

Telerehabilitation in Children with Disabilities in the COVID-19 Pandemic from the Perspective of Families and Clinicians: Review

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ABSTRACT

The COVID-19 pandemic has disproportionately affected specific groups since it first emerged. After the precautions were taken, individuals had to rearrange their daily lives and routines. Due to the higher incidence of COVID-19 disease among elderly individuals, children with disability, who are a vulnerable population, have not been the focus of discussions related to the pandemic. The rapid global spread of the COVID-19 pandemic has required education and health systems to develop new strategies and experience changes. In the health system, many institutions have switched to rapidly expanding telehealth infrastructure and applications. Telerehabilitation services for children with disability are an alternative to face-to-face clinical health services. Telerehabilitation has many advantages such as overcoming geographical barriers and reducing treatment costs, but it also has disadvantages such as low usage rate, low acceptance level by clinicians, and service payments.

Our study aims to review the problems and developed solutions for rehabilitation applications in children with a disability during the COVID-19 pandemic, to examine the telerehabilitation applications, which are widely used in the pandemic process, from the perspective of families and clinicians, and to summarize innovative approaches and strategies for clinicians and researchers working in the field.

Keywords: Child; COVID-19; telerehabilitation; family.

Ailelerin ve Klinisyenlerin Perspektifinden COVID-19 Pandemisinde Özel Gereksinimli Çocuklarda Telerehabilitasyon: Derleme

ÖZ

COVID-19 salgını, ortaya çıkışından bu yana belirli grupları orantısız bir şekilde etkilemiş, önlemler alındıktan sonra bireyler günlük hayatını ve rutinlerini yeniden düzenlemek zorunda kalmıştır. Yaşlı bireyler arasında COVID-19'un görülme sıklığının daha yüksek olması nedeniyle, savunmasız bir nüfus olan özel gereksinimli çocuklar, pandemi ile ilgili tartışmaların odak noktası olmamıştır. COVID-19 salgınının hızla küresel yayılması, eğitim ve sağlık sistemlerinin yeni stratejiler geliştirmesini ve değişiklikleri deneyimlemesini gerektirmiştir. Sağlık sisteminde birçok kurum hızla yaygınlaşan tele-sağlık altyapı ve uygulamalarına geçiş yapmıştır. Özel gereksinimli çocuklara yönelik telerehabilitasyon hizmetleri, yüz yüze klinik sağlık hizmetlerine alternatif bir yöntemdir. Telerehabilitasyonun coğrafi engellerin aşılması ve tedavi maliyetlerinin düşürülmesi gibi birçok avantajı vardır ancak düşük kullanım oranı, klinisyenlerin düşük kabul düzeyi, hizmet ödemeleri vb. gibi dezavantajları da mevcuttur. Çalışmamızın amacı, COVID-19 pandemisi sürecinde engelli özel gereksinimli çocuklarda rehabilitasyon uygulamalarına yönelik sorunları ve geliştirilen çözümleri derlemek, pandemi sürecinde yaygın olarak kullanılan telerehabilitasyon uygulamalarını aileler ve klinisyenler açısından incelemek ve alanda çalışan klinisyenler ve araştırmacılara yenilikçi yaklaşım ve stratejilerini özetlemektir.

Anahtar Kelimeler: Çocuk; COVID-19; telerehabilitasyon; aile.

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INTRODUCTION

Children with Disabilities in the COVID-19 Pandemic

The COVID-19 pandemic has disproportionately affected specific groups since it first emerged. Governments have taken restrictive precautions to stop the spread of the virus (1). After the precautions were taken, everyone had to rearrange their daily lives and routines (2). Due to the higher incidence of COVID-19 disease among elderly individuals, children with disability, who are a vulnerable population, have not been the focus of discussions related to the pandemic (3). It can be said that children with disability are among the groups most affected by the negativities in society from the beginning of the pandemic until today. Among the precautions, there are curfews, the closing of entertainment venues, closure of special education and rehabilitation centers among educational institutions (4). In addition, children with disability who need health services due to the physical distance precautions are encouraged to stay at home instead of visiting the hospital environment that may endanger them (5).

Coping with the effects of the COVID-19 pandemic

The rapid global spread of the COVID-19 pandemic has required education and health systems to develop new strategies and experience changes. As a result of the changes, children with a disability had to start distance education, to which they were not accustomed, to continue their educational activities. They have been faced with various negativities during distance education (Figure 1) (6). In the health system, many institutions have switched to rapidly expanding telehealth infrastructure and applications (7).

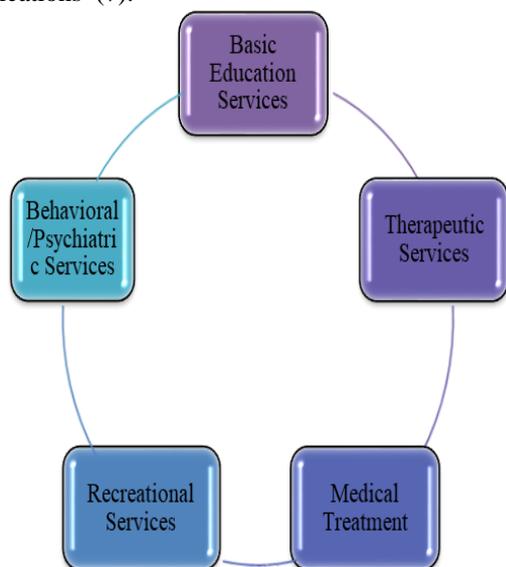


Figure 1. Services that children with disabilities cannot access and have difficulty accessing during the COVID-19 pandemic

Parental involvement is very important in pediatric rehabilitation compared to adult rehabilitation. According to our clinical observations, during the pandemic process, the parent's home-remote working processes overlapped with the care, care and rehabilitation processes of the children, resulting in a decrease in the interest in the child. We think that while the family's interest in telerehabilitation contributes positively to the satisfaction

and motivation of the parents, we think that it is a disadvantage that the sessions have to be determined according to the parent's suitability.

Telerehabilitation in Children with Disability

The World Health Organization defines telehealth, which translates to "healing at a distance," as the use of information and communication technologies for the prevention, diagnosis, treatment of illnesses and injuries, research, evaluation, and training of healthcare professionals in health services where accessibility is a key concern (8). Telehealth tools include computers, the internet (websites, blogs, and e-mails), live broadcast technologies (radio, television, and webcast), recorded broadcast technologies (podcast, audio and video players, and storage devices), and telephone (9). It provides synchronous (real-time) or asynchronous (forward to storage) audio-visual communication between healthcare professionals and patients (10). The continuity of treatment is guaranteed through the telerehabilitation service, which is defined as the delivery of rehabilitation services via telehealth (5). The telerehabilitation service in children with disabilities is aimed at maintaining the therapeutic alliance, providing parental coping strategies, helping maintain the routine, and to prevent functional deterioration (11). Telerehabilitation services for children with disability are thought to be as effective as face-to-face clinical health services due to their advantages such as overcoming geographical barriers and reducing treatment costs, but the low rate of delivery of this service, low acceptance levels of clinicians, and service payments reduce its availability (11,12).

In light of this information, our study is to review the problems and developed solutions for rehabilitation applications in children with disabilities during the COVID-19 pandemic, to examine the telerehabilitation applications that are widely used during the pandemic process, and to summarize innovative approaches and strategies for clinicians and researchers working in the field.

Solution-Focused Innovative Approaches in the Rehabilitation Process for Children with Disability

Services that children with disabilities cannot access and have difficulty accessing essential education services, medical treatment, physical therapy, speech therapy, occupational therapy, behavioral/psychiatric services (applied behavioral therapy, social skills, counseling), and recreational services during the COVID-19 pandemic (13). During the global COVID-19 pandemic, the importance of utilizing digital approaches to improve pediatric healthcare services has been emphasized more than ever. Considering the restrictions; limitations of face-to-face interviews have enabled many patients, families, and clinicians to realize the potential of these innovative approaches. Telemedicine/telehealth, web-based interventions, mobile applications and other new digital strategies are included in the scope of remote pediatric healthcare. Basically, these services can be defined under 3 headings (14).

1. Home-Based Family-Centered Applications
2. Mobile Applications
3. Hybrid Applications (Figure 2).

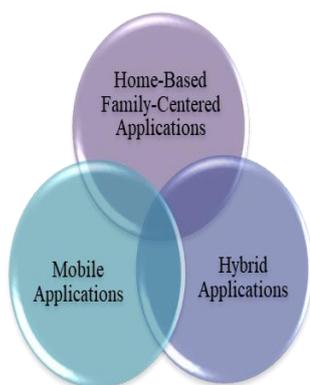


Figure 2. Remote pediatric healthcare during the global COVID-19 pandemic

The family-centered service approach, in which the physiotherapist and family members work as a team and design individualized assessment and rehabilitation programs, is one of the innovative approaches that can reach the broader masses in rehabilitation. Rehabilitation is carried out one-on-one or with smaller groups of participants through video-based platforms and using web-based applications such as mobile phones (smartphones), Zoom, Skype, and WhatsApp. Regular sessions by the physiotherapist provide guidance during interventions through video calls, recorded videos, relevant pictures, and written information to adjust parent practices and assess the child's progress. The benefits of family-centered telerehabilitation applications are discussed in terms of the children and the parents. In addition, family-centered telerehabilitation services contribute to assessment, coaching, communication, cooperation, and patient care thus supporting face-to-face rehabilitation services. In the study, which included 152 children with Duchenne Muscular Dystrophy (DMD), a video containing breathing exercises was shown to the child and their parents via teleconference. Parents were found to be highly satisfied with the method. The rate of participation in exercise has been reported as 83% (15). In the study conducted with 69 children with DMD, the exercises were presented as videos to the appropriate children after the evaluation, and the link containing the videos was shared with the families. 60-minute online workshops were organized for children and families. Videos were found more acceptable than online workshops (16). In a retrospective observational study of 514 children with musculoskeletal insufficiency, 938 videos and 150 telerehabilitation interviews were conducted. 93% of therapists reported that caregivers actively participated (17). The study with children with Rett syndrome included 47 individualized rehabilitation goals for each patient. It has been reported that 78.7% of the goals were achieved and an increase in gross motor functions was observed (18). In the study performed on children with arthrogryposis multiplex congenital, an exercise program was created with the Physiotec software program. As a result of this program, which was applied for 12 weeks and twice a week, significant changes were observed in pain and pediatric outcome measures (19). During the pandemic, two studies systematically evaluated

the responses of children with neurodevelopmental disorders to teleintervention. First, the EnFORCE telehealth program in Italy includes personalized rehabilitation sessions with parent support. The second was a multidisciplinary team at the COVID-19 Neurodevelopmental Disorders Clinic in Canada's home-based consultation program. A virtual evaluation which lasted between 60 and 90 minutes focused on problematic behaviors. More than 80% of parents perceived an improvement in their child's development, and 40% also reported that this intervention was more effective than face-to-face application (20). Family-centered telerehabilitation service is provided with the following online platforms and mobile applications: Fun and Games is a website with bimanual activity instructions for using specific toys developed for unilateral CP. It guides children to do the movements they have difficulty with and the activities are shown step by step with photos. Parental support should be used to play with toys.

CPtoys App is an interactive platform that combines the individual upper extremity goals of children with CP according to age and diagnosis with fun and motivating toys. According to the initial evaluation by the physiotherapist, an individual treatment home program is created and shared with parents or caregivers via the online portal. It is supported and followed during the implementation of the program.

Baby moves App is an application that allows health professionals to evaluate the video containing the baby's movements recorded by the parents. It allows the detection of neurodevelopmental delays.

TwoCan Project is an application for children with unilateral CP that records the movements of the upper extremity with the wrist-worn device (similar to Fitbit) and the movement data are recorded to the smartphone application via Bluetooth. At the end of the day, feedback is provided and the target level of upper extremity movement level is determined. Participation is voluntarily and is applied with the TwoCan kit (2 wristbands, USB charger and application guide). The aim of this project is to determine the effectiveness of simple and game-based practices that can be applied at home.

Zingo is an app that uses behavior change principles and games to encourage participation in therapist-provided home programs and goal attainment. Provides reward and motivation in response to the child's interaction.

SameView App is an online platform that provides connections and information sharing to parents and therapists, doctors, educators, people and organizations providing disability support from a single place. Patient history is uploaded to the system and personal goals are determined. The support team is invited and collaboration and knowledge sharing is ensured. Regularly shared webinars can be followed, e-mail support can be received, and one-on-one sessions can be requested via video conference.

ImPACT ONLINE is an online platform that provides support to families to improve the social and communication skills of children with autism spectrum disorder.

WECARE (Web-based Early-intervention for Children using multimodal Rehabilitation) is designed for children aged 3-8 years with motor impairment. The coaching

approach is used to set individual goals and involve parents in the process. 30-minute video conference sessions are usually held every 2 weeks (23).

Benefits of Telerehabilitation Applications for Children

1. Continuity of care and therapeutic bond is ensured.
2. Follow-up and support are provided during the development process.
3. Behavioral problems are reduced and it contributes to skill development.

Benefits of Telerehabilitation Applications for Parents

1. Personalized support is provided and process partnership is increased.
2. Feelings of isolation and burnout are reduced.
3. The sense of control and self-confidence increase (21).

We can list the application areas of telerehabilitation in children with disabilities as follows:

- Duchenne muscular dystrophy
- Cerebral palsy
- Neuromuscular diseases
- Genetic and malformation syndromes
- Psychomotor and cognitive developmental delay
- Premature and low birth weight
- Rett syndrome: individualized program
- Autism spectrum disorders
- Artrogriposis multiplex congenita
- Musculoskeletal and neurodevelopmental problems (22).

The purposes of telerehabilitation can be listed as data collection, evaluation, clinical observation, consultation, follow-up, coaching, discussion and suggestion, monitoring and reviewing the current situation within the scope of pediatric rehabilitation. In line with these purposes, telerehabilitation services are provided through telephone calls, e-mail, online information, artificial platform/web forums, mobile applications (connected to therapy portals or single applications), personalized online programs, video conferencing, and artificial game platforms (23).

It is predicted that hybrid models in which both face-to-face and remote services can be used together will be the norm in the future. Hybrid approaches are complementary to telehealth, facilitating the delivery of the right information and support at the right place and at the right time, and accelerating the treatment gains achieved with face-to-face therapies (24).

Telerehabilitation from Families and Clinicians' Perspectives

During the pandemic, when access to rehabilitation services was limited, alternative methods were needed to continue physical therapy services for children with disability (22). In this section, we will examine the alternative methods of telerehabilitation, which is a continuation of physical therapy services, from the perspectives of clinicians and families.

Telerehabilitation from the Perspective of Families

During the pandemic, telerehabilitation applications have advantages for families as well as disadvantages. Camden et al. (2020) addressed telehealth services from the perspective of families. In the literature, telerehabilitation

applications have valuable advantages such as can strengthen current model applications like home-based family-centered applications, allowing the sessions to be applied in a natural environment, providing the opportunity to use videos and photographs at different times during the session, enabling the use of tips such as dolls, videos and other accessories to demonstrate the exercises, providing communication and communication opportunities and providing less travel and less stress (23). There are also disadvantages such as increased difficulties occur while trying to implement the program in the home environment, the feeling of not feeling self-sufficient or self-confident due to the need for the family to manage technology and activity simultaneously, isolation from other people and networks when everything is done online, and the child's inability to communicate with therapists as a result of which the level of stress and anxiety increases (23). The advantages and disadvantages of telerehabilitation applications for families are shown in Figure 3. Camden et al. draw attention to the fact that hybrid service models combining face-to-face and telehealth services can be a good method to overcome the difficulties experienced in telerehabilitation practices. They emphasize that hybrid models, in which both face-to-face and remote services are used together, are complementary to telehealth, facilitate the delivery of the right information and support for families at the right time and in the right place, and accelerate the treatment gains achieved with face-to-face therapies (23). In addition, in the study published by Tenforde et al. in 2020, the COVID-19 process was interpreted as a unique opportunity for research on the feasibility and satisfaction of telerehabilitation applications (24).

In pediatric rehabilitation, the low level of digital literacy of families, difficulty in technological adaptation, and low socioeconomic level were among the problems we observed. For this reason, parents' motivation and cognitive levels are important factors to consider in terms of technology dominance and digital literacy. In addition, we believe that the rich environment created for exercise and environmental factors can be distracting from time to time in telerehabilitation applications. According to our clinical observations, not every child and not every family is suitable for telerehabilitation. For this reason, we believe that the selection of the appropriate child and the appropriate environment are key points in order to obtain maximum efficiency.

Telerehabilitation from the Perspective of Clinicians

The COVID-19 process has affected clinicians working with children with disability in the field of pediatric rehabilitation as well as children and families. Hall et al. mentioned remarkable points in their survey study to identify the important factors, facilitators, and barriers to the effectiveness of telehealth practices for pediatric physiotherapists (PTs) in the transition from face-to-face to telehealth during COVID-19 (25). The study categorized questions about defining the pediatric PT's telehealth practice, questions about the effectiveness of factors, facilitators, and telehealth services, and questions about the PT's willingness to continue telehealth after the pandemic is over.

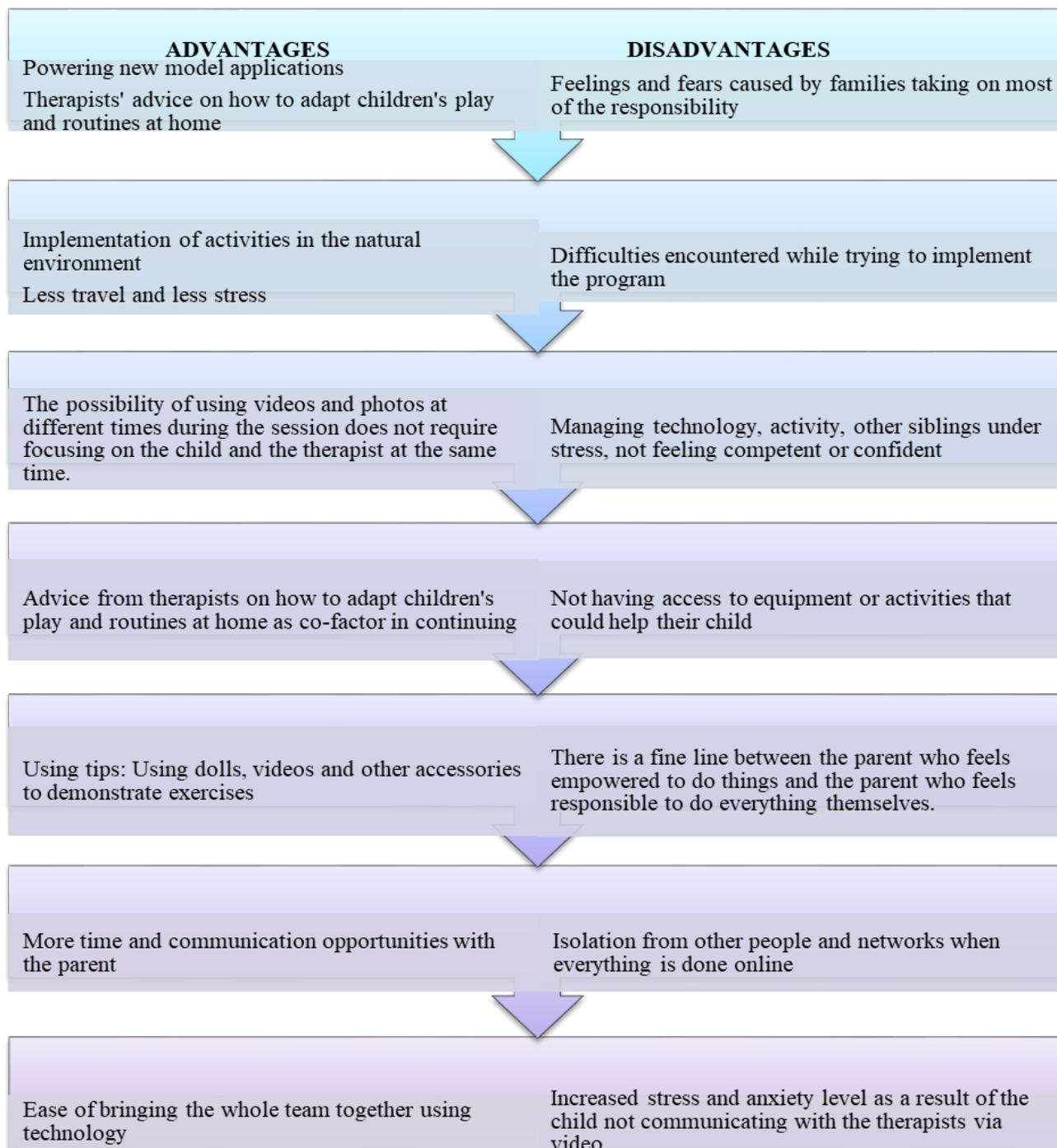


Figure 3. Advantages and disadvantages of telerehabilitation practices for families (Camden et al)

As a result of the study, clinicians reported that there were three overarching themes for the effectiveness of Telehealth Practices, consisting of the parameters Participation, Technology, and Resilience, accompanied by 3 sub-themes of Personality, Equality, and COVID-Specific Considerations (25). The Child/Carer interaction, internet connection, and family characteristics which are regarded as the most significant aspects connected to the effectiveness of telehealth—were used to support the themes. In addition, they emphasized that the telehealth

service model meets a need during the pandemic period and can be accepted as an effective form of service delivery after the pandemic (25). Gefen et al. (2021) to determine the feasibility and post COVID-19 sustainability of the telerehabilitation model for children with disability who receive physiotherapy, occupational therapy, language and speech therapy and psychology sessions, discussed the issue from the perspectives of both families and clinicians. With the SWOT analysis method, telerehabilitation practices were discussed in categories such as technique, continuity, environment and resources,

and cooperation in terms of both families and clinicians (26). In terms of clinicians, there are gains such as tidy equipment, the ability to consult other staff when needed, and easier access to records in terms of telerehabilitation, environment, and resources. In addition, there are disadvantages such as room requirement with appropriate technical support, and lack of some basic equipment in the family home, and this situation causes the therapy goals to be changed. Parent involvement is an opportunity for the child to be more interested in and share in therapy, but there are also challenges for the clinician to need work and personal planning and to take more responsibility for the appointment (27). In addition, while telerehabilitation applications provide clinicians with the necessary time to structure sessions and reorganize therapeutic goals, it can make it difficult to establish a one-to-one relationship with the child because the parents are always with the child. Some clinicians also believe that nothing can replace person-to-person contact (26). Table 1-3 shows the SWOT analysis results in 3 categories for both families and clinicians, according to the study by Gefen et al. We think that clinician education is very important for the spread and applicability of telerehab applications. The number of specialists interfering to children with special education in pediatric rehabilitation is more than the children waiting for service in this field, and each has separate application areas. However, the number of therapists specializing in the field of telerehabilitation is low. Therefore, we believe that clinician education is as important as family education in the routine of pediatric rehabilitation.

Effectiveness of Telerehabilitation Practices

According to a systematic review in which 13 studies were examined to investigate the effectiveness of telerehabilitation practices in pediatric rehabilitation during the COVID-19 pandemic, it was reported that both the rehabilitation team and the parents were satisfied with the telerehabilitation services (13). Effective methods are required in the present research on measuring the effectiveness of telehealth in the delivery of pediatric healthcare. The National Quality Forum (NQF) framework

offers detailed instructions for the creation of telehealth measures under 53 measurement concepts and 4 areas (access to treatment, financial impact and/or cost, experience, and efficacy). The American Academy of Pediatrics and its departments on Telehealth inspired the Supporting Pediatric Research on Outcomes and Utilization of Telehealth (SPROUT) to create methods that researchers can use. In the SPROUT Telehealth Evaluation and Measurement (STEM) profile, the concepts are organized into 4 basic categories and subcategories. The main categories are “Access, Financial Impact / Cost, Experience, and Effectiveness” (27). Patients, their families or caregivers, the care team, and information access parameters are all included in access. The patient, family and/or caregiver, care team, health system or payer, and societal parameters are all included in the financial impact and cost. Experience can be categorized as belonging to the patient, their family or caregivers, the care team, or the community. System, clinical, operational, and technical aspects all fall within effectiveness (22). The main category and subcategories are shown in Figure 4.

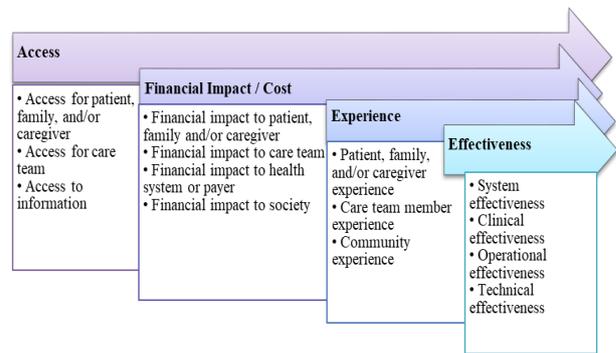


Figure 4. In the SPROUT Telehealth Evaluation and Measurement (STEM) profile, the concepts are organized into 4 basic categories and subcategories (22).

Table 1. Telerehabilitation in terms of environment and resources according to the SWOT analysis of Gefen et al

Telerehabilitation in terms of Environment and Resources				
	Strengths	Weakness	Opportunities	Threats
Families	More flexibility and convenience	Lack of privacy and suitable space for treatment sessions.	They can see and share the child's therapy so they can be more interested.	Treatment in non-optimal conditions (loud noise from the next room, etc.) may distract the child and reduce the effectiveness of the treatment.
Clinicians	Tidy equipment, ability to consult other staff when needed, easier access to records.	Room requirement with appropriate technical support. Some essential equipment may not be available in the family home. This may lead to modification of therapy goals.	More parent involvement can lead to a child's greater interest in therapy and more sharing.	Business and personal scheduling needs Take more responsibility for the appointment.

Table 2. Telerehabilitation in terms of technical aspects according to the SWOT analysis of Gefen et al

Telerehabilitation in terms of Technical Aspects				
	Strengths	Weakness	Opportunities	Threats
Families	Simple, easy to learn platform use (Zoom)	Potential data security issues	Leveraging the positive experiences of a simple technology so that complex technologies can be adopted.	Fear of technical problems that lead to refusing to use online therapy
Clinicians	Simple, easy to learn platform use (Zoom)	Despite Zoom's simplicity, there is a learning curve in how to use it in optimal ways.	Training to better know technology possibilities, mapping of alternative technologies that could be more suitable for therapy at home.	Fear of technical problems that lead to refusing to use online therapy

Table 3. Telerehabilitation in terms of continuity according to the SWOT analysis of Gefen et al

Telerehabilitation in terms of Continuity				
	Strengths	Weakness	Opportunities	Threats
Families	Easier to follow the child's progress in therapy and provide feedback to the therapist from session to session	Most families think that nothing can replace person-to-person contact.	Spending more time with the child.	The child may feel too much attention is on him without developing a good rapport with the therapists.
Clinicians	With other therapies, it is possible to achieve the ideal number of sessions.	Most clinicians believe that nothing can replace person-to-person contact.	Possibility to configure sessions. Having time to realign therapeutic goals	It can be difficult to establish a one-on-one relationship with the child since the parents are always there for her/him.

CONCLUSION

The COVID-19 pandemic has affected pediatric healthcare services for children with disability needs in many ways. Keeping contact to a minimum due to the spread of the virus has greatly affected the child, the family, and the healthcare team working in the field. For this reason, a solution was sought for the problem in the field of pediatric rehabilitation. Innovative approaches such as telerehabilitation applications, which were also applied before COVID-19, but whose usage rate has increased considerably during the epidemic, have added a different dimension to the rehabilitation process. It is expected that hybrid practices combining face-to-face treatment and telerehabilitation will become increasingly widespread in rehabilitation practices for disabled children in the coming years. In recent years, clinical and academic studies in this field have been increasing in the world and in our country, especially after the pandemic (28, 29). In the study published by Kenis-Coskun et al (2022), they compared telerehabilitation and home-based video exercises in patients with Duchenne muscular dystrophy (DMD) who

lost their access to rehabilitation due to the COVID-19 epidemic. At the end of the study, they found that the telerehabilitation approach was superior to a video-based home exercise in improving muscle strength, but none of the programs improved functional outcomes in outpatients with DMD (28).

In a different study, Kenis-Coskun et al. investigated the impact of telerehabilitation on caregivers' mood and anxiety levels as well as the quality of life, depression, and anxiety levels in children with cystic fibrosis. They found that a short-term telerehabilitation program improved the patients' body image, functional status, and anxiety and depression levels, while the caregivers' anxiety and depression levels did not alter significantly (29).

Gagnon et al (2021) evaluated the feasibility and effectiveness of a home exercise program through telerehabilitation, which they see as a potential solution to provide frequent follow-up in young people with Arthrogryposis multiplex congenital (AMC) who have limited access to special care due to geographical distance.

They found promising results in the effectiveness of a telerehabilitation-based home exercise program in helping young people with AMC reach their goals. They recommended future studies to evaluate the effectiveness of this exercise program in a randomized controlled trial (19).

In future studies, there is a need for bilateral studies where instant evaluations can be made during the session and where we can get interaction with the patient. We believe that adding software and hardware that provide an instant evaluation of the exercise we do during the session will be very valuable. For this reason, we believe that technological approaches such as virtual reality and augmented reality and sensors and assistive-adaptive technologies that will enable this technology are valuable in pediatric telerehabilitation applications.

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