

ARTICLE



The impact of the pandemic on physical and functional disabilities in children and adolescents with spina bifida

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STUDY DESIGN: Retrospective and cross-sectional study.

OBJECTIVES: The study aimed to carry out telemonitoring to identify the impact of the pandemic on physical and functional disabilities in children and adolescents with SB, as reported by their caregivers, and to investigate adherence to a teleservice.

SETTING: Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto da Universidade de São Paulo (HCFMRP-USP).

METHODS: Retrospective and cross-sectional study. Fifty-three patients with SB (mean age 12.0 (4.0) years; 23 males) participated in the telemonitoring. A questionnaire – ‘Health management, health conditions, rehabilitation, interest in teleservice, and the well-being of the main caregiver’ – investigated the clinical impact of the coronavirus pandemic. Only three caregivers participated in the teleservice (video call).

RESULTS: According to telemonitoring, 62% of the patients discontinued physiotherapy sessions, and 69% reported needing adjustments in locomotion devices. The main complaints were muscle weakness and pain.

CONCLUSION: We monitored general health and identified demands related to physical rehabilitation using telemonitoring in 42.4% of children and adolescents with SB monitored at the HCFMRP-USP. Telemonitoring and teleservice may be methods used for monitoring health conditions in patients with SB.

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INTRODUCTION

Spina bifida (SB) is a congenital malformation resulting from the failure of the neural tube to close, usually between the 17th and 30th days of foetal growth [1]. Because the spinal cord becomes dysplastic [2], children and adolescents diagnosed with SB may have neurological dysfunction [1] and urological and dermatological impairments [3]. The muscular and sensory functions of the trunk, upper limbs, and lower limbs will be influenced by the level of spinal cord injury and lifestyle [1–4]. The rehabilitation process plays a significant role in the curative and preventive contexts.

In 2020, the coronavirus pandemic imposed severe limitations on individual freedoms through social distancing to avoid the collapse of the health system. There was an increase in the use of technologies (smartphones, notebooks, tablets and other devices) and a significant restriction on physical activity during this important physical and mental developmental phase [5, 6].

Many healthcare centres adopted telemedicine during the pandemic [7–9]. The telemedicine approach has increased substantially during the last two years, and it can be defined as the use of technologies to transmit medical information between health professionals and patients. It is a trend with continuous international growth [9]. Telemonitoring is a simple model – the patient receives support from the health professional based on their report of their symptoms and specific difficulties during a

phone call [9]. In teleservice, a video call provides additional visual information and diagnostic signs [10], facilitating the ability of health professionals to offer guidance. Some studies have already shown that patients assisted with this last intervention had the same quality of care as those who received it in person [11–13].

In this context, the present study hypothesised that children and adolescents with SB who participated in an outpatient service situated in a tertiary clinical hospital suffered significant losses in their motor skills and were interested in participating in teleservice. Thus, the objectives of the study were twofold: (1) to carry out telemonitoring to diagnose the impact induced by the pandemic on the functionality and quality of life of children and adolescents with SB as reported by their caregivers, and (2) to investigate their adherence to a teleservice that would mitigate the physical and functional disabilities caused by social distancing.

MATERIALS AND METHODS

Study characterisation

In this retrospective, cross-sectional study, participants were recruited from the outpatient clinic at the Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto da Universidade de São Paulo (HCFMRP-USP) during the period between March and September 2021. In the pre-pandemic period, patient follow-up occurred in the outpatient clinic at least every 12 months.

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Ethical aspects

During the initial telephone contact the informed consent was obtained from all subjects. The Human Research Ethics Committee of the HCFMRP-USP approved this study (CAAE 55835721.0.0000.5440/2022).

Subjects

The study included 125 children and adolescents with SB who were treated in the outpatient clinic. Inclusion criteria included the following: (1) diagnosis of spina bifida, (2) age between 2 and 18 years, and (3) accompaniment by at least one clinical professional of the HCFMRP-USP team. Exclusion criteria included the following: (1) unsuccessful phone call (two attempts were made), (2) network/telephony signal fluctuation, (3) unreceptive family and (4) unavailability of the primary caregiver. A team of three physical therapists specialising in paediatric disorders participated in the entire process.

Procedures

The study was divided into two stages. The first stage focused on telemonitoring, and the second stage on teleservice.

Telemonitoring. Initially, we collected and organised data from each participant (full name, HCFMRP-USP registration number, date of birth, main caregiver's name and phone numbers) in an Excel® spreadsheet.

A questionnaire about the clinical conditions and impact of the pandemic on health conditions in children and adolescents with spina bifida was developed by our research group and used to collect telemonitoring information (Supplementary material 1). The questionnaire consisted of 20 items divided into 6 categories: (1) general data, (2) health management, (3) health condition, (4) rehabilitation, (5) interest in participating in teleservice and (6) the well-being of the primary caregiver. The questionnaire was created on Google Forms, and caregivers' responses were recorded during phone calls.

Teleservice. After the telemonitoring stage, we analyzed the responses to start the teleservice with the interested participants. A computer from the Rehabilitation Centre at HCFMRP-USP was used to carry out the video calls.

Based on the clinical experience and the demands identified in the first stage, our research group formulated the teleservice form (Supplementary material 2), which was used during the video calls. This form contained questions regarding the following: (1) complaints regarding the musculoskeletal system, such as the presence of pain and muscle weakness; (2) complaints regarding the cardiorespiratory system, such as tiredness and dyspnoea; (3) the level of independence for daily life activities, for example, personal hygiene, feeding and transfer; (4) the use and quality of wheelchair and/or auxiliary devices and orthotics and (5) the performance of home-based exercises, including type, duration, intensity and frequency.

In addition, during the teleservice, participant's demands were identified, and guidance was offered, directing them to face-to-face service if necessary. The information collected in the teleservice was recorded in each participant's electronic medical record in the HCFMRP-USP system.

Statistical analysis

An exploratory analysis of the data was performed. Subsequently, the descriptive statistical analysis of all variables was performed and presented as mean, standard deviation, absolute value and percentage in Microsoft Excel software.

RESULTS

Of the 125 potentially participants, 45 participants did not answer the phone call after two attempts made on different days, 12 participants abandoned the HCFMRP-USP, 2 participants were unreceptiveness and 13 participants were being over 18 years old. Therefore, 53 participants were included in the study.

Telemonitoring

The mean age of the participants was 12.0 (SD = 4.0) years, 23 participants were males ($M = 12.3$ [SD = 4.19] years) and 30 females ($M = 11.8$ [SD = 3.16] years). The survey with the caregivers indicated that 21% of the participants had declined health management compared to the pre-pandemic and 11% had decreased in their functional status since their last in-person assessment (Fig. 1). In addition, 26% reported have had illnesses such as urinary tract infections or seizures.

Regarding rehabilitation, most caregivers (62%) reported that participants stopped physiotherapy sessions due to social-distancing recommendations and the interruption of services provided during the coronavirus pandemic. The other participants (38%) completed their physical therapy treatment at private clinics (94.7%) or at home (5.3%). Ninety-eight percent (98%) of the total participants used wheelchairs, assistive devices and orthotics for locomotion in different length paths. Of this total, 69% reported a need to adjust the equipment (or device) (Fig. 2).

Concerning the impact of the pandemic on health conditions in children and adolescents with spina bifida, 16% of the caregivers reported insecurity about returning to outpatient clinics for assessments, 40% of caregivers shared their household and childcare tasks with others. All caregivers felt welcomed, and 87% felt better after the care provided by phone call (Table 1).

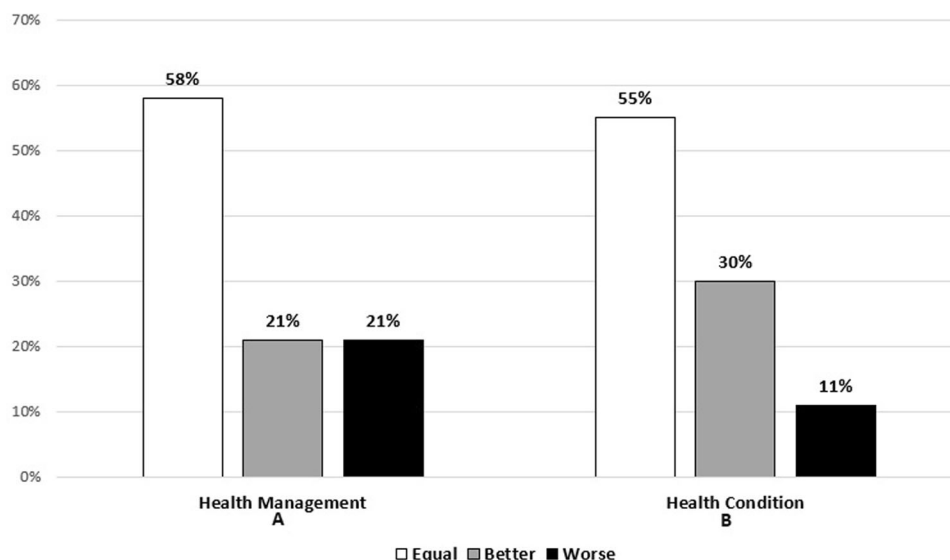
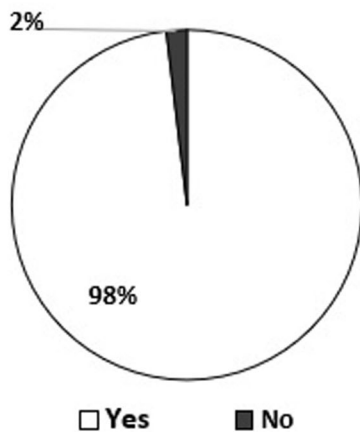


Fig. 1 The impact of the pandemic on health in children and adolescents with spina bifida. Results of the health management (A) and health condition (B) reported during telemonitoring compared to the pre-pandemic period.

Use of mobility devices



Need for adjustments in mobility devices

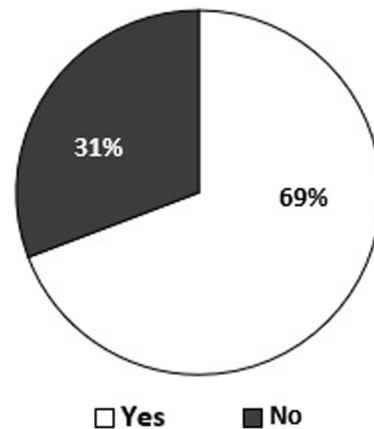


Fig. 2 The mobility devices used by children and adolescents with spina bifida. Percentage of use (A) and need for adjustments (B) to these devices during the coronavirus pandemic.

Table 1. Frequency of responses of the caregivers of children and adolescents with spina bifida about their well-being during the coronavirus pandemic.

	Yes	Partially	No
Does someone share the household chores and care of your son/daughter (the child or adolescent with spina bifida) with you?	60%	0%	40%
Do you feel better after this phone call?	87%	11%	2%
Do you feel welcome during this phone call?	100%	0%	0%

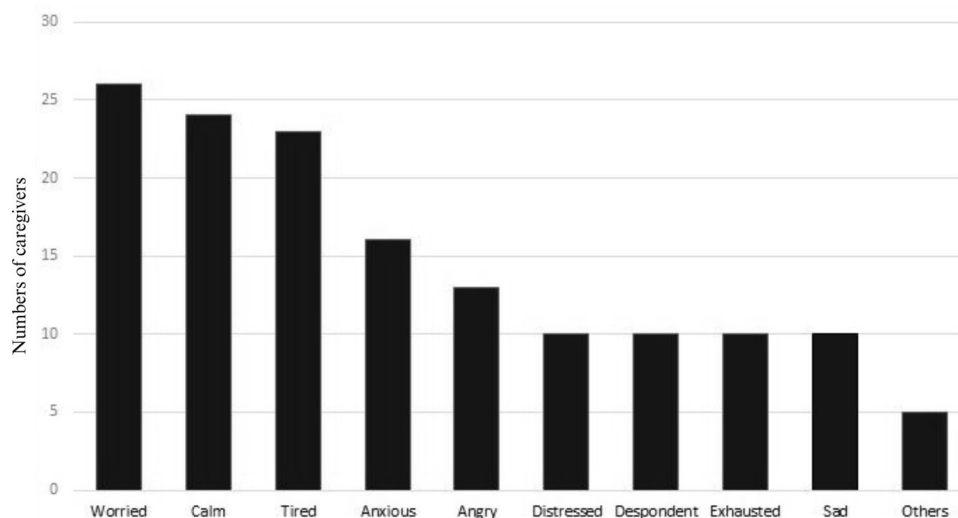


Fig. 3 Distribution of the responses from caregivers about their feelings during the coronavirus pandemic.

Also, concerning the well-being of the primary caregiver, they reported feeling 'worried', 'calm' and 'tired' (Fig. 3).

Teleservice. Fifty families (94%) from the telemonitoring expressed interest in participating in the teleservice. Subsequently, we scheduled 17 families, but only 3 completed the video call. The other 14 did not answer the phone and did not return the call. Consequently, after six weeks, the teleservice was interrupted.

The first participant was a 6-year-old community ambulatory female. The patient and her mother participated in the video call. The child was attending physical therapy at a private clinic, but her mother reported lower limb muscle weakness and requested an appointment at our Rehabilitation Centre for possible orthotic modifications. Considering the facts reported, both agreed to be assessed in our outpatient clinic (Table 2).

The second participant was a male 12-year-old adolescent, who was wheelchair-user. The patient and his mother participated in

Table 2. Characteristics and demands related to the health and rehabilitation conditions of children and adolescents with spina bifida treated using teleservice.

	Participant 1	Participant 2	Participant 3
Age (years)	6	12	13
Sex	Female	Male	Female
Level of spinal cord injury	Low lumbar	High lumbar	Thoracic
Type of locomotion	Independent ambulation	Wheelchair	Wheelchair
Auxiliary devices for locomotion and orthotics	None	Bilateral ankle and foot orthosis	None
Complaints regarding the musculoskeletal system	Weakness in lower limb muscles	Neck and shoulder pain; weakness in upper limb muscles	Back pain
Complaints regarding the cardiorespiratory system	Fatigue when walking long distances	No complaints	No complaints
Level of independence in daily life tasks	Caregiver assistance with feeding, bathing and dressing	Caregiver assistance with feeding, bathing and dressing	Caregiver assistance with feeding, bathing and transferring from the wheelchair to the sofa
Home-based exercises	Physiotherapy in private service twice per week	None	None
Guidelines and referrals	Good guidance by the other medical services; orthosis order checked, awaiting delivery	Child interested in returning to face-to-face physical therapy treatment	Child interested in receiving home exercise booklet

the video call. They reported that since the beginning of the pandemic, he has not had physical therapy and has a tight orthosis that should be re-assessed. He described pain and weakness in his shoulders. The professionals provided exercise guidelines for this symptom. The adolescent and his caregiver agreed to be assessed in our outpatient clinic (Table 2).

The last successful video call was performed with a female 13-year-old patient, who was a wheelchair user for all distances, and her mother. The patient stopped attending physiotherapy sessions when she was 8 years old. Currently, the patient complained of back pain. The professionals provided an exercise guideline for this symptom. The patient and the caregiver agreed to be assessed in our outpatient clinic (Table 2).

DISCUSSION

The telemonitoring allowed us to identify demands related to physical rehabilitation in 42.4% of children and adolescents with SB followed in our outpatient clinic. Most of these participants stopped attending physiotherapy sessions due to restrictions imposed by the coronavirus pandemic. Among the main complaints described by the caregivers, the most common was the need for adaptations/adjustments to devices used in locomotion, such as wheelchairs and orthotics. The reduction in physical therapy sessions (62%) and the need for orthotic or equipment modifications may have contributed to the reported functional decline related by the participants. In addition, the pandemic may have assisted to a more sedentary behaviour also supported to changes in our participants' functional and health status. Social isolation may additionally lead to symptoms of depression and anxiety which may result in reduced physical activity level and functional decline [14].

Although 16% of the caregivers interviewed reported insecurity about returning their children to face-to-face evaluations and treatment at the Rehabilitation Centre and 94% of them demonstrated interest in participating in the teleservice, only 17.6% participated in the teleservice (video calls). Several factors may have contributed to low adherence to teleservice, for example, a lack of time and overload of caregivers [15, 16]. Socioeconomic factors may also contribute to low adherence, as approximately 12.6 million Brazilian families do not have internet access [17], making teleservice a restricted facility. Research on

telerehabilitation is ongoing by other research groups, and there are several questions to be answered, such as the effectiveness of and patient satisfaction with this new modality of care [18].

Limitations of the study include the fact that some telephone numbers were outdated in our electronic system. Difficulties with internet access or the use of the electronic devices were not questioned, and they could partially explain the low adherence to the teleservice.

CONCLUSION

The coronavirus pandemic has significantly changed the health care routines of children and adolescents with SB. The educational, health care and rehabilitation domains were fully transferred to caregivers. Telemonitoring provided a method for tracking functional and health changes in the study population. Adherence to the teleservice was low, requiring further investigation of the related factors for future applications.

DATA AVAILABILITY

The dataset is stored in a research cabinet at the Department of Health Sciences at the Ribeirão Preto Medical School at the University of São Paulo.

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AUTHOR CONTRIBUTIONS

ESE was responsible for data curation, formal analysis, funding acquisition, investigation, methodology, resources, visualisation, and original draft writing. CSBF was responsible for formal analysis, funding acquisition, investigation, methodology, resources, visualisation, supervision, visualisation, and original draft writing. EJM, DCPA, and KLTC were responsible for software, funding acquisition, investigation, methodology, resources, and writing - review, and editing. ACMS was responsible for conceptualisation, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, resources, software, supervision, visualisation, writing - review, and editing. All authors confirm that they have full access to all the data in the study. All authors critically read and approved the final manuscript before submission and publishing. The authors and co-authors agree that they should be accountable for all aspects of the work in the present article.

COMPETING INTERESTS

The authors declare no competing interests.

ETHICAL APPROVAL

The research is in accordance with the Declaration of Helsinki. During the initial telephone contact, informed consent was obtained from all subjects. The Human Research Ethics Committee of the HCFMRP-USP approved this study (CAAE 55835721.0.0000.5440/2022).

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at <https://doi.org/10.1038/s41394-024-00674-x>.

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