Research, Society and Development, v. 10, n. 3, e27710313460, 2021
(CC BY 4.0) | ISSN 2525-3409 | DOI: http://dx.doi.org/10.33448/rsd-v10i3.13460

Caregivers and Physical therapists' Perceptions of Telehealth for infants with Down Syndrome during COVID-19: Case reports

Percepções dos Cuidadores e Fisioterapeutas sobre a Telessaúde em bebês com Síndrome de Down durante a COVID-19: Relato de casos

Percepciones de los Cuidadores y Fisioterapeutas sobre la Telesalud para bebés con Síndrome de Down durante el COVID-19: Informes de casos

Received: 03/02/2021 | Reviewed: 03/07/2021 | Accept: 03/07/2021 | Published: 03/16/2021

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Abstract
The aim of this study is to describe the caregivers and physical therapists' perceptions of telehealth strategies in two cases of infants with Down syndrome during the COVID-19 pandemic in Brazil. Methodology: The physical therapy intervention program was carried out using synchronous and asynchronous methods according to the social context of each family. Results: The telehealth strategies were positively evaluated by caregivers and physical therapists. Conclusion: The study concluded that telehealth has promoted satisfactory results in infants' physiotherapeutic monitoring, and it could be an additional tool for early intervention after the pandemic.
Keywords: Telemonitoring; Early intervention; Child health.

Resumo
O objetivo deste estudo é descrever as percepções de cuidadores e fisioterapeutas sobre estratégias de telessaúde em dois casos de bebês com síndrome de Down durante a pandemia de COVID-19 no Brasil. O programa de intervenção fisioterapêutica foi realizado utilizando métodos síncronos e assíncronos de acordo com o contexto social de cada família. As estratégias de telessaúde foram avaliadas positivamente por cuidadores e fisioterapeutas.O estudo concluiu que a telessaúde tem promovido resultados satisfatórios no acompanhamento fisioterapêutico de lactentes, podendo ser uma ferramenta adicional para intervenção precoce após a pandemia.
Palavras-chave: Telemonitoramento; Intervenção precoce; Saúde da criança.

Resumen
El objetivo de este estudio es describir la percepción de los cuidadores y fisioterapeutas sobre las estrategias de telesalud en dos casos de bebés con síndrome de Down durante la pandemia de COVID-19 en Brasil. El programa de intervención de fisioterapia se llevó a cabo utilizando métodos sincrónicos y asincrónicos según el contexto social de cada familia. Las estrategias de telesalud fueron evaluadas positivamente por cuidadores y fisioterapeutas. El estudio concluyó que la telesalud ha promovido resultados satisfactorios en el seguimiento fisioterapéutico de los lactantes y podría ser una herramienta adicional para la intervención temprana después de la pandemia.
Palabras clave: Telemonitorización; Intervención temprana; Salud del niño.

1. Introduction

The first case of COVID-19 in Brazil was notified on February 27, 2020 in the city of Sao Paulo. Social distancing measures were taken on March 16, 2020 in several Brazilian states (Brazil., 2020; Brazil., 2020). Due to the COVID-19 pandemic, people are at home to cooperate with social distancing policies, especially risk groups such as the elderly, patients with comorbidities and children with disabilities (Minghelli et al., 2020). Thousands of children who had been undergoing early intervention treatment had to leave the monitoring carried out in physical therapy clinics, units and rehabilitation centers due to the risks of social contact (Wijesooriya et al., 2020). Physical therapist professionals in the area of neuropediatric intervention had to find a way to ensure care for children and families, adapting to the "new normal" the COVID-19 pandemic has imposed worldwide (Field-Fote, 2020).

Telehealth, which is defined as any strategy built and guided by a qualified professional and carried out using information and communication technology (ICT) to improve the patient-health professional communication (Minghelli et al., 2020), has occupied a prominent place in the world scenario we are experiencing (Smith et al., 2020). Many countries have adopted national policies to improve their telehealth services, including the Global Strategy on Digital Health developed by the World Health Organization (World Health Organization, 2018).

The telehealth strategies for physical therapy present a high volume of scientific evidences showing benefits in the care of patients with neurological, orthopedic and cardiac diseases (Smith et al., 2020; Veerapandiyan et al., 2020). Studies showing benefits, support and efficiency in telehealth for pediatric care, though, are seldom (Hashikawa et al., 2020; Ray et al., 2020; Sisk et al., 2020), especially in early intervention on high-risk infants (Sgandurra et al., 2016).

Despite being used in several countries around the world (dos Santos et al., 2014), telehealth in Brazil had been, until then, restricted to some professional categories and following specific professional council legislation (Brazil., 2019). In the physical therapy field, the Federal Council of Physical Therapy and Occupational Therapy has authorized remote professional performance through the resolution No. 516 of March 23, 2020 (Federal Council of Physiotherapy and Occupational Therapy., 2020).

Brazil has an estimation of 240,000 physical therapists in all its national territory (Federal Council of Physiotherapy and Occupational Therapy, 2018) of which 5% operate in the area of neurorehabilitation, involving children and adults. Faced with the context of the COVID-19 pandemic, there are intervention procedures that need to be started immediately or that cannot be stopped, such as the cases of developing children. Efficient digital health strategies can boost accessibility, quality, safety and efficiency in healthcare services (Agency., 2020; Minghelli et al., 2020).

This new situation demands adaptation and inventive measures with prudency and serenity by professionals, patients and their families. In the case of physical therapy care in neuropediatrics, infants should not miss opportunities for early intervention due to the neuroplasticity issues that accompany the growth and development processes in early childhood (Hadders-Algra, 2001; Sgandurra et al., 2017).

In this context, the aim of this study is to describe the caregivers and physical therapists' perceptions of telehealth strategies in two cases of infants with Down syndrome during the COVID-19 pandemic in Brazil.

2. Methodology

2.1 Type of Study

The study is a case report involving two infants diagnosed with Down syndrome, and their caregivers and physical therapists. The case, context and telehealth strategies used for each infant will be presented below. A case study is a description and analysis as detailed as possible of a case that presents some particularity that makes it special (Pereira et al., 2018).

2.2 Ethical Aspects

This study was approved by the UFSCar Human Research Ethics Committee (CEP/UFSCar CAAE No. 33456720.9.0000.5504), through the Regulatory Guidelines and Norms for Research Involving Humans (Resolution No. 466/2012, of the National Health Council, Brazil). In both cases reported below, the guardians signed an informed consent form and signed an authorization term for the use of images.

2.3 Description of Intervention

In both cases, the concepts recommended by the biopsychosocial model of health were adopted for evaluating the infants, considering the structure and body function, activity and participation, besides personal and environmental factors about the family and the home (World Health Organization, 2001). The activities and guidelines were developed based on the best interest of the infants and their families, the health professionals' experience and on the best scientific evidence available in early intervention, which demonstrates that a child and family-centered treatment has produced better results than traditional treatments (Dirks et al., 2011; Morgan et al., 2013).

In the current study, telehealth strategies were adopted to monitor the development of the infants and to provide guidance to caregivers based on the guidelines for telehealth in Brazil within the scope of the Brazilian Public Health System (SUS) (Brazil., 2019) (universality, equity, completeness, decentralization and popular participation), the recommendations of the World Health Organization (World Health Organization, 2018), considering the individual a product of a social context and environment opportunities, and the intervention centered on the infant's family (appreciation of the parents' roles in dealing with their children's health conditions). These principles are the guidelines for the application of early intervention on high risk infants in the scope of public health.

Early intervention through telehealth consisted of weekly appointments conducted by physical therapists, who adopted synchronous and asynchronous methods according to the availability and acceptance of each family. Table 1 presents the synthesis of the strategies adopted by the therapists in attendance. Table 2 shows the general care that has been taken for the performance of telehealth sessions involving infants with Down syndrome.

Table 1 - Main telehealth strategies in early intervention.

Asynchronous Methods	Synchronous Methods
Sending of demonstrative videos of exercises for home application	Verbal guidance to parents and caregivers while performing activities in real time
Sending of didactic and illustrated material personalized with list of exercises	Demonstration of exercises on dolls or anatomical models
Use of web applications to assess the skills performed by the child	Exercises prescription for the child with joint definition between parents and therapists
Use of questionnaires and/or web applications for parents to register their opinions and difficulties in conducting the treatment program	Assessment of the home environment for adaptation guidelines as appropriate
Sending of an intervention kit containing manual, toys and guidelines for the early intervention program	Video calls using a cell phone, tablet or computer.

Source: Own authorship.

Table 2 - General care for performance of telehealth sessions.

Item	Care
Language	Use of simple and appropriate language for communicating with the child's parents and caregivers
Resources	Use of simple, inexpensive and accessible resources for adjusting posture and stimulating the child's sensory systems and skills
Safety	Ensuring child safety and protection when carrying out exercises performed by parents
Home Environment	Adaptation of the home environment according to the reality and availability of each family
Family Routine	Assessment of routine aspects of the family and parents and caregivers' roles to avoid overload of tasks
Daily Care	Daily care activities (bathing, feeding, changing clothes and diapers) were used as opportunities for posture correction and providing adequate stimulation for the infant

Source: Own authorship.

2.4 Assessment Instruments

A structured questionnaire was created for assessing the families' perception of telehealth strategies, and sent to the caregivers for obtaining information about language, material resources, physical space, infant's safety, technology, internet, responsibility, degree of difficulty for those responsible for carrying out the activities, family routine, daily care, satisfaction, participation, preferences regarding the new method of action and data on the infants' health history and conditions.

The Poverty Income Ratio (PIR) was used in association with the level of maternal education (Karlamangla et al., 2010) to identify the socioeconomic level of the families. The Alberta Infant Motor Scale (AIMS), which is a validated and highly reliable instrument (Piper, 1994) frequently used on infants with Down syndrome (Moriyama et al., 2020), was used to assess the motor development of the infants.

A second structured questionnaire was created to assess the therapist's perception of telehealth practice, involving aspects related to the use of technology, easiness, reliability, quality and recommendation of use during and after the pandemic in Brazil.

3. Case Description 1

The infant 1's mother sought out the physical therapist responsible for the Early Intervention Project in the second month in which social distancing measures had been taken due to COVID-19 in Brazil. Her infant, a male, was 35 days old and had been born by cesarean delivery at a gestational age of 36 weeks, and was diagnosed with Down syndrome upon birth. The conversation happened through a messaging application. After the mother exposed the infant's health condition and explained her concern, the therapist proposed to use telehealth strategies, which the mother readily accepted. Infant 1's mother is 35 years old and the father is 39 years old.

The physical therapist asked the guardian to record and send a short video of the infant in the prone, supine, sitting and standing positions (according to the AIMS), for carrying out the evaluation. After evaluating with AIMS, the intervention goals were defined according to the deficiencies of the body's structures and functions, activity limitations and participation restrictions. The expectations of the guardians were also considered as goals. For this, the maternal experience, the objects for stimulation of the infant and the environmental conditions were taken into account.

The proposed activities were simple, allowing the guardians to carry them out during the day, that is, in the moments of play and during the infant's daily care. In addition, the guardians were instructed that the infant should be in an alert state and very comfortable during the activities, which should be interrupted as soon as the infant showed any displeasure.

In the first 43 days, the asynchronous method was chosen; it was carried out by the project coordinator. The infant's guardians were asked to communicate with the physical therapist in case of any doubts before putting the guided activities into practice; it should be carried out three times a day in the morning, afternoon and evening periods, but the real frequency and duration would be determined by the infant, that is, while his responses were of acceptance. The physical therapist would send new tasks weekly, complementing the previous ones, according to the guardian's practice adherence and the infant's participation.

For each proposed activity, the therapist would set the appropriate environment for the infant's positioning and safety, the necessary materials, and the positioning of the infant's guardians. Then, the therapist would define what stimulus to give and the expected response, pointing out that due to the infant's health condition, the delay between stimulus and response might be relatively long and that the guardian should be patient, observing the expected behavioral responses and facial expressions of the infant. If he showed displeasure by frowning, arching their back, crying, or grumbling, the activity should be interrupted. In order to obtain better results and greater adherence to physical therapy by the mother, the activities should be pleasurable for both the infant and their guardian.

The therapist recorded the activities using a good-resolution camera. The activities were performed on an articulated fabric doll made by the therapist. During the recording, the therapist demonstrated step by step the activities on the doll, and explained everything calmly and in simple language, so that the guardians could easily understand the guidelines (Figure 1). In addition to the recording, the guardians were sent illustrations of books showing the stimulations, guided activities and informative texts about Down syndrome.

Figure 1 - Illustration of an asynchronous telehealth strategy. Therapist demonstrating the exercise on the doll (A) and the child's mother performing at home at a different time (B).

Source: Own authorship.

After 43 days, the early intervention was continued by another therapist under the supervision of the coordinator. The strategy now became synchronous and the therapist could perform the necessary activities and corrections with the infant's guardian in real time.

The therapist prioritized using a free and safe video call application that was suitable for both. The video calls were made once a week at a time previously scheduled according to the availability of the guardians and at a suitable time for the infant. The physical therapist would request in advance the materials that would be used and how the physical space should be organized. During the calls, the therapist would ensure that the infant's guardian was comfortable, and clearly listening and watching the instructions. The activities would be, then, explained step by step using the articulated fabric doll while carefully observed by the guardian. If there were no doubts about the activities, the guardian would replicate the same activities in the infant. The therapist would always ensure that the mother was carrying out the oriented activities correctly (Figures 2 and 3).

Figure 2 - Illustration of a synchronous strategy. The therapist demonstrating the exercise on the doll (small screen) and the child's mother performing at home after the demonstration (larger screen).

Source: Own authorship.

Figure 3 - Illustration of a synchronous strategy. The therapist demonstrating the exercise on the doll (A) and the child's mother performing at home after the demonstration (B).

Source: Own authorship.

When internet network was not stable enough to carry out the video calls, the hybrid strategy was adopted, that is, the association of synchronous and asynchronous methods.

4. Description of Case 2

The infant 2, a female, was born by cesarean delivery at a gestational age of 35 weeks, when both her parents were 36 years old. She started face-to-face physical therapy treatment when she was 57 days old in the pre-pandemic period of COVID-19. It lasted for 90 days until the beginning of the social distancing. The infant is the second child of a planned pregnancy with uneventful prenatal care. However, she was diagnosed with Down syndrome upon birth.

During social distancing, the physical therapist kept in contact with the family and was informed that both the infant and the other family members tested positive for COVID-19. The infant developed a fever in the first days but did not develop any other symptoms, and remained at home in social distancing. After the infant's recovery, the therapist contacted the family to invite them to participate in the telehealth strategies. The infant's guardian accepted the invite and a face-to-face visit was scheduled at their home. AIMS was used to assess the infant and outline the goals of the intervention. The therapist explained the activities that should be practiced by demonstrating them on the infant and gave a booklet to the infant's guardians with descriptions and illustrations of the activities.

The booklet consisted of a series of activities and postures for a three-week period. The postures proposed in the booklet evolved each week. The activities should be carried out three times a day, according to the infant's acceptance. The therapist would exchange weekly text messages with the infant's guardians for monitoring the guided activities and determine their continuity. The therapist could be contacted at any time in case there were any doubts.

Therefore, the telehealth strategy was hybrid, the assessment and the initial guidelines were carried out in person, and the monitoring was carried out by virtual means asynchronously.

5. Results

The cases presented involved two infants with Down syndrome who started the early intervention treatment at 35 days and 57 days old. Both families were classified according to the Poverty Income Ratio with high socioeconomic status (7.8 and 8.4 scores).

The results of the caregivers' perceptions of telehealth strategies are shown in Table 3 and the physical therapists' perceptions in Table 4.

Table 3 - Results of caregivers' perception of the telehealth strategies.

Nº.	Assessed items	Case 1	Case 2
1	Language	10	10
2	Material resources	10	10
3	Physical space	10	10
4	Safety	10	8
5	Technology means	10	10
6	Internet	10	10
7	Responsibility	8	5
8	Level of easiness	9	9
9	Family routine	9	5
10	Daily care routine	10	8
11	Satisfaction and participation	10	10
12	Infant's improvement	10	8
13	Participation of other home members	10	3
14	Template preferences	Hybrid (asynchronous and synchronous)	Hybrid (face-to-face and asynchronous)

Note: Questionnaire answers were organized using a visual analog scale from zero to ten. Zero being the worst possible response and ten the best possible response. Source: Own authorship.

According to Table 3, the caregivers' perceptions of telehealth strategies were positive, with infant's guardians for Case 1 presenting answers with higher scores, especially in items related to responsibility, family routine and participation of other family members, compared to the infant's guardian of Case 2.

According to Table 4, the physical therapists' perceptions were positive, with similar scores, demonstrating easiness with the application of strategies used in telehealth, handling of technological resources and recommendations for the continuity of telehealth in Brazil during and after the COVID-19 pandemic.

Table 4 - Results of the physical therapists' perception of telehealth strategies.

N	Assessed items	A	B	C
1	Years of professional experience of the physical therapist	43	3	14
2	Confidence in telehealth physical therapy care	10	10	10
3	Level of easiness for practical use of telehealth	10	10	10
4	Level of experience with technological resources	8	9	9
5	Communication and understanding of the infant's guardians in relation to the proposed activities	10	9	10
6	Easiness of equipment usage / materials to guide and demonstrate activities	10	10	8
7	Perception about the home environment	10	10	10
8	Opinion on the acceptance of the guardians	10	10	10
9	Recommendation for using telehealth during social distancing	9	9	9
10	Recommendation for using telehealth after the pandemic	9	9	9

Note: Questionnaire answers were organized using a visual analog scale from zero to ten. Zero being the worst possible response and ten the best possible response.
Source: of their own authorship.

Table 5 describes the main factors pointed out by therapists as facilitating or limiting the telehealth service in early intervention.

Table 5 - Factors that facilitate and limit access to the telehealth service.

Facilitating Factors	Limiting Factors
Reduction of costs with transportation of patients	Absence of physical contact with the infant and physical interaction with the family
Decreased time of travel of the patient to the physical therapy service's location	Difficulty with understanding and orienting certain exercises
Reduction of waiting lines and crowding in Physical therapy services	Little training / experience of telehealth professionals
Facilitating access to infants and families who live far away from specialized Early Intervention services' location	Family adherence difficulties for this type of service
Compliance with the basic principles of health care quality: safe, timely, effective, efficient, equitable and patient-centered	Low level of education of parents and families may make it difficult for them to understand the guidance and instructions of therapists
Closer knowledge of the infants and their families' personal and environmental factors in the home environment.	Not enough scientific evidence to assess the impact of telehealth on the health and development of infants in early intervention
Possibility to care for more infants a day	Difficulties in accessing communication and internet devices at the infants' home

Source: Adapted from WHO[7] and the Australian Digital Healthcare Agency[17].

6. Discussion

The present study described the caregivers and physical therapists' perceptions of the practice of telehealth in two cases of infants with Down syndrome during the COVID-19 pandemic in Brazil. The strategies used were available to Brazilian physical therapists after the release of the Professional Council in March 2020.

Considering the COVID-19 pandemic in the global context, Veerapandiyan et al.[8] recommended the continuity of remote physical therapy sessions, analyzing each case individually and the context of each service. Likewise, we find early intervention necessary since the first months of life in high-risk infants, such as in Down syndrome cases. The development of infants is a dynamic process, the product of biological, environmental and social interactions. The environment has a fundamental role in neuropsychomotor development, since the process of functional plasticity of body systems is in full activity, indicating the windows of opportunity for the development of basic motor skills (Hadders-Algra, 2001; Sgandurra et al., 2017). In this sense, it was necessary to implement telehealth strategies in our specialized service in early intervention, adopting synchronous, asynchronous and hybrid strategies in infants with Down syndrome who needed to start and continue with care.

Following the guidelines from WHO (World Health Organization, 2018) and the Australian Digital Healthcare Agency (Australian Digital Healthcare Agency., 2020), the guided activities were simple (performed in the routine of daily care) and based on the socioeconomic and educational level of the caregivers. Thus, the care offered in this study obtained acceptance and adherence from families during the three months of care, which provided autonomy for caregivers to carry out the oriented activities, and according to their perceptions, improvement of the infants' motor development.

Despite these positive factors, it is important to highlight the importance of the participation of other family members in the treatment, since one of the families reported signs of tiredness and overload due to the accumulation of domestic tasks. In addition, the therapist must be aware that the responsibility for the physical therapeutic intervention should not be transferred to the guardians, be empathetic with the dynamics of each family, and also resolve the doubts presented. On the other hand, the family must actively participate in the guidelines provided and request help whenever it is necessary (Dimer et al., 2020).

Three telehealth modalities have been used in this study. In the asynchronous modality, the caregivers have had more flexibility in managing time to carry out the activities proposed by the physical therapist; in its turn, the synchronous modality has enabled the caregiver to solve any doubts in real time. The hybrid model mixes both modalities and is the families' favorite. The results are concordant with the study by Wijesooriya et al. (Wijesooriya et al., 2020), defending that this was one of the lessons left by the COVID-19 pandemic, which is directing public health care strategies towards telehealth, making the patients and their families the protagonists of their health conditions and actively monitoring their own treatment.

In the present study, family members showed preference in adopting the hybrid telehealth model. Since this model allows the guardians to practice the activities previously oriented (asynchronously) and to solve doubts about the activities with the therapist in real time (synchronously). The results are in agreement with the study by Wijesooriya et al. (Wijesooriya et al., 2020) in arguing that this was one of the lessons left by the COVID-19 pandemic, which is directing public health care strategies towards telehealth, making the patients and their families the protagonists of their health conditions and actively monitoring their own treatment.

As for the professionals' perceptions, the results revealed that both the most experienced and the least experienced therapists had similar opinions regarding the conduct of telehealth strategies and recommend their continuity even after the COVID-19 pandemic. These results were in accordance with another Brazilian study (Dimer et al., 2020) which evaluated the benefits of speech therapy using telehealth strategies.

It is important to note that regardless of the strategies used by the physical therapists, all procedures adopted in telehealth must follow the same technical and ethical precepts used in face-to-face care. In addition, professionals must respect the requirements of cybersecurity and protection of personal data in accordance with the General Data Protection Law (Brazil., 2019).

There are some limitations in performing high quality early home intervention that may differ from family to family, because the home environments are varied and difficult to control. On the other hand, the main advantage for families is not needing to travel to early intervention service's locations and the possibility of learning how to stimulate their infant from home (Dimer et al., 2020). In our proposal, the limiting factors described in the results could be overcome thanks to the option to remotely manage training at home. In addition, the easiness found by professionals for families to adhere to telemonitoring service may be related to the socioeconomic conditions of the infants' families and their maternal educational level, these factors are considered protective to the infants' development (Wood et al., 2020).

In Brazil, which is a country of continental dimensions and with many social and economic inequalities (Brazil., 2020), telehealth strategies may be a more accessible way for low-income families or for those who live in regions which are far from specialized services' locations, because the cost with transportation would be minimized, corroborating to the World Health Organization's recommendations[7]. However, not all families have good quality internet access. Reinforcement to public policies that bring technologies to such families would be needed in order to implement telehealth country-wide (Ray et al., 2020).

Since telehealth is an innovative practice for physical therapy, it is important to highlight that this is a pioneer study in the scope of physical therapy in early intervention. Therefore, professionals are being trained and updated on how to

implement such a method in an effective and responsible way; doubts and uncertainties may arise during the process. Despite the favorable results of the present study, it is important to highlight that telehealth is not a substitute for face-to-face care, and can be adopted as a complementary intervention for monitoring infants in catastrophic situations, geographical distance, lack of professionals in the area and during vacation periods.

7. Conclusion

The study revealed that the telehealth strategies adopted allowed the physical therapists to achieve the goals proposed in the evaluation of the infants with Down syndrome. The caregivers and physical therapists' perceptions were positive and favorable to early telehealth intervention. The results of this study are preliminary and further research is needed to assess the impact of telehealth on the infants' development and quality of life the medium and long-term.

Acknowledgments

We thank the family members for participating in the research and the São Paulo State Research Support Foundation (FAPESP), process nº 2018/24930-0.

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