Original Article

The Effect of Pediatric Telerehabilitation on Parental Stress, Caregiver Burden, and Satisfaction of Children with Disabilities during the COVID-19 Outbreak in Thailand

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ABSTRACT

Objectives: To assess the effect of pediatric telerehabilitation on parental stress, caregiver burden, and satisfaction of children with disabilities during the corona virus disease 2019 (COVID-19) outbreak in Thailand.

Study design: A retrospective cohort study.

Setting: Department of Rehabilitation Medicine, Siriraj Hospital, Thailand.

Subjects: A total of 40 caregivers of patients with disabilities who were followed up at the outpatient unit of the Pediatric Rehabilitation Service between February 1, 2021 and November 30, 2021 were divided into a participating telerehabilitation group (n = 20) and a non-participating telerehabilitation or non-intervention group (n = 20). Only caregivers who answered the questionnaires completely were included in the study.

Methods: The researchers collected information from caregivers using both pre-intervention questionnaires (before commencing telerehabilitation) and post-intervention questionnaires (after two months of telerehabilitation) including general data, the Depression Anxiety and Stress Scales (DASS-21), the Zarit Burden Interview (ZBI), and The Client Satisfaction Questionnaire (CSQ-8). The primary outcome of interest was pre-intervention to post-intervention change in DASS-21. The secondary outcomes were pre-intervention to post-intervention changes in ZBI in the telerehabilitation and non-intervention groups and telerehabilitation satisfaction (CSQ-8) in the telerehabilitation group

Results: Changes reduction in ZBI scores was statistically significantly greater in the telerehabilitation group than in the non-intervention group. Caregivers in the telerehabilitation group indicated high satisfaction and reported good compliance with the online intervention. However, there was no statistically significant difference in DASS-21 change between the telerehabilitation and non-intervention groups. No clinical complaints were reported in either group.

Conclusions: Pediatric telerehabilitation during the COVID-19 outbreak helped relieve caregiver burden with a high level of satisfaction and without clinical complaints.

Keywords: caregiver burden, COVID-19, pediatric, telerehabilitation, Thailand

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Introduction

Pediatric rehabilitation helps disabled children with neurological diseases, musculoskeletal diseases, and multiple congenital anomalies to maximize their functions. Not only physical problems that should be a concern, but also the mentality of parents and patients. Because a family that understands and accepts their child's disability with a positive attitude tends to develop an effective coping process and achieve a better therapeutic outcome.[1]

Nowadays, in Thailand, technologies have more essential roles in the medical field, such as videoconferences for exchanging medical information among healthcare providers or virtual appointments between doctors and patients. These technologies are defined as telehealth.[2,3] Due to these online communications, patients can easily access medical services wherever they want.

In 2020, there was an outbreak of COVID-19 worldwide, including in Thailand. This pandemic led to lockdown as people needed to stay home and could not move freely to reduce disease transmission. Consequently, the hospital had to postpone the medical appointments of patients without emergency conditions. As a result, an early and intensive pediatric rehabilitation program, which was crucial for vulnerable children, had to be temporarily discontinued. Therefore, The Pediatric Rehabilitation Service at Siriraj hospital started to use telerehabilitation during the COVID-19 outbreak. The treatment team provided telerehabilitation services to various pediatric patients, such as a child with a disability, cerebral palsy, global delay development, multiple congenital anomalies, Down's syndrome, torticollis, flatfeet, scoliosis, and congenital facial palsy.

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To date, there is a lot of established evidence showing the benefits of telerehabilitation in adults and children. Nevertheless, most studies concluded that there should be more research on telerehabilitation because of insufficient significant outcomes to provide more available data. Moreover, previous studies were conducted in developed countries, where people seemed familiar with advanced technology.[4-9] To the author's knowledge, no prior publication reported the use of telerehabilitation for children in Thailand. Therefore, the authors used this opportunity to lead this present study and evaluate telerehabilitation outcomes. Our study aimed to assess pediatric telerehabilitation's effect on parental stress, caregiver burden, and satisfaction during the Coronavirus disease 2019 (COVID-19) outbreak in Thailand.

Methods

The Siriraj Institutional Review Board approved this retrospective cohort study (SIRB), Faculty of Medicine Siriraj Hospital, Mahidol University (SIRB Protocol number 208/2564 (IRB2)). We collected questionnaires that had been interviewed during the COVID-19 outbreak between February 1, 2021, and November 30, 2021. Our telerehabilitation referred to videoconference for providing physical or occupational therapy through online video calls. Caregivers use their computers or smartphones at home to communicate with physicians or therapists at the hospital. Each session lasted approximately 30 minutes. We made an appointment with the caregivers to attend the 2-month program, one session a week. The caregivers of children, who did not receive online intervention, were defined as a non-intervention group. Physicians and therapists would telephone them once a month to follow the child's symptoms and ask whether there were any complications. Caregivers in the non-intervention group were asked to do the physical and occupational therapy by themselves, using the last hospital-based rehabilitation programs they received before the lock-down period in 2020-2021. (Figure 1)

Caregivers in both telerehabilitation and non-intervention groups were interviewed via telephone before commencing (Pre-intervention) and after two months of telerehabilitation (post-intervention). The questionnaires included the general data and caregiver-reported outcomes to evaluate the caregiver's stress reduction and satisfaction after participating in telerehabilitation. The sample size was 18 per group, calculated by referring to the Connell et al. study[10] by type I error was 0.05, and β was 0.20. The estimated missing data was 10%, so the number of subjects to be recruited was 20 per group. A total of 40 caregivers were interviewed between February 1, 2021, and November 30, 2021. The inclusion criteria were the presence of both pre-intervention and post-intervention questionnaires. Incomplete interviews and caregivers in a telerehabilitation group participating in an online intervention of fewer than two sessions in 2 months were excluded. Therefore, we included 40 caregivers according to the inclusion and exclusion criteria. The caregiver reported outcomes which were the depression anxiety and stress scales (DASS-21), the Zarit burden interview (ZBI), the Client Satisfaction Questionnaire-8 (CSQ-8), and the questionnaires collecting the baseline demographic and clinical characteristics of children and caregivers.

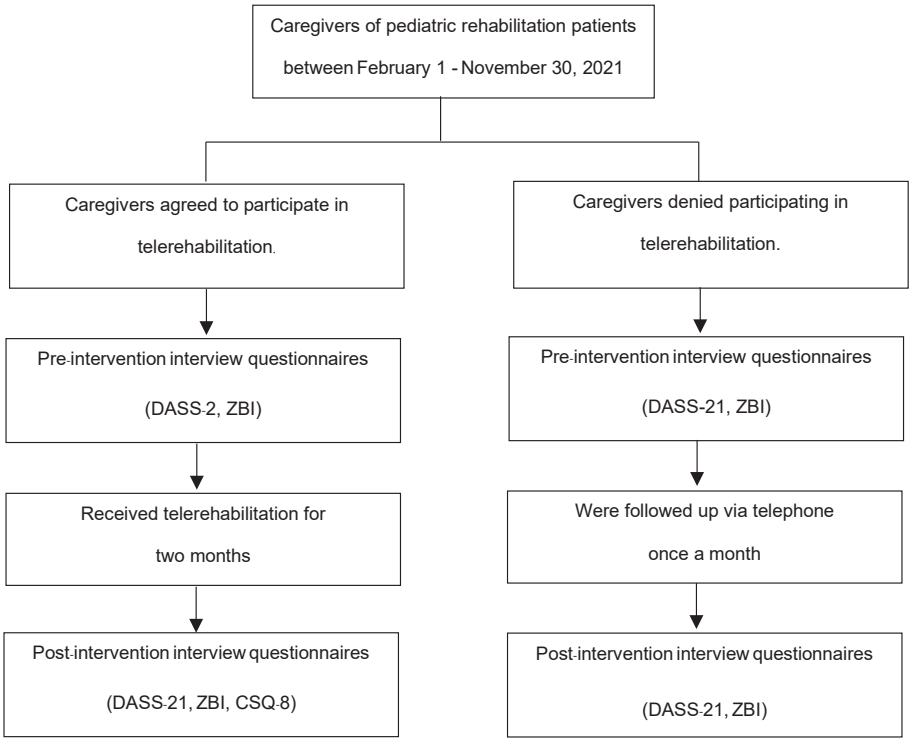

Figure 1.

DASS-21, Depression anxiety and stress scales; ZBI, Zarit burden interview; CSQ-8, The Client Satisfaction Questionnaire.

Outcome measurements

The primary outcome was the changes in caregivers' negative emotion reduction assessed by DASS-21. The DASS-21 was developed by Lovibond et al.[11,12] to screen depression, anxiety, and stress and translated into Thai by Sukanlaya Sawang from The National Centre in HIV Epidemiology and Clinical Research.[13] The questionnaires included 21 questions. The scores ranged from 0-42, with 0 representing no or rarely depression, anxiety, or stress. Cronbach's alpha coefficient was 0.91, 0.81, and 0.89 for depression, anxiety, and pressure, respectively.[11] The DASS-21 had been used as parents reported outcomes in pediatric telerehabilitation research.[5,10]

The secondary outcomes were caregiver burden reduction and satisfaction assessed by ZBI and CSQ-8, respectively. Pre-intervention to post-intervention change in ZBI was compared between telerehabilitation and the non-intervention group. The satisfaction was evaluated in caregivers receiving an online intervention. The Zarit burden interview (ZBI) was created by Zarit et al.[14] to assess caregiver burden and translated into Thai version by Toonsiri et al.[15] It involved 22 questions, scoring from 0-88, which 0 meant no or rarely had caregiver burden. Cronbach's alpha coefficient was high at 0.92.[16] The Client Satisfaction Questionnaire-8 (CSQ-8) was used to assess customer satisfaction. Larsen and Attkisson et al. developed it,[17] the authors used the Thai version of CSQ-8 from CSQScales®. It consisted of 8 questions. Each question was rated on a scale of 1-4, with 1 showing the least satisfaction. Total scores ranged from 8-32. Items include questions enquiring about caregivers' opinion of the telerehabilitation services they have received, which is a four-point scale (response options: 1 = "Quite dissatisfied," 2 = "Indifferent or mildly dissatisfied," 3 = "Mostly satisfied," 4 = "Very satisfied"). This instrument was once used to assess parent satisfaction in pediatric telerehabilitation.[18] The questionnaires also had high reliability, with Cronbach's alpha coefficient up to 0.94.[7,19] The CSQ-8 was assessed post-intervention for the telerehabilitation group only.

Statistical methods

This study used SPSS version 18.0 for analysis. Qualitative data were represented by mean (SD) for normal distribution and median with IQRs for non-normal distribution following the Kolmogorov-Smirnov and Shapiro-Wilk tests. The quantitative data was shown by numbers and percentages. In comparisons between the telerehabilitation and non-intervention groups, we used independent sample t-tests or Mann-Whitney U-test for continuous variables and the Chi-squared test or Fisher exact test for categorical variables. Within-group comparisons of DASS-21 and ZBI scores between pre and post-intervention, we used a dependent sample t-test or Wilcoxon test.

Results

A total of 40 eligible caregivers were divided into a telerehabilitation group (n = 20) and a non-intervention group (n = 20). Table 1 represents the baseline demographic and clinical characteristics of children and caregivers. The caregiver's characteristics showed statistical differences in the estimated travel time to the hospital (hours). The median estimated travel time to the hospital was 6 hours in the telerehabilitation group and 5 hours in the non-intervention group. There was no statistical difference found in a child-caregiver relationship, caregiver's helper, health care coverage, financial income, the estimated travel cost to the hospital, and other caregiver's characteristics, including gender, age, marital status, education, occupation, health problem, the presence of anxiety or depression, presence of helpers and family incomes. Most caregivers (> 85%) of the two groups were familiar with the voice and video calls via the LINE application, the mobile messenger application used for telerehabilitation in this study.

Table 2 compares pre- and post-intervention scores in DASS-21 total score in each telerehabilitation and non-intervention group. There was no statistical difference in the DASS-21 total score comparing the pre-score and post-intervention between telerehabilitation and non-intervention groups.

This table also shows the comparison between the pre-intervention and post-intervention scores of ZBI in each telerehabilitation and non-intervention group. There was a statistical difference in ZBI comparing the pre-intervention score between the two groups. The median pre-intervention ZBI score of the telerehabilitation group was 10.50, while the median pre-intervention ZBI score of the non-intervention group was 3. This data shows that the caregivers of the telerehabilitation group started with a higher caregiver burden score at baseline compared to the non-intervention group. However, after receiving the intervention, the caregiver burden score of the telerehabilitation group was significantly lower in telerehabilitation group. The median post-intervention ZBI score was 2, while the median post-intervention ZBI score of the non-intervention group was 5.

Furthermore, the two groups had a statistical difference ($p < 0.05$) in the post-intervention score. Figure 2 illustrates the scatter plot with a 45-degree line of ZBI score compared between the two groups. The ZBI scores of the telerehabilitation group were below the 45-degree line, referring to the pre-intervention ZBI score being higher than the post-intervention ZBI score. On the contrary, the ZBI scores of the non-intervention group were mostly above and on the 45-degree line. It means that the post-intervention ZBI scores of the non-intervention group were mainly higher or equal to the pre-intervention ZBI score.

Table 1. Baseline demographic and clinical characteristics of caregivers and children

Characteristics	Telerehabilitation group (N = 20)	Non-intervention group (N = 20)	*p*-value
Median of the children's age (Q1, Q3) in months	37 (21,50.2)	43 (8.5,76.5)	.989[b]
Homeland (rural), n (%)	10 (50)	7 (35)	.337[c]
Gender (male), n (%)	11 (55)	10 (50)	.752[c]
Parents' marriage status, n (% marriage)	19 (95)	16 (80)	.342[d]
Severity, n (%)			
- Severe disability*	20 (100)	16 (80)	.106[d]
- Mild problem/disease**	0 (0)	4 (20)	
Children's relationship, n (%)			
- Parents	20 (100)	18 (90)	.487[d]
- Relatives & others	0 (0)	2 (10)	
Mean (SD) of the caregiver's age and [range]	34.8 (7.09) [23-53]	37.85 (9.89) [23-62]	.269[a]
Female caregiver, n (%)	19 (95)	18 (90)	1.000[d]
Caregiver's education, n (% uneducated/primary school)	1 (5)	2 (10)	1.000[d]
Presence of caregiver's health problem, n (%)	3 (15)	4 (20)	1.000[d]
Presence of caregiver's anxiety or depression, n (%)	1 (5)	1 (5)	1.000[d]
Caregiver's employment status, n (% employed)	9 (45)	11 (55)	.527[c]
Presence of caregiver's helper, n (%)	18 (90)	16 (80)	.661[d]
Healthcare coverage, n (% universal health coverage)	20 (100)	17 (85)	.231[d]
Sufficient financial income, n (%)	17 (85)	18 (90)	1.000[d]
Median of the estimated travel cost to the hospital (Q1, Q3) in baht	450 (150,1800)	500 (225,900)	.902[b]
Median of the estimated travel time to the hospital (Q1, Q3) in hours	6 (6,24)	5 (4,6)	.014[b]
Familiar with Line call, n (%)	17 (85)	17 (85)	1.000[d]
Familiar with Line VDO call, n (%)	17 (85)	18 (90)	1.000[d]

[a]T-test for Equality of Means, [b]Mann-Whitney U test, [c]Pearson Chi-Square, [d]Fisher's exact test, [e]Linear-by-Linear Association

*Cerebral palsy, Global delay development, Multiple congenital anomalies, Down's syndrome

**Torticollis, Flatfeet, Scoliosis, Congenital facial palsy

Table 2. Pre-intervention and the post-intervention score of DASS-21 and ZBI comparison

	Telerehabilitation group (N = 20)	Control group (N = 20)	*p*-value	Telerehabilitation group (N= 20)	Control group (N= 20)	*p*-value
	DASS- 21	DASS- 21		(N = 20)	ZBI	
Pre-intervention	0 (0,2)[1]	0 (0,1)[1]	0.721[a]	10.5 (4.25,20.75)[1]	3 (2,11.75)[1]	0.013[b]
Post-intervention	0 (0,0.75)[1]	0 (0,0.75)[1]	0.929[a]	2 (0,7.75)[1]	5 (2,13.5)[1]	0.046[b]

[1]Median (Q1, Q3); [a]Mann-Whitney U test; [b]Wilcoxon signed ranks test

Table 3. DASS-21, anxiety, depression, and stress score, ZBI change comparison

		Telerehabilitation group (N = 20)	Non-intervention group (N = 20)	*p*-value
Pre-test – post-test	DASS-21	0.00 (.00,1.00)[1]	0.00 (.00,0.00)[1]	0.867[a]
Pre-test – post-test	anxiety score	0.00 (.00,0.00)[1]	0.00 (.00,0.00)[1]	0.739[a]
Pre-test – post-test	depression score	0.00 (.00,0.00)[1]	0.00 (.00,0.00)[1]	0.180[a]
Pre-test – post-test	stress score	0.00 (.00,0.75)[1]	0.00 (.00,0.00)[1]	0.416[a]
Pre-test – post-test	ZBI	4.5 (2.25,9.75)[1]	0 (-2.00, 0)[1]	< 0.001[a]

[1]Median (Q1, Q3); [a]Mann-Whitney U test

Table 3 shows the primary outcome comparison (DASS-21) total score, anxiety, depression, and stress score of the two groups. According to the data, there was no statistical difference in DASS-21, anxiety, depression, and stress score change between these two groups. However, the median pre-intervention and post-intervention DASS-21, anxiety, depression, and stress scores for the telerehabilitation and non-intervention groups were normal (score = 0). It means that many respondents score at or near the lowest possible value on a DASS-21 questionnaire, making it impossible to compare the average scores between each group to determine if the intervention made any difference. In addition, comparing the change in score between the pre-intervention and post-intervention scores also makes it challenging to measure dispersion accurately.

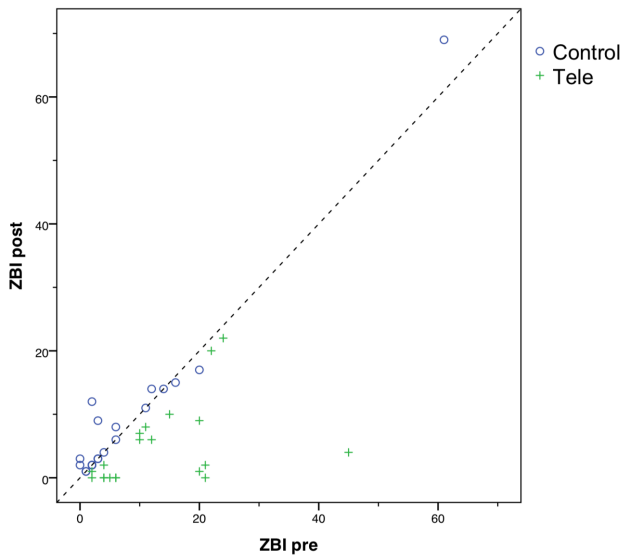

Figure 2. The scatter plot with a 45-degree line of ZBI score

This table also shows a statistical difference ($p < 0.05$) in ZBI change score compared between these two groups. Caregivers reported a significant reduction in caregiver burden after receiving telerehabilitation intervention. There was no significant difference in caregiver burden scores in the non-intervention groups. The CSQ-8 score was illustrated in table 4, in which all the items got a median score above three. The CSQ-8 score ranges from 8 to 32, with higher values indicating higher satisfaction. The mean overall satisfaction score was 29.60 (SD = 3.315), close to the maximum score range.

Most patients (95%) received telerehabilitation service with good compliance, which was more than 80% of appointments. The mean telerehabilitation treatment duration was 23 minutes (SD = 7.847), ranging from 15 to 45 minutes. Most caregivers (90%) reported that telerehabilitation helped relieve anxiety during COVID-19 without any complications or disadvantages. It was convenient and saved cost and time when compared with on-site treatment. Furthermore, most patients (95%) cooperated well, similar to or better than on-site treatment. However, one-fourth of caregivers reported internet connection problems during the treatment.

Discussion

This present study found that caregivers in the telerehabilitation group report a longer estimated travel time to a hospital than non-intervention groups. We expected these results, as people who required longer commuting to the hospital usually tended to accept the telerehabilitation programs.

Both groups started with standard DASS-21 scores at baseline and did not show a significant score of depression, anxiety, and stress in our subjects. Therefore, we could not find the statistical difference between the two groups' pre-intervention and post-intervention DASS-21 total scores. There was no significant difference between DASS-21, anxiety, depression, and stress score change between these two

Table 4. Telerehabilitation satisfaction

CSQ-8	Mean	SD	Range
Total score	29.60	3.315	24-32
1. Quality of service	3.75	0.550	2-4
2. Kind of service	3.70	0.470	2-3
3. Met need	3.50	0.761	2-4
4. Recommend to a friend	3.55	0.759	1-4
5. Amount of help	3.75	0.444	3-4
6. Deal with problems	3.75	0.444	3-4
7. Overall satisfaction	3.85	0.366	3-4
8. Come back	3.75	0.444	3-4

groups. On the contrary, Dhima et al. study found a high prevalence of Indian caregivers' depression (62.5%), anxiety (20.5%), and stress (36.4%) symptoms, which were also assessed by DASS-21 during the COVID-19 outbreak. They reported main associated risk factors with poor psychological health was caregivers who were not using telerehabilitation and had a negative perception of home-based therapy.[20] Alenezi et al. found high anxiety levels in Saudi caregivers during the pandemic.[21] Furthermore, the study from Italy by Grumi et al. also reported the caregivers' depression, anxiety, and stress of neurodevelopmental disabilities children during a COVID-19 situation due to concerns about the lack of rehabilitation programs. They suggested that telerehabilitation programs for families with disabled children should be promoted and continued.[22] Our study did not find a caregiver with significant depression, anxiety, and stress scores at baseline. This finding might be from the difference in culture and healthcare resources. Furthermore, most of our subjects had received hospital-based rehabilitation or home programs before the lockdown period.

We found that the ZBI score in the telerehabilitation group showed a significant reduction after receiving this online intervention for two months. Furthermore, there was a statistical difference in the change of ZBI score between the two groups, which could be implied that using telerehabilitation in the COVID-19 situation can relieve the burden of the caregiver, who is the crucial person taking care of the patients.

However, the caregivers of the telerehabilitation group started with a higher caregiver burden score at baseline. This reason might explain why the caregivers of this group chose to use telerehabilitation. In contrast, the non-intervention group (lower ZBI score at baseline) has no problems or concerns to require treatment intervention.

The study revealed a high level of caregiver satisfaction and adherence to telerehabilitation services, which helped alleviate caregiver anxiety during the COVID-19 pandemic. Our telerehabilitation programs could handle caregivers' needs and problems, and they preferred to use telerehabilitation again. The caregivers also reported that this online intervention is convenient and saves costs and travel time to the hospitals without any clinical complaints. These findings are consistent

with Kruse et al.[2] who conducted a systemic review study, which found that telehealth was a preferred modality because it can improve outcomes and communication. In addition, it is easy to use, has low cost, and decreases travel time.

Telerehabilitation helps the patients maintain the treatment, especially those unable to access the on-site service. Not only for the COVID-19 situation, but we should apply to patients who live far from the hospital in a normal situation too. Edirippulige et al.[23] suggest that traditional face-to-face service for pediatric cerebral palsy patients does not meet the patient's needs compared to the telehealth service since most patients in this study (96%, n = 307) were from remote or rural areas.

Telerehabilitation is one of the effective interventions for pediatric disability groups. Our study found that the children can engage and cooperate reasonably during telerehabilitation. Since they have undertaken treatment with their parents in a familiar environment or their living places, this finding might help the child with anxiety or fear with the therapist's on-site treatment. Many studies also found that telehealth is a feasible and satisfactory method with pediatric patients.[3,4,23] Camden et al. conducted a systematic review of the characteristics and effectiveness of pediatric telerehabilitation interventions and found that telerehabilitation showed improvement of 56.1% of evaluating outcomes.[4] Furthermore, the therapist can effectively coach the parents with a video call, a simple and easy-access technology in this era. The physicians and therapists can monitor the progression of the patient's conditions and parental skills via telerehabilitation. After training, the parents and patients can continue the daily home-based treatment program, which Beckers et al. reported was feasible, acceptable, and practical for implementation with moderate to high compliance.[24]

Limitations and suggestions

This present study only identified the advantages of using pediatric telerehabilitation in the COVID-19 situation in the aspect of burden reduction and satisfaction of caregivers. It could not be generalized to other conditions use. Moreover, our primary outcome or DASS-21 change was not found any significant improvement because the baseline caregivers' mental health was in a normal range. Future telerehabilitation research should focus on the effectiveness of telerehabilitation compared with face-to-face interventions and explore the cost-effectiveness. Furthermore, from our experiences, telerehabilitation has some limitations, especially for a new family who needs a hands-on demonstration of the therapy program. Telerehabilitation might be better for monitoring the progression and training at the follow-up visits for the parents and caregivers who had received the hospital-based rehabilitation programs.

Conclusions

Using pediatric telerehabilitation in the COVID-19 situation helps relieve the caregiver burden without any clinical complaints. This approach should be considered for disabled children who require a maintenance therapy program. We suggested an ongoing comprehensive treatment plan for families with children with disabilities after the pandemic, especially for patients living in remote and rural areas. The benefits of telerehabilitation should be studied in a randomized controlled trial focusing on the effectiveness of telerehabilitation compared with face-to-face interventions.

Disclosure

The author(s) declared no potential conflicts of interest concerning this article's research, authorship, or publication.

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