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Original article

Requirements for tele-health in children with obstetric brachial plexus palsy during Covid-19-like situations



Exigences de la télésanté chez les enfants atteints de paralysie obstétricale du plexus brachial dans des situations similaires à la Covid-19

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ABSTRACT

The purpose of the study was to investigate families' concerns and service requirements during the Covid-19 lockdown. In case of tele-consultation, we also aimed to assess the effects of this service on coping and the family's worries. At end of lockdown, we contacted the parents of 67 obstetric brachial plexus palsy patients (0–10 years age) by e-mail. During lockdown, 42 of the families had had a tele-consultation with our team, while 25 reported that not receiving any service. A questionnaire consisting of 6 questions was sent to the families, and data were analyzed according to 4 age-groups. Parents' concerns varied according to the children's age group ($p = 0.001$). All families replied that their children should receive remote services during Covid-19-like situations ($p = 0.173$). Parents of the 42 children who had tele-consultations reported that this had alleviated their worries, independently of age-group ($p = 0.160$). The usefulness of tele-consultation to manage the lockdown situation differed according to age-group ($p = 0.002$). The parents of under-3-year-olds experienced more worry during lockdown, but all respondents reported needing remote services. Although the tele-consultation alleviated the worries of almost all families, it was most useful in managing lockdown in families with under-3-year-olds.

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R É S U M É

Le but de l'étude était d'enquêter sur les préoccupations des familles et les besoins en matière de services pendant le confinement à domicile de la Covid-19. De plus, s'ils avaient bénéficié d'un service de téléconsultation, nous visions à évaluer les effets de ce service sur la gestion des processus et les préoccupations de la famille. À la fin de la période de confinement à domicile, nous avons contacté les parents de 67 patients (âgés de 0 à 10 ans) par e-mail. Au cours de ce processus, 42 des familles avaient reçu un service de téléconsultation de notre équipe, tandis que 25 d'entre elles ont déclaré ne pas avoir reçu de service. Un questionnaire composé de 6 questions ouvertes a été envoyé à ces familles et les données ont été analysées dans 4 groupes d'âge différents. Selon les 67 parents, l'inquiétude des parents variait selon les groupes d'âge des enfants ($p = 0,001$). Toutes les familles ont déclaré que leurs enfants devraient recevoir des services dans des formats à distance pendant une situation similaire à la Covid-19 ($p = 0,173$). Les parents de 42 enfants souffrant de paralysie obstétricale du plexus brachial qui avaient reçu un service de téléconsultation ont déclaré que le service qu'ils avaient reçu, quel que soit leur groupe d'âge, réduisait leur inquiétude ($p = 0,160$). L'utilité du service de téléconsultation différait pour gérer le processus en fonction des groupes d'âge ($p = 0,002$). Les parents d'enfants de moins de 3 ans ont été les plus préoccupés pendant le processus de Covid-19, mais tous les parents qui ont participé à l'étude ont

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déclaré qu'ils avaient besoin de services à distance. Bien que le service de téléconsultation ait réduit les inquiétudes de presque toutes les familles, il était plus utile dans la gestion du processus dans les familles avec des enfants de moins de 3 ans.

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Introduction

Obstetric brachial plexus palsy (OBPP) is a flaccid paralysis resulting from injury to the brachial plexus during delivery. Incidence ranges from 0.42 to 5.1 per thousand births. Lesion extent varies depending on severity of the injury, from single nerve root to all nerve roots [1,2]. Clinically, OBPP ranges from transient functional deficit to lifelong total disability, depending on injury severity [2].

Due to the nature of nerve recovery, OBPP entails long medical follow-up. The first year following birth, denervation and re-innervation processes are observed in the muscles, and, if necessary, primary surgeries are performed at this age [2,3]. Generally, muscle strength increases until the 2nd year and then reaches a plateau [4]; at these ages, secondary reconstructive surgeries can be performed [5,6]. Regular physiotherapy sessions, home exercise programs and family education as well as surgery are used in treatment [3,7].

Parents play a role in both treatment and rehabilitation [7,8]. Difficulties in managing treatment, the responsibility of the home exercise program and having a more-or-less disabled child all affect the parents [8,9]. The family's social and daily life are deeply affected [9], parents' emotional reactions are altered, with depression and stress; mothers' quality of life is impaired, with fatigue and negative perception of life [8,10,11].

Corona virus disease (Covid-19) spread all over the world and was declared a "Public Health Emergency of International Concern" by the World Health Organization (WHO) on January 30, 2020, and a pandemic on March 11. It was emphasized that disabled people with comorbidity were at higher risk. In many countries during the epidemic, to reduce risk of contamination, social spaces were temporarily restricted. The WHO emphasized the importance of staying home [12,13]. In various countries during lockdown, children's daily social and physical activity routines were disrupted; they had difficulty in concentrating and were restless [14]. At the same time, there were psychological repercussions, such as depression in parents [15]. Children with chronic diseases could not leave home for a long time and did not receive regular face-to-face physiotherapy and rehabilitation [16].

In many countries, including Turkey, therapists rapidly set up remote services [17]. It is important to develop and optimize these services, which are urgent in order to meet patients' needs, over the next few years [17,18]. Tele-health as a service delivery model became more prominent, with sub-areas of tele-evaluation, tele-intervention, tele-consultation, tele-monitoring and tele-supervision [18,19]. Although studies in recent years showed that tele-health services are beneficial when physical access to the hospital is limited and that patients can continue rehabilitation with enjoyable and motivational programs [20,21], there are very limited data for applications in children with OBPP.

For these reasons, we firstly aimed to investigate families' anxieties and service requirements and functional changes in children with OBPP who could not receive face-to-face physiotherapy and rehabilitation during lockdown. Secondly, focusing on families receiving tele-consultation, we aimed to investigate the effects of this remote service.

Patients and methods

This study was conducted after the Covid-19 lockdown. It had review board approval from the Hacettepe University Non-Interventional Clinical Research Ethics Committee (Project no: GO 20/421). Parents were informed about the study, and voluntary consent was obtained.

Medical and physiotherapy follow-up of patients with OBPP takes place in our university hospital. The patients are given individual home exercise programs by physiotherapists specialized in this field, according to the type of the OBPP, the age of the child, and the physiotherapy and surgical treatment history. Home exercise programs are updated, on the basis of family feedback and the needs of the children, after clinical evaluation in the monthly routine follow-up. There were 98 children in the 0–10 age range (mean age: 2.79 ± 2.59 years).

In Turkey, due to the Covid-19 pandemic, rehabilitation services were interrupted between March 16 and June 15, 2020 [22]. Children with OBPP were not able to go out for physiotherapy, and face-to-face physiotherapy in our hospital was not possible. At end of lockdown, we sent an e-mail to the parents of the 98 patients implementing home physiotherapy programs and asked for information about their concerns and service requirements and functional changes in their children, with 3 questions with 3 possible responses and a box for "free comment" (Part-A Questions, Table 1). The parents of 31 patients did not respond. Sixty-seven parents confirmed that face-to-face physiotherapy and rehabilitation were interrupted during lockdown. Forty-two had tele-consultations with our team, but 25 parents stated that they had not been able to communicate with our team.

During lockdown, 42 families contacted our team by e-mail or phone to update their children's home exercise program. Our team communicated with them via video chat and video posting (tele-consultation) and updated their home programs. In addition to the first 3 questions (Part-A Questions, Table 1), we asked them 3 additional questions with 3 possible responses and a box for "free comment" (Part-B Questions, Table 1). The study flowchart is shown in Fig. 1.

Tele-consultation was an individualized service based on problem-solving. The focus of intervention for infants and toddlers was limb integration, range of motion (ROM), strength and child development. For these ages, suggestions were made to stimulate use of the upper limb and support symmetrical motor development, in the form of classical massage, sensory input, full passive ROM movements, stretching for the joints, and bilateral and unilateral games appropriate for the child's age. In preschool and school-age children, interventions focused more on activity limitation, hand function and preferences, with exercises in the form of play, bilateral and unilateral activities, and daily living activity training.

Differences were analyzed according to age-group: group 1, 0–1 years old; group 2, 1–2 years old; group 3, 2–3 years old; and group 4, 4–10 years old. Demographic data according to age group are shown in Table 2.

Statistical analyses used IBM SPSS 26.0 software (IBM Corp., Armonk, NY, USA). Demographic and clinical characteristics were reported as number and percentage for categorical variables.

Table 1
Study survey.

Questions	Responses
Part A Questions	
1 Were you ever worried about your child's treatment and follow-up during lockdown?	No, I wasn't worried Yes, I was a bit worried Yes, I was very worried
2 Are remote services (such as telephone or video chat) necessary for the treatment of your child in situations like that of the COVID-19 lockdown?	Not necessary Sometimes necessary Absolutely necessary
3 How did the function of your child's affected arm change during lockdown?	Less or poorer use No change Better use
Part B Questions	
4 Did tele-consultation alleviate your worries?	No A bit A lot
5 Was tele-consultation helpful in managing lockdown?	No A bit A lot
6 How was your child's adherence to the home rehabilitation program during lockdown?	Less than usual, reluctant No change More adherent and willing than usual

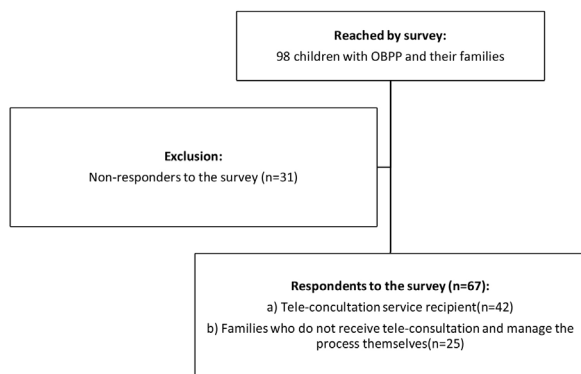


Fig. 1. Study flowchart.

Proportions of questionnaire answers were presented by age group using cross-tabulation. The chi-square test (or Fisher's exact test in case of small numbers) was used to compare proportions between groups, and also to assess the significance of pairwise differences, with Bonferroni correction to adjust for multiple comparisons. The significance threshold was set at $p < 0.05$.

Results

According to the information obtained from the parents of 67 children with OBPP who could not meet physiotherapists face-to-face during lockdown, the parents' concerns varied according to the age group of the children ($p = 0.001$); **Fig. 2** shows answers to the first question of part A graphically. Families stated that their children should receive tele-health services in case of Covid-19 or

similar lockdowns, whatever the age group ($p = 0.173$); **Fig. 3** shows answers to the second question of part A graphically. There were differences in hand function between age-groups ($p < 0.001$). **Table 3** includes the first 3 questions of the study questionnaire and the answers given by the parents of the 67 children.

Parents of 42 OBPP children who had tele-consultations during lockdown stated, regardless of age-group, that this reduced their worry either a lot or a bit ($p = 0.160$). The parents of 2 children over the age of 3 stated that they did not experience anxiety during this period; **Fig. 4** shows answers to the first question of part B graphically. Answers as to whether the tele-consultation service was useful for managing lockdown differed between age-groups ($p = 0.002$); **Fig. 5** shows answers to the second question of part B graphically. There were no differences in children's adherence to home rehabilitation programs during lockdown ($p = 0.083$). **Table 4** shows the questions and answers for the 42 parents who received the tele-consultation service.

Discussion

The present results showed that, in situations where face-to-face rehabilitation services could not be provided for a long time, families with children under the age of 3 (and especially between 0–1 years old) had more worries about treatment and follow-up, while families with older children had less or no concerns. All parents reported that remote service was required when face-to-face service could not be provided. According to all families who could not receive face-to-face service during lockdown, the function of the affected arm generally improved or did not change in children under the age of 2; on the other hand, it was reported that the use of the affected arm was generally unchanged or worse

Table 2
Demographic characteristics of children with OBPP participating in the study.

			All patients without face-to-face physiotherapy (n = 67)	Only patients with tele-consultation (n = 42)
Age (years)	0–1	n (%)	17 (25%)	13 (31%)
	1–2	n (%)	14 (21%)	11 (26%)
	2–3	n (%)	15 (22%)	8 (19%)
	4–10	n (%)	21 (31%)	10 (24%)
Type of injury	C5–6	n (%)	26 (39%)	18 (43%)
	C5–6-7	n (%)	30 (45%)	15 (36%)
	Total	n (%)	11 (16%)	9 (21%)
Gender	Girls	n (%)	38 (57%)	23 (55%)
	Boys	n (%)	29 (43%)	19 (45%)

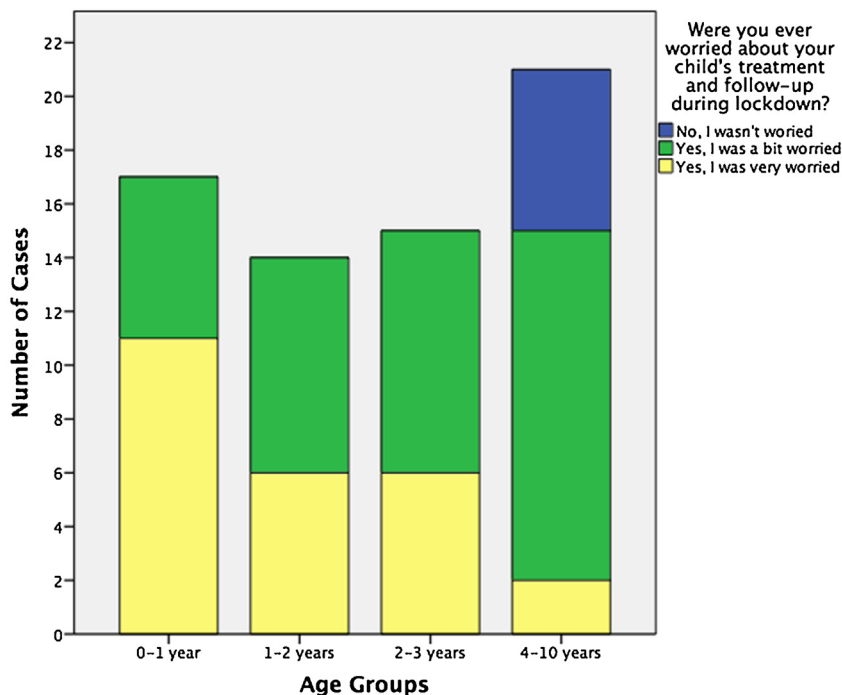


Fig. 2. Graph of the families' answers to the first question of part A.

in children aged 2–3 years and above 4 years during this period. The parents who had tele-consultations reported that this reduced their worries, and those with children between 0–1 years and 1–2 years of age reported that the service was very or at least a bit useful. While some of the parents reported that there was no change in their children's adherence to the home rehabilitation program, many reported decreased adherence.

The fact that 42 of the 67 parents (63%) had access to tele-consultations was a positive finding; but 25 (37%) were unable to

access rehabilitation services remotely, indicating the inadequacy of health services in situations that cause major social or physical limitations such as the Covid-19 pandemic. Moreover, the tele-consultation service we provided was not to be considered as a general health service but was on a purely voluntary basis. There is a process whereby physiotherapists provide similar emergency and problem-solving-based services in pandemic conditions all over the world, and the importance of optimizing remote physiotherapy and including health insurance in this service is

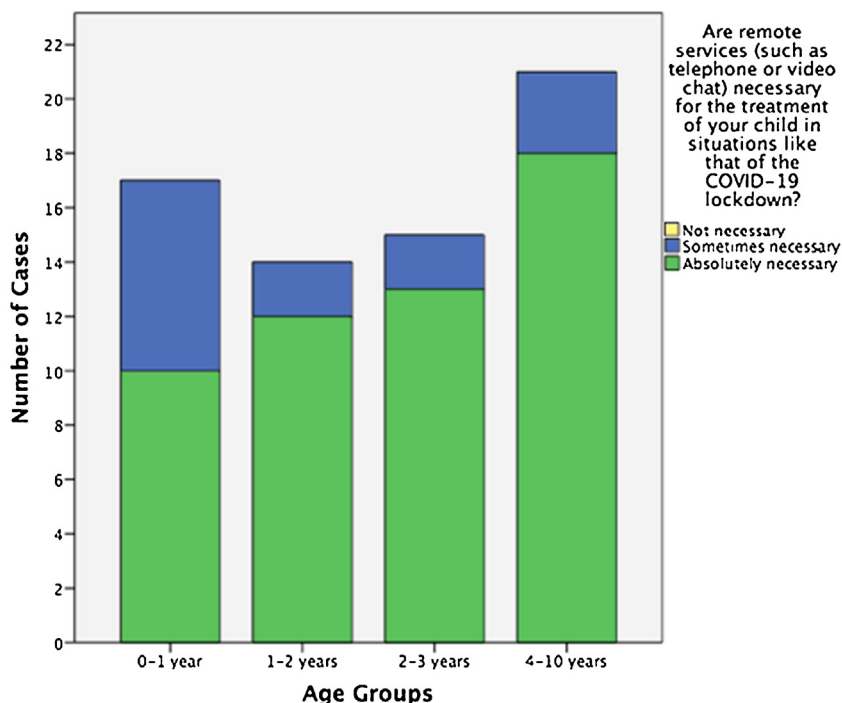


Fig. 3. Graph of the families' answers to the second question of part A.

Table 3

The answers given to the questionnaire by the parents of the 67 children with OBPP who could not receive physiotherapy for more than 8 weeks during the Covid-19 lockdown and could not meet physiotherapists face to face.

All patients without face-to-face physiotherapy (n = 67)						
Questions (Part A of Questionnaire)	Parents' response	Age groups				p
		Group 1 Age 0–1 n = 17 n (%)	Group 2 Age 1–2 n = 14 n (%)	Group 3 Age 2–3 n = 15 n (%)	Group 4 Age 4–10 n = 21 n (%)	
Were you ever worried about your child's treatment and follow-up during lockdown?	No, I wasn't worried	0 (0)	0 (0)	0 (0)	6 (28.6)	0.001 ^c
	Yes, I was a bit worried	6 (35.3)	8 (57.1)	9 (60)	13 (61.9)	
	Yes, I was very worried	11 (64.7)	6 (42.9)	6 (40)	2 (9.5)	
Are remote services (such as telephone or video chat) necessary for the treatment of your child in situations like that of the COVID-19 lockdown?	Not necessary	0 (0)	0 (0)	0 (0)	0 (0)	0.173
	Sometimes necessary	7 (41.2)	2 (14.3)	2 (13.3)	3 (14.3)	
	Absolutely necessary	10 (58.8)	12 (85.7)	13 (86.7)	18 (85.7)	
How did the function of your child's affected arm change during lockdown?	Less or poorer use	1 (5.9)	4 (28.6)	4 (26.7)	7 (33.3)	<0.001 ^{b,c}
	No change	4 (23.5)	4 (28.6)	11 (73.3)	12 (57.1)	
	Better use	12 (70.6)	6 (42.9)	0 (0)	2 (9.5)	

a: There is a difference between Group 1 and Group 2. b: There is a difference between Group 1 and Group 3. c: There is a difference between Group 1 and Group 4. d: There is a difference between Group 2 and Group 3. e: There is a difference between Group 2 and Group 4. f: There is a difference between Group 3 and Group 4.

emphasized for the future [17]. In OBPP, since the first years after birth are an important period for both recovery of motor function and surgery [3,4,7], it is very important for patients to be followed up and benefit from health services. Therefore, when face-to-face healthcare services cannot be ensured due to situations like the Covid-19 pandemic, it is very important to configure remote services. The results of our study showed that these services were necessary from the parents' perspective in all age groups.

In OBPP, it has been well established that unexpected injury at birth causes financial, social and psychological problems for parents and impairs quality of life [8,9]. Mothers of children aged 0–2 years have poorer quality of life and show more emotional reactions than mothers of children aged 2–7 years [8]. Similarly, the present study found that families of children aged 0–1 experienced more worries about treatment, and that families experienced less anxiety as the age of the children increased. Since family functioning is related to the well-being of the child and

families play a key role in treatment, it is very important for the parents to cope with the ongoing situation [7,8,10]. In the present study, the remote service helped families manage lockdown and alleviated their worries, doubtless having positive impact on the health status of both parents and children. Although parents of children of all age groups emphasized the necessity of remote services, the need for structured and well-planned tele-consultation especially concerned families of children under the age of 3 years.

All parents who had tele-consultations reported that this alleviated their worries, but the usefulness of the service from the parents' perspective varied according to the age-group of the children. Generally, the service was reported to be very useful in the 0–1-year age-group, but benefit was slightly less with increasing age. The fact that this service was more beneficial for young children may be due to functional gain resulting from the natural course of OBPP. Due to the nature of OBPP, spontaneous

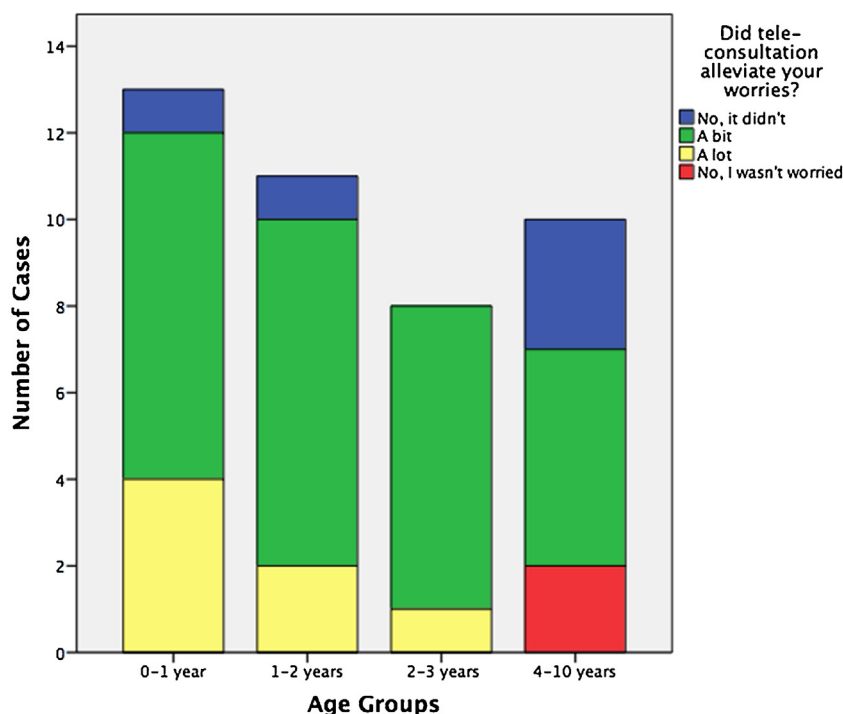


Fig. 4. Graph of the families' answers to the first question of part B.

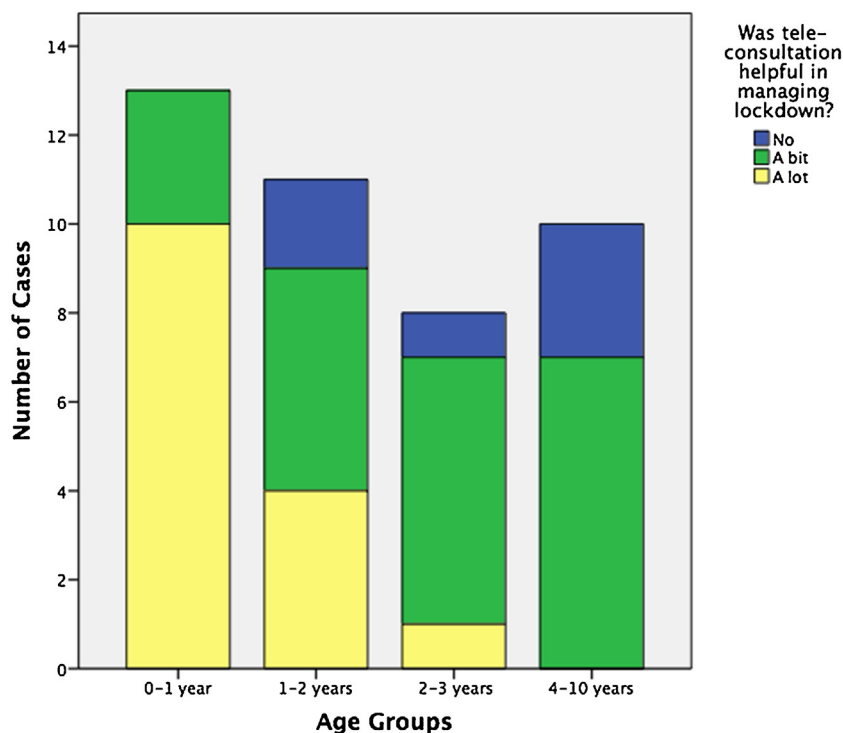


Fig. 5. Graph of the families' answers to the second question of part B.

Table 4
Questions and answers for the 42 families who had tele-consultations.

Only patients with tele-consultation (n = 42)						
Questions (Part B of Questionnaire)	Parents' response	Age-groups				p
		Group 1 Age 0–1 n = 13 n (%)	Group 2 Age 1–2 n = 11 n (%)	Group 3 Age 2–3 n = 8 n (%)	Group 4 Age 4–10 n = 10 n (%)	
Did tele-consultation alleviate your worries?	No, I wasn't worried*	0 (0)	0 (0)	0 (0)	2 (20)	0.160
	No, it didn't	1 (7.7)	1 (9.1)	0 (0)	3 (30)	
	A bit	8 (61.5)	8 (72.7)	7 (87.5)	5 (50)	
	A lot	4 (30.8)	2 (18.2)	1 (12.5)	0 (0)	
Was tele-consultation helpful in managing lockdown?	No	0 (0)	2 (18.2)	1 (12.5)	3 (30)	0.002 ^c
	A bit	3 (23.1)	5 (45.5)	6 (75)	7 (70)	
	A lot	10 (76.9)	4 (36.4)	1 (12.5)	0 (0)	
	More adherent and willing than usual	1 (7.7)	1 (9.1)	1 (12.5)	0 (0)	
How was your child's adherence to the home rehabilitation program during lockdown?	Less than usual, reluctant	3 (23.1)	7 (63.6)	3 (37.5)	8 (80)	0.083
	No change	9 (69.2)	3 (27.3)	4 (50)	2 (20)	
	More adherent and willing than usual	1 (7.7)	1 (9.1)	1 (12.5)	0 (0)	
	More adherent and willing than usual	1 (7.7)	1 (9.1)	1 (12.5)	0 (0)	

*"No I wasn't worried" was a free-text response.

a: There is a difference between Group 1 and Group 2. b: There is a difference between Group 1 and Group 3. c: There is a difference between Group 1 and Group 4. d: There is a difference between Group 2 and Group 3. e: There is a difference between Group 2 and Group 4. f: There is a difference between Group 3 and Group 4.

recovery is seen in the 0–1 age bracket: increase in muscle strength and functional gain occur at mainly at young ages [2,4,7]. Parents may have reported that the service was more beneficial for younger children due to spontaneous recovery, but it is nevertheless positive that tele-consultation was beneficial for young children from the parents' perspective.

The fact that the tele-consultation service did not provide satisfactory benefit for children aged 4–10 may be due to the children's poor adherence in the activity-based practices we recommended for home rehabilitation. Adherence varied. While young children complied well with passive practices (such as massage, stretching, sensory input) and play-based approaches, older children showed poorer adherence to this activity-based

approach. On the other hand, the fact that our study was conducted during lockdown in the unexpected situation brought about by the pandemic caused changes in factors such as activity rhythm, sleep pattern, psychological well-being and the working conditions of the entire household [14,15]. This situation may negatively affect adherence to home programs in older children with physical disabilities, as in our study. Whatever the reasons, these results show that one of the prime issues in the development of family-based remote rehabilitation is ensuring the children's adherence.

The fact that a fully structured and planned tele-health service was not available was the main study limitation. For this reason, the study aimed at determining problems and needs

during lockdown from the perspective of the family, in an observational study rather than an assessment of the efficacy of the remote service. In addition, it should be borne in mind that all the children in our study had been followed face-to-face and had medical records before the Covid-19 pandemic: there were no cases with remote diagnosis and children who had not been followed up previously were not included. The fact that the study only covered families and children living in Turkey can be considered as a limitation, with purely local interest, but it is important that this was the first study to draw attention to the importance of remote services in this disease group.

Conclusion

All parents participating in the study reported that they needed tele-consultation services in conditions similar to the Covid-19 lockdown; however, parents of children under the age of 3 experienced more worry during lockdown. From the parents' perspective, although tele-consultation was useful for managing lockdown in families with children under the age of 3 years and especially in the 0–1-year age group, it did not provide sufficient benefit for older children. In the light of these findings, there is a need for structured remote services with different applications for different age-groups for children with OBPP and their families, to advance treatment in a planned manner. Family and child adherence and the integration of clinical evaluations into the system are very important. Assessing the capacity of parents to implement home rehabilitation programs and checking whether the home program is being followed correctly can increase the success of remote services. In addition, validity and reliability studies are required for the clinical evaluations to be used in online or remote services.

Conflicting interests

The authors have no conflicts of interest to declare.

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Ethics approval

Hacettepe University Non-Interventional Clinical Research Ethics Board approved the research plan on May 5, 2020 (GO 20/421).

Informed consent

All the families signed a declaration of informed consent.

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