemic in the 0-18 age group with a diagnosis of CP (10-15). In the studies conducted, the rates of COVID-19 infection of children with CP during the lockdown period, the possibilities of reaching special education or hospitals, and the use of telemedicine and telerehabilitation facilities were investigated. Most of these studies cover the 3-month period in the lockdown period. We planned this study to evaluate the situation in our own clinic due to the feedback and demand from the patients we followed up during pandemic,

to investigate the situation in a year when the number of cases was the highest, and to contribute to the literature.

This study aimed to determine the changes and problems of children with CP and their families regarding health and special education due to the COVID-19 pandemic.

Materials and Methods

Children who were followed up in Pediatric Rehabilitation Unit of Physical Medicine and Rehabilitation Department, Ankara University Faculty of Medicine with the diagnosis of CP were invited to participate in the study. Hundred patients aged 0-18 years, who accepted to participate, were included between January 1, 2021 and January 31, 2022. This research was conducted within the scope of good clinical practice. The research was carried out with the decision of Ankara University Faculty of Medicine, Human Research Ethics Committee numbered İ2-128-21, and dated 19.02.2021.

The patients who accepted to participate were informed about the study and invited after routine outpatient control examinations. Afterwards, questions were asked to the parents within the scope of the questionnaire consisting of 25 open- and close-ended questions (SEÖT, MT, ŞK, BST). The survey was administered only once. The interview took about 15 minutes.

Questionnaire consists of 5 main headings;

1. Special education, physical medicine and rehabilitation outpatient follow-up, home exercises programme,
2. Medical treatment, injection, supplemental vitamin,
3. Assistive device,
4. COVID-19 infection assessment,
5. Internet access at home, telemedicine and telerehabilitation.

Inclusion Criterias

Patients with CP aged 0-18 years who applied to Ankara University Faculty of Medicine physical medicine and rehabilitation, Pediatric Rehabilitation Unit and volunteered to participate in the study and/or their parents reported.

Exclusion Criterias

Those who did not volunteer to participate in the study.

Statistical Analysis

Statistical analysis was performed using the R Statistical Software version 3.6.2 (R Statistical Software, Institute for Statistics and Mathematics, Vienna, Austria) was used in the analysis of the data. While descriptive statistics were used for demographic data (mean ± standard deviation), percentage distribution was used in the answers to the questionnaire questions.

Results

A total of 100 children, 47 female and 53 male, with a diagnosis of CP, aged 0-18 years, with a mean age of 7.4 (2-16 years), were included in the study. Thirty (30%) of the children included in the study were hemiplegic type CP, 49 (49%) diplegic type CP, and 21 (21%) had quadriplegic CP. The characteristics of the children showing age, gender and type of involvement are presented in Table 1.

The evaluation results of the patients for COVID-19 infection are presented in Table 2.

During the pandemic, %38 of children with CP could not continue special education. The most common reason for this was stated as the closure of special education centers. On the other hand, it was determined that 81% of the participants were able to go to regular physical medicine and rehabilitation outpatient clinic control. Most of the children who use regular medicine (36%) did not have any problems in the supply of drugs because they could buy drugs directly by applying to the pharmacy. It was determined that 28 (28%) children using anti-epileptic drugs used their drugs without stopping, and 1 child did not use anti-spastic drugs. Sixty-seven (67%) children used assistive devices for resting and walking, 36 (53.7%) renew their orthosis, and the majority (78.4%) had no problems with orthosis replacement. It was observed that 31 children needed botulinum toxin A injection during the pandemic and only 17 children were given botulinum toxin A injections. It was determined that 21 children could not use a face mask due to being restless and crying.

Table 1: Demographic information of the participants (n=100)

Age (years) [mean (min.-max.)]		**7.4 (2-16)**
Gender n (%)	Female Male	47 (47%) 53 (53%)
CP type n (%)	Hemiplegic	30 (30%)
	Diplegic	49 (49%)
	Quadriplegic	21 (21%)

min.-max.: Minimum-maximum, CP: Cerebral palsy

Table 2: Assessment for COVID-19 infection

	Yes n (%)
Have you had a COVID-19 infection?	19 (19%)
Has there been any deterioration in functional status after COVID-19 infection?	2 (10.5%)
After the COVID-19 infection was over, was she/he able to return to her/his old rehabilitation program?	17 (89.5%)
Have family members had COVID-19 infection?	52 (52%)

COVID-19: Coronavirus disease-2019

Although 92% of the parents stated that they had internet access at home and 76% used the internet for their child with CP, only 2 (2%) of the parents were found to have knowledge about telemedicine or telerehabilitation and 2% of the families participated in the telerehabilitation program.

In this process, it was stated that 68% of the children continued to exercise at home, and 44% did home exercises every day, and 30% did more than 3 days a week.

Discussion

The COVID-19 pandemic has caused social, economic, physical and psychological changes in the all the people. During this period, it was observed that children with CP who needed special education and rehabilitation were affected as well as all people. During the isolation period, when full lockdown is experienced, they were restricted from going to special education and routine outpatient clinic control. Since special education centres were closed between March 16 and June 15, 2020 in our country, children with CP could not continue special education for about 3 months. With the measures taken later, most of the children attended special education regularly. It has also been observed that most of the children do the regular home exercise program under the supervision of their families.

In this study, it was observed that children with CP had a lower rate of COVID-19 infection during the pandemic. Other family members, on the other hand, had a higher rate of COVID-19 infection. Most children with CP who had COVID-19 infection were able to return to their old rehabilitation program after infection. In the study conducted by Karbuz et al. (16), covering pediatric cases between March 16 and June 15, 2020, it was determined that there were 1156 pediatric patients with COVID-19 infection, and the mean age of these children was 10.75.

In the study conducted by Akpinar et al. (10), COVID-19 infection was detected in the immediate family members, coworkers and relatives of 39 families, and the father in one family had COVID-19 infection. Cankurtaran et al. (14) found that 5 (5.3%) children and 13 (13.8%) caregivers had of COVID-19 infection. We think that children with CP have a lower incidence of COVID-19 infection, as their social contacts are restricted more than other individuals during the pandemic. In the study conducted by Capan et al. (17), in which 309 children with CP, spina bfida and neuromuscular disease diagnoses were included, 2 (0.6%) children diagnosed with Angelman Syndrome and Becker Muscular Dystrophy had COVID-19 infection.

In our hospital, which provides tertiary health care, regular follow-up of children with CP was continued during the pandemic. Thanks to the arrangements made for the direct supply of the prescribed drugs from the pharmacy, most of the patients using regular drugs had no difficulty in obtaining their drugs. Compared to their access to oral medical treatments, they had difficulty accessing treatments such as botulinum toxin A injection. Botulinum toxin A injections are performed under anesthesia in operating rooms; during the pandemic, the number of these procedures has been reduced as there is a risk of infection, so their access to these treatments has decreased.

Akpinar et al. (10), in their study between 28 May and 26 June 2020, found that 42 (20.4%) children postponed their routine outpatient clinic appointments and 26 (12.6%) children postponed their botulinum toxin A injection appointments, but all children took antiepileptic and antispastic drugs. Twenty-three (11.2%) children did not exercise at home during the pandemic, 86 (41.7%) children performed a regular home exercise program (at least 3 days a week, 30 minutes), while 97 (47.1%) children applied the home exercise program irregularly (10).

In another study, it was found that 63 (67.1%) children did not come to their routine control during the pandemic and 9 (9.6%) children were injected with botulinum toxin A. Thirty-two (34%) children continued their routine physical therapy sessions, and 50 (53.2%) children continued their routine physical therapy sessions despite taking a break between March 2020 and November 30, 2020. Twelve children stopped attending physical therapy sessions (14).

It was reported that 247 (80%) children had scheduled physical medicine and rehabilitation outpatient clinic appointments during the lockdown period, but only 14 (6%) of them showed up for their appointment, 172 (70%) children's families did not prefer to go to the hospital by Capan et al. (17). It was determined that 24% of children's appointments were canceled because physical medicine and rehabilitation physicians were assigned to COVID-19 clinics. It was observed that 94% of the children in this study could not attend the planned special education and speech language therapy sessions, 12 children could attend the telerehabilitation sessions, and 2 children continued the exercise program at home with a physiotherapist. Seventy three (25%) of the families and caregivers reported that they did not apply home exercises, 49 (17%) reported that they continued home exercises but they did not find it sufficient. Botulinum toxin A injection was administered to 91 of 137 children with CP in this study before the pandemic and re-injection was planned for 44 children during the pandemic, but 40 (91%) children could not be injected. As the reasons for this situation; It was observed that families did not prefer to go to the hospital during the pandemic (74%), appointments were delayed (10%) due to changes in the health system, families could not get an appointment (8%) or personal reasons (8%) (17).

In these studies, it was thought that most of the children could not go to the routine outpatient clinic control because the

evaluation was made during the full lockdown period. Although our study also covers the lockdown period between March-June 2020, since we evaluated a one-year period between January 1, 2021 and January 31, 2022, the rates of attendance to routine outpatient clinic control and special education were found to be higher.

It has been observed that most of the children using orthoses continue to use the device and have no problems with device replacement. In the study of Cankurtaran et al. (14), it was found that 29 (30.9%) children did not continue to use orthoses during the pandemic.

Since the COVID-19 pandemic occurred unexpectedly and suddenly, of course, it effected the entire health system, including rehabilitation practices. During the pandemic, the field of pediatric rehabilitation had to find new and creative applications such as telemedicine and telerehabilitation to support children with CP and their families. There are studies showing the positive effects of telerehabilitation in patients with CP during the COVID-19 pandemic. Cristinziano et al. (18) found that telerehabilitation had a positive effect on gross motor function and stated that could help the patient or caregiver to acquire skills in performing home exercises. Celikel et al. (19) found that motor learning-based telerehabilitation had positive effects on quality of life. According to these studies telerehabilitation can be considered an effective tool that can temporarily replace the in-person therapy especially during situations like COVID-19 pandemic.

In this study and other studies, it has been emphasized that health services can be continued with telemedicine and telerehabilitation applications in situations that require social isolation such as the COVID-19 pandemic (11,15). However, in our study, we found that only 2% of their families have knowledge about telemedicine or telerehabilitation and participated in the telerehabilitation program.

It was reported that 77% of children's examinations were canceled or postponed during the lockdown period of the COVID-19 pandemic in France between on 6-17 April 2020, it was determined that 77% of the children's medical consultations were canceled or postponed. It has been stated that 4% of ongoing medical consultations were conducted face-to-face, and 18% by telemedicine method (13).

In Italy, 5.9% of 68 children attended special education during the COVID-19 pandemic, 23.5% attended a structured telerehabilitation program, 42.6% attended the program directed by the physiotherapist by phone or video call, 16.1% continued home exercises only with family without supervision. It was found that 13.2% of them continued to exercise, and 13.2% left the exercise program completely (12).

In European data, we see that telemedicine applications are used more than in our country. As a result of our experiences from this pandemic, it is clear that telerehabilitation practices should be a part of rehabilitation programs in our country as well.

Study Limitations

Limitations of this study are; the sample size of the study is quite small and consists of children with CP followed in the university hospital. Therefore, the findings cannot be generalized to all children with CP in our country. Secondly, the information of the families of the children included in the study was not evaluated.

Conclusion

In conclusion, although there were some limitations in accessing health services during the COVID-19 pandemic, it was determined that the most basic problem was that children with CP could not continue special education and that telerehabilitation practices were not used enough in our country. Today, developments in technology are used in many medical fields. Due to this pandemic, we see that we should include these developments in technology more frequently in rehabilitation programs by adapting them to the fields of telemedicine and telerehabilitation. Thus, we can use telerehabilitation methods to maintain rehabilitation practices, especially during periods that require social isolation, such as pandemics. We suggest that future studies which evaluate the effects of telerehabilitation on motor functions and quality of life of children with CP could provide more information. And comparing the effects of telerehabilitation and face-to-face treatment could give further information about the rehabilitation of children with CP.

Ethics

Ethics Committee Approval: The research was carried out with the decision of Ankara University Faculty of Medicine, Human Research Ethics Committee numbered İ2-128-21, and dated 19.02.2021.

Informed Consent: The patients who accepted to participate were informed about the study and invited after routine outpatient control examinations.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Concept: S.E.Ö.T., Y.G.S., M.T., B.S.T., Ş.K., Design: S.E.Ö.T., Y.G.S., M.T., B.S.T., Ş.K., Data Collection and Processing: S.E.Ö.T., Y.G.S., M.T., B.S.T., Ş.K., Analysis or Interpretation: S.E.Ö.T., Y.G.S., M.T., B.S.T., Ş.K., Literature Search: S.E.Ö.T., Y.G.S., M.T., B.S.T., Ş.K., Writing: S.E.Ö.T., Y.G.S., M.T., B.S.T., Ş.K.

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