







Original article

Perception of parents and caregivers of children with disabilities about rehabilitation services during the COVID-19 pandemic in Brazil

Percepção de pais e cuidadores de crianças com deficiência sobre os serviços de reabilitação durante a pandemia da COVID-19 no Brasil

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ABSTRACT | INTRODUCTION: During the coronavirus pandemic in Brazil, the suspension of rehabilitation sessions for children with disabilities was observed. OBJECTIVE: To analyze the progress of rehabilitation sessions during the pandemic, as well as the form of support that parents/caregivers received during this period. MATERIALS AND METHODS: Qualitative study, with a cross-sectional design, conducted online through the Survey Monkey platform. Parents and caregivers of children with motor disabilities aged zero to four years old participated, and were recruited through social media. Data collection took place by a questionnaire with 17 open and closed questions, accessible for a period of three months during the period November 2020 to January 2021. RESULTS: All questionnaires were read in full and after observing saturation of responses, 37 were eligible. The suspension of sessions in rehabilitation services ranged from 2 to 9 months. During this period, twenty-six families received guidance from the professional or the institution to stimulate the child at home, for the others who did not receive guidance, the justification provided was to wait for the resumption of care. Sixteen families had difficulties performing the activities/exercises proposed by health professionals in the home environment. **CONCLUSION:** Parents' responses identified feelings of concern and anxiety about the suspension of rehabilitation services during the pandemic and fear of possible damage to children's neuropsychomotor development. In addition, parents felt helpless by health services and professionals.

KEYWORDS: COVID-19. Disabled Children. Rehabilitation Services. Physical Therapy.

coronavírus no Brasil a suspensão das sessões de reabilitação de crianças com deficiência. OBJETIVO: Analisar o andamento das sessões de reabilitação durante a pandemia, bem como a forma de suporte que os pais/cuidadores receberam neste período. MATERIAIS E MÉTODOS: Estudo qualitativo, com delineamento transversal, conduzido on-line pela plataforma Survey Monkey. Participaram pais e cuidadores de crianças com deficiência motora de zero a quatro anos de idade, que foram recrutados através das mídias sociais. A coleta de dados ocorreu por um questionário com 17 perguntas abertas e fechadas, acessível por um período de três meses durante o período de novembro de 2020 a janeiro de 2021. RESULTADOS: Todos os questionários foram lidos na íntegra e após observada saturação das respostas, 37 foram elegíveis. A suspensão das sessões nos serviços de reabilitação variou de 2 a 9 meses. Durante este período, vinte e seis famílias receberam orientações do profissional ou da instituição para estimular a criança em casa; para os demais, que não receberam orientações, a justificativa fornecida era que deviam aguardar a retomada dos atendimentos. Dezesseis famílias tiveram dificuldades para realizar as atividades/exercícios propostos pelos profissionais de saúde em ambiente domiciliar. CONCLUSÃO: Foram identificados, através das respostas dos pais, sentimentos de preocupação e ansiedade com a suspensão dos serviços de reabilitação durante a pandemia e medo com os possíveis prejuízos no desenvolvimento neuropsicomotor das crianças. Além disso, os pais se sentiram desamparados pelos serviços de saúde e profissionais.

RESUMO | INTRODUÇÃO: Observou-se durante a pandemia do

PALAVRAS-CHAVE: COVID-19. Crianças com Deficiência. Serviços de Reabilitação. Fisioterapia.

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1. Introduction

During the beginning of 2020, when the World Health Organization raised the threshold of the epidemiological situation of the new coronavirus, until then a worldwide public health emergency, to the pandemic status, the world found itself facing a virulent and difficult-to-control disease, leading countries to decree "lockdown" measures, quarantine, adopting social isolation and distancing as a sanitary measure to avoid contamination by the virus and reduce lethality.¹⁻³

Public and private health facilities had to adjust their services to ensure safe and continuous access to care.² In Brazil, social isolation was present by the determination of the Ministry of Health.^{4,5}

This scenario during the initial months of the pandemic forced the entire world population to reorganize their ways of living, adopting remote work and deprivation of leisure/cultural activities and other social activities to avoid agglomerations. Despite the protective measures, families of children with disabilities were directly affected, who observed their children's rehabilitation sessions being reduced or totally suspended due to the pandemic.^{3,6}

It is understood that during the first few years of a child's life with neuromotor impairment, the family environment has a total influence. Families need to understand their real potential and needs to provide ideal care for their children with disabilities.²

Some authors recommend that parents choose the professionals who will play the role of caring for their children, citing that they are therapeutic "instruments", but it is the parents who bear the greatest responsibility on a daily basis. Brazilian and international studies have highlighted the barriers encountered during the pandemic and presented solutions such as family-centered practice and telerehabilitation that should be improved and enhanced in this post-pandemic moment. 3.9.10

This study aimed to identify the perceptions of parents and caregivers of children with disabilities regarding the follow-up by rehabilitation services during the COVID-19 pandemic and to list the possible difficulties parents encountered during this period.

2. Material and methods

This is a qualitative study with cross-sectional design. The research project was approved by the Research Ethics Committee with Human Beings of the Universidade Estadual de Campinas, no. 4.367.726. All participants signed the Informed Consent Form (ICF) in compliance with the requirements of Resolution 466/2012 of the National Health Council.

It was carried out online, and to select participants an invitation text was created and posted on social networks (Facebook, Instagram and WhatsApp groups); parents who agreed to take part in the research were contacted by the researcher, who explained the details of the study; after agreeing and explaining any doubts, a link was sent to access the semi-structured questionnaire via the Survey Monkey Platform. Before accessing the questionnaire, parents had access to the informed consent form and were only able to proceed to the questions after reading and accepting it.

Parents and/or caregivers of children with disabilities aged between zero and four years old, with a clinical diagnosis of the main neurological conditions of childhood (Cerebral Palsy, Myelomeningocele, Microcephaly, Brain Injury Sequelae)¹¹ were included; and all participants whose child did not correspond to the age group, as well as those with a clinical diagnosis of other non-neurological pathologies or syndromes (such as Down's Syndrome) and those who did not sign the informed consent form were excluded.

The questionnaire for the participants contained 17 questions, 11 of which were closed and 6 open, which were accessible between November and December 2020 and January 2021. The questions were aimed at identifying the sociodemographic characterization such as age, state and city of residence, clinical diagnosis and age of the child and questions related to the period of the pandemic and rehabilitation services such as: which rehabilitation therapies the child received, frequency of sessions, whether or not therapies were suspended during the pandemic, whether parents received any instruction from the institution or health professionals on how to stimulate the child at home, in addition to other aspects related to the topic.

Parents who contacted the researcher on social networks to complement information, had the statements compiled in a field diary and transcribed in full. Atlas.ti (Qualitative Data Analysis) software was used to help analyze the units.

3. Results

A total of 104 responses were collected during the time the questionnaire was available. All the questionnaires were read in full. Four were discarded because they didn't agree to sign the ICF, 21 because there was no recorded response, 02 because the child's age didn't meet the inclusion criteria, totaling 77 eligible answers, which after critical analysis and saturation, i.e. after grouping together the similar responses, 37 were chosen to make up the results. In order to ensure the ethical confidentiality of the transcription of responses, we have named the participants P1 to P37. Table 1 shows the sociodemographic characteristics of the participants and the children.

Table 1. Characteristics of the children and parents taking part in the research (to be continued)

Participant	Location	Child Clinical	Children's	Age of the
		Diagnosis	age group	person
				responsible
COV1	São Paulo	Cerebral Palsy	2 to 3 years	45 years
COV2	Paraná	Cerebral Palsy	2 to 3 years	34 years
COV3	São Paulo	Myelomeningocele	2 to 3 years	30 years
COV4	São Paulo	Cerebral Palsy	3 to 4 years	42 years
COV5	São Paulo	Cerebral Palsy	3 to 4 years	40 years
COV6	São Paulo	Cerebral Palsy	3 to 4 years	32 years
COV7	São Paulo	Cerebral Palsy	2 to 3 years	25 years
COV8	Paraná	Cerebral Palsy	2 to 3 years	31 years
COV9	Santa Catarina	Cerebral Palsy	2 to 3 years	37 years
COV10	Paraná	Cerebral Palsy	3 to 4 years	38 years
COV11	Minas Gerais	Cerebral Palsy	1 to 2 years	40 years
COV12	Pará	Cerebral Palsy	3 to 4 years	36 years
COV13	Minas Gerais	Myelomeningocele	2 to 3 years	40 years
COV14	São Paulo	Cerebral Palsy	3 to 4 years	28 years
COV15	São Paulo	Cerebral Palsy	1 to 2 years	34 years
COV16	São Paulo	Myelomeningocele	1 to 2 years	35 years
COV17	Paraná	Myelomeningocele	2 to 3 years	41 years
COV18	São Paulo	Microcephaly	2 to 3 years	29 years
COV19	Rio Grande do Sul	Myelomeningocele	3 to 4 years	44 years
COV20	Rio Grande do Sul	Myelomeningocele	3 to 4 years	26 years
COV21	Santa Catarina	Myelomeningocele	Less than	40 years
			1 year	
COV22	Paraná	Myelomeningocele	1 to 2 years	36 years
COV23	São Paulo	Myelomeningocele	Less than	28 years
			1 year	
COV24	Rio de Janeiro	Myelomeningocele	2 to 3 years	35 years
COV25	Goiás	Myelomeningocele	3 to 4 years	38 years
COV26	Pernambuco	Cerebral Palsy	3 to 4 years	30 years
COV27	São Paulo	Myelomeningocele	3 to 4 years	52 years
COV28	Alagoas	Myelomeningocele	1 to 2 years	33 years
COV29	Ceará	Myelomeningocele	3 to 4 years	28 years
COV30	São Paulo	Cerebral Palsy	3 to 4 years	36 years
COV31	São Paulo	Cerebral Palsy	3 to 4 years	40 years
COV32	Rio Grande do Sul	Myelomeningocele	1 to 2 years	35 years
COV33	Ceará	Myelomeningocele	3 to 4 years	39 years
COV34	Paraná	Cerebral Palsy	3 to 4 years	34 years

Table 1. Characteristics of the children and parents taking part in the research (conclusion)

Participant	Location	Child Clinical Diagnosis	Children's age group	Age of the person responsible
COV35	São Paulo	Myelomeningocele	Less than 1 year	24 years
COV36	Minas Gerais	Myelomeningocele	Less than 1 year	31 years
COV37	São Paulo	Myelomeningocele	3 to 4 years	27 years

Source: the authors (2023).

The average time spent to answer the questionnaire was approximately six minutes (ranging from 3 minutes and 13 seconds to 16 minutes and 30 seconds). The first five answers comprised the pre-test and there was no need to adapt the questionnaire after analyzing these answers. The respondents' ages ranged from 24 to 45 years and the age range of the children is shown in figure 1.

Children's age group

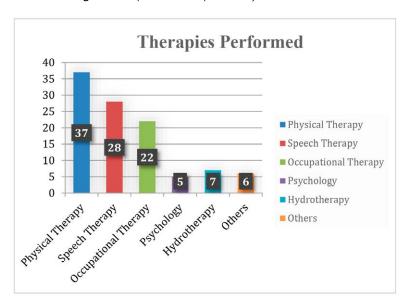
18
16
14
12
10
10
8
6
4
2
1ess than 1 1 to 2 years 2 to 3 years 3 to 4 years year

Figure 1. Distribution of the participating children's age groups

Source: the authors (2023).

Figure 2 shows the therapies the children received. Parents could select more than one option when answering and as noted, physiotherapy was the only one present in all the answers. In the period before the pandemic, 14 (37.8%) participants answered that their children attended sessions once a week, 9 (24.3%) twice, 6 (16.2%) three times and 8 (21.6%) more than three times a week. Rehabilitation services are considered to be those carried out at primary care level and secondary care level by the Unified Health System, as well as private clinics.

Figura 2. Terapias realizadas pelas crianças com deficiência



Source: the authors (2023).

When parents were asked if rehabilitation was suspended during the pandemic, 17 (46%) answered yes, 13 (35%) answered that it was still suspended at the time, and 7 (19%) answered that it was not suspended. Sessions were suspended from 2 to 9 months. This is the response of one of the families:

"Therapies have been suspended since March 2020 and haven't returned yet". (P36)

During this period, 26 (70.2%) parents/families received guidance from the professional or the institution to stimulate the child at home. Those who reported that "did not receive guidance" had as justification provided by the facilities "waiting for the return of in-person care."

"I didn't receive any guidance, they just asked to wait for the return of activities". (P28)

When parents and caregivers were asked which resources were used to provide guidance, the WhatsApp® (considering text messages only) application was mentioned the most (21/56.7%), followed by video calls (11/29.7%), telephone calls (8/21.6%), illustrated guides, support materials, and booklets (4/10.8%), and meetings via Google Meet, Zoom, and others services (3/8.1%). Only one participant reported that they received written information by email.

When asked if, despite receiving guidance, the family member had difficulties carrying out the instructions/stimulating the child at home, sixteen families (43.2%) answered "yes" and also raised questions such as: doubts about whether they were doing it correctly, time management and difficulty adapting to the home, and seven (18.9%) had difficulties carrying out the proposed activities and opted for home care for physiotherapy and speech therapy services.

"I had a hard time managing my remote work and my other kid's homeschooling". (P1)

"I had difficulty adapting my home for physical therapy activities". (P8)

"Not having adequate space". (P12)

For the close-ended question "During the pandemic, even performing the exercises at home, did you notice that your child's motor development was impaired?" A total of 22 parents answered that the "motor development of their children would be impaired without going to rehabilitation facilities."

For a better understanding of the parents' perceptions, associating the pandemic and rehabilitation services, three clusters were built, among them one that represents the change of daily routine during the pandemic.

a) Parents who reported changes in daily routine during the pandemic:

"The therapist seems to make a better evolution, the therapy time is shorter during the pandemic, we have to do the activities and do remote work, home routine and therapy is extremely overwhelming.". (P6)

"Home rehabilitation at home is a hard task, at least with my daughter. Besides her I have 2 children, a 4-year-old enrolled at the public elementary school, and a 1-year-old baby, so taking care of 2 children besides my daughter's rehabilitation is not easy. During the pandemic she was really stressed and irritated,". (P7)

"The doctors suggested us to maintain social isolation. We follow this recommendation to the letter and I will not say that this is an easy task, even with all pieces of equipment I have at home, the biggest challenge is to manage all therapy exercises with school activities without overloading my children". (P9)

b) Parents who reported that the pandemic caused losses regarding the suspension of care:

"My children's progress has regressed, the clinical environment makes a lot of difference". (P2)

"The pandemic has greatly impaired therapeutic care and there is no date to resume the appointments, it is difficult to perform all activities without the professional's oversight". (P3)

"This year has been tough, we have lost several procedures, Botox, specialized appointments, we did and we do what we can at home. (P8)

"With the beginning of the pandemic, we were unable to perform all the activities, the exercises. We had a frequency of five appointments a week, which were reduced to three. She's lost a lot of leg muscle". (P30) c) Perceptions about physical therapy care and health services:

"We received much guidance! We were able to accomplish all activities, we were only overwhelmed with many daily tasks, but we made a great effort, dedicate ourselves and we are managing to win and to see positive results!". (P14)

"In my city the physical therapy service is aimed to the general public, unfortunately with professionals without specialization and precarious care in Apae. We had to travel to a neighboring city, what made it even more difficult during the pandemic". (P17)

"At the beginning of the pandemic we opted for online physical therapy. The therapist showed the movements and the father copied. (P18)

"My son's physical therapist works on the health center of the city and attends at home. As we live in the countryside, the appointments were never suspended". (P21)

"The lack of preparation, in the institution that my son goes I was not prepared for what to do at home, we try to find a way." (P29)

"We did the exercises according to the physical therapist' guidance". (P33)

4. Discussion

The COVID-19 pandemic has brought a new meaning to our lives, social isolation has led to a readjustment of ways of living life.3,12 In addition to the feelings already expected in parents of children with disabilities, the pandemic has added other perceptions, especially in relation to the possible damage to children's neuropsychomotor development and the child's relationship with the family, caused by the stoppage of therapies. 12-16 But it has also initiated discussions to find strategies/solutions to continue caring for children with disabilities, such as deepening and improving information and communication technologies as an option for health services to expand access for users.3 Telehealth is a type of non-face-to-face care recognized by the Conselho Federal de Fisioterapia e Terapia Ocupacional - COFFITO (Federal Council of Physiotherapy and Occupational Therapy) and can be divided into: teleconsultation, telemonitoring, teleconsulting, synchronous and asynchronous. 11

According to the literature, early childhood is the most important years for the acquisition of brain neuroplasticity and the first three years of a child's life are important for optimizing its development.^{10,11}

For the participants of this study, it was precisely during this age that the world faced the COVID-19 pandemic and families had to adapt lifestyles because of social isolation. Health facilities suspended many therapies appointments during the pandemic. Then, we ponder: how are children with these conditions being stimulated? Will they return to rehabilitation with an impaired development? Are families receiving the necessary support and/or guidance? It is known that an enriched environment can benefit the modeling of the structures and functions of the central nervous system thus contributing to the improvement of the clinical picture. We developed our research based on this reasoning.

Even though health professionals/services working in child neurology were aware of the need for early stimulation^{9,11} and brain neuroplasticity in children during neuropsychomotor development, during the pandemic period, therapies were suspended for 46% of participants and even after the ten-month period that Brazil was in lockdown, therapies for another 35% were still suspended. For Borges¹³, 87.5% of the patients analyzed in his study had sessions interrupted during 2020, as well as other studies found in the Brazilian and international literature that corroborate the same situation that happened with the participants in this research. 3,10,13 The author cited presented as results perceptions reported by parents such as: significant motor changes such as decreased strength, increased spasticity, worsening or appearance of bone deformity, decrease and loss of functional skills such as head and trunk control. 13

The study by Magalhães et al.¹⁴ demonstrated the impacts of the pandemic on a specialized rehabilitation center and one of the strategies performed by the health team was to perform telehealth, mostly using WhatsApp®.¹⁴ The same happened in the study by Hall et al.¹⁷, who also presented telehealth as a physical therapists' resource, which increased from 2 to 47% during the pandemic in the United States of America.¹⁴ Studies whose results are similar to the findings of this research refer to families who received guidance through applications that enabled video calls.¹⁷

Some authors have been critical of the use of technology to provide guidance to parents of children with disabilities, arguing that although telecare has been a promising solution during the pandemic, it can point to health inequalities, in other words, it can increase the barriers to access to health services for families who already have them. In addition, there are families who live in remote areas where there are internet signal failures and the use of the internet may expose socioeconomic conditions, since internet services are paid for and in order to make video calls you must have a compatible electronic device. 3,5,18,19 We would also highlight the fact that Brazil still has a third of its households without internet access.⁵ One of the limitations of the online survey is the selection of participants, since most of the responses collected came from states in the southeast of Brazil, where there is a higher concentration of income and better access to the internet.

Another point to be taken into consideration is the suggestion by some authors about the need to implement home-based programs for children in low- and middle-income countries like Brazil, based on the family-centered approach, but for this to happen, parents need to receive adequate training and guidance from professionals and that they are also listened to, welcomed and trained in how to carry out the correct guidance.^{5,19-22}

The premise of the family-centered approach/service is one of the pillars for pediatric physical therapy that underscores child development. The family will provide important information to the therapist, regarding emotional, physical aspects and about the child's performance in everyday life. The family becomes co-responsible for the treatment of their child. 9.11.23 However, it is observed that when families receive no guidance on how to stimulate their children at home, the therapist becomes solely responsible for this care. 11.23 In exceptional cases where the services are suspended—as occurred during the pandemic—it is understood that all forms (or strategies) of continuing the child care are also suspended.

We found that 30% of those who did not receive any kind of guidance to encourage their children at home, the reason given was "waiting for the face-to-face sessions to resume".

One of the prerogatives of the family-centered approach is to understand that the optimal development of the child occurs within a supportive family and community environment. The therapist should seek to understand the reality in which families live, identify their needs and recognize their strengths, in addition to understanding how the family faces different situations and encouraging them in decision-making. 7.9.11,23

The pandemic exposed the limitation of some health services to help and instruct parents on how to stimulate their children at home and not only wait for the return of in-person care, without providing them with any possible date of return.

Silva²⁴ indicated that 70% of parents who care for children and adolescents aged from 4 to 18 years felt helpless during the pandemic, and 17% had difficulties in assisting in self-care activities and these parents also presented feelings of fear and anguish.

The research by Rodrigues et al.¹⁰, which involved identifying the perceptions of parents of children and adolescents with disabilities about the telerehabilitation used during the pandemic, reported that all participants agreed that the care provided contributed to improving the child's health, to understanding which exercises and/or postures are important and how stimulation should be included in the family's daily routine.¹⁰

One of the limitations found in this study was the size of the sample. Qualitative research is restricted to a small number of cases when compared to quantitative research. The number is not defined a priori, but some authors recommend varying between 02 and 60 participants.²⁵ Another limiting point to consider is the fact that there was no face-to-face interview and that some questions could have been better clarified if the interviewer had been able to talk to the children's guardians and health professionals.

We believe that more studies need to be carried out to identify specific repercussions that may have affected the neuropsychomotor development of these children. In addition to identifying why the barriers to rehabilitation services do not provide the necessary support to family members. There is a need to rethink the care practices that are carried out with families of children with disabilities.

Parents' and caregivers' responses regarding health services during the pandemic revealed feelings of concern about the suspension of rehabilitation services and fear about the possible damage to children's neuropsychomotor development.

Authors' contributions

Souza JS participated in the conception of the research question, methodological design, analysis of the research data, interpretation of the results and writing of the scientific article. Lima MCMP took part in conceiving the research question and reviewing the writing of the scientific article. All the authors have reviewed and approved the final version and are in agreement with its publication.

Conflicts of interest

No financial, legal or political conflicts involving third parties (government, private companies and foundations, etc.) have been declared for any aspect of the submitted work (including but not limited to grants and funding, participation in advisory boards, study design, manuscript preparation, statistical analysis, etc.).

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