

TELEHEALTH FOR CHILDREN AND ADOLESCENTS WITH PHYSICAL DISABILITIES DURING THE COVID-19 PANDEMIC

TELEATENDIMENTO A CRIANÇAS E ADOLESCENTES COM DEFICIÊNCIAS FÍSICAS DURANTE A PANDEMIA COVID-19

PATRICIA MORENO GRANGEIRO^{1,2} , MOISÉS DE FREITAS LAURENTINO^{1,2} , FERNANDA GÉA DE LUCENA GOMES² , DANIELA SIMONE ALVAREZ² , CÉSAR AUGUSTO MOREIRA² , NATÁLIA ANGÉLICA DE SOUZA² , JENNIFER MACENA BALBINO² , CANDIDO LEONELLI² , RICARDO MARCONDES MACÉA² , CLOVIS ARTUR ALMEIDA DA SILVA³ 

1. Universidade de São Paulo, Faculty of Medicine, Hospital das Clínicas, Institute of Orthopedics and Traumatology, HC-FMUSP, São Paulo, SP, Brazil.

2. Instituto Remo Meu Rumo, Non-Governmental Sports Organization, São Paulo, SP, Brazil.

3. Universidade de São Paulo, Faculty of Medicine, Hospital das Clínicas, Adolescent Unit, Children and Adolescent Institute, HC-FMUSP, São Paulo, SP, Brazil.

ABSTRACT

Children and adolescents with physical disabilities have motor and social-emotional challenges that interfere with their health-related quality of life and put them at greater risk of developing secondary conditions. Moreover, services that provide them therapies are more likely to be restricted, especially for the low-income population. There must be broader actions towards health promotion, offering not only means for physical habilitation and rehabilitation but for social and emotional improvements as well. This goal is attainable by adaptive sports and recreational activities where physical conditioning is accompanied by an improvement in self-esteem and social benefits. With the COVID-19 pandemic and social isolation, children and adolescents with physical disabilities were even further deprived of assistance. Our aim was to report the efforts of a non-governmental sports organization in maintaining physical and psychological care through virtual consultations and to analyze the perceptions of those affected by the process. **Level of evidence IV; case series.**

Keywords: Telemedicine. Disabled Persons. Child Health. Adolescent. COVID-19. Organization, Non-Governmental.

RESUMO

Crianças e adolescentes com deficiência física apresentam desafios motores e socioemocionais que interferem na qualidade de vida relacionada à saúde e os colocam em maior risco de desenvolver doenças secundárias. Além disso, estão mais sujeitos a restrições de serviços adequados que ofereçam terapias, principalmente para a população de baixa renda social. Torna-se necessário oferecer ações voltadas para a promoção da saúde em um sentido mais amplo, oferecendo não só meios de habilitação e reabilitação física, mas também de ganhos sociais e emocionais. Este objetivo pode ser atingido com esportes adaptados e atividades recreativas nos quais o condicionamento físico é acompanhado por ganhos em autoestima e benefícios sociais. Com a pandemia de COVID-19 e o isolamento social, crianças e adolescentes com deficiência física ficaram ainda mais privados de assistência. Relatamos aqui o esforço de uma organização não-governamental esportiva em manter o atendimento físico e psicológico por meio de consultas virtuais, e avaliamos as percepções das partes interessadas no processo. **Nível de evidência IV; série de casos.**

Descritores: Telemedicina. Pessoas com Deficiência. Saúde da Criança. Adolescentes. COVID-19. Organização não Governamental.

Citation: Grangeiro PM, Laurentino MF, Gomes FGL, Alvarez DS, Moreira CA, Souza NA, Balbino JM, Leonelli C, Macéa RM, Silva CAA. Telehealth for Children and Adolescents with Physical Disabilities during the COVID-19 Pandemic. *Acta Ortop Bras.* [online]. 2022;30(1)Esp.: Page 1 of 4. Available from URL: <http://www.scielo.br/aob>.

INTRODUCTION

Children and adolescents with physical disabilities have a myriad of challenges throughout their lives that may hinder interactions with others and the environment. Motor impairment in this age group interferes with psychosocial health and health-related quality of life and impairs their full development into adulthood. Due to mobility restraints and lack of proper facilities they lead a more sedentary lifestyle and are at risk of secondary chronic conditions. Interventions promoting physical activity and sports participation among children

and adolescents with disabilities should be stimulated as a means to improve health and wellbeing in this population.

A large group of neurological and musculoskeletal conditions results in motor disabilities and are heterogeneous in etiology, severity and associated impairments. In spite of that, health should not be defined as a medical issue only. As of 2011, the World Health Organization (WHO) proposed a more comprehensive concept of health with the publication of the International Classification of Health, Disability and Function (ICF)¹ and depicted body function

All authors declare no potential conflict of interest related to this article.

The study was conducted at Universidade de São Paulo, Faculty of Medicine, Hospital das Clínicas, Institute of Orthopedics and Traumatology, HC-FMUSP, Sao Paulo, SP, Brazil and at Instituto Remo Meu Rumo, Non-Governmental Sports Organization, Sao Paulo, SP, Brazil.

Correspondence: Patricia Moreno Grangeiro. Rua: Dr. Ovidio Pires de Campos, 333, Sala 317, 3o andar, Cerqueira César, Sao Paulo, SP, Brazil. 05403-010. patricia.moreno@hc.fm.usp.br

Article received on 01/29/2021, approved in 04/30/2021.



and structure, activity and participation as the three dimensions of health. Participation is defined in the ICF as 'involvement in a life situation' and is an essential aspect of children and adolescents' health, development, and wellbeing.¹ In this way, it is just as important treating individuals concerning their illness or impairment as it is promoting participation in activities and settings that provide an appropriate level of challenge, social engagement, belonging, and autonomy so young people with disabilities reach their full potential throughout their life.²

The most prevalent chronic condition that causes disability in childhood is cerebral palsy (CP) and much has been published on the benefits for children and adolescents with CP engaging in physical activity and sports programs. Rosenbaum and Gorter pointed out that children and adolescents with disabilities are often "deprived" of opportunities to practice a skill and develop their potential without expecting "normality".³ They emphasize that the six "f"s - function, family, fitness, fun, friends and future - are relevant key elements for a child with CP to develop a sense of achievement.

Furthermore, mobility restraints interfere greatly with many aspects of these youngsters' lives including school attendance and education, ultimately leading to less employment opportunities.⁴ Young people with physical disabilities and their families are at a higher risk of being at an economic disadvantage.⁴ Thus, in addition to activity limitation and participation restrictions, they have less access to health services. There must be actions towards health promotion in a broader sense offering not only means for physical habilitation and rehabilitation but for social and emotional gains as well. This goal is attainable by adaptive sports and recreational activities where physical conditioning is accompanied by an improvement in self-esteem and social benefits. Rowing is one of the most complete sports. Because it is an aerobic sport, it provides caloric burning and gains in muscle strength combined with a consequent global postural alignment, given the use of several muscle chains whilst rowing. Adapted rowing presents children and young people with physical disabilities the opportunity not only to engage in an activity that brings health benefits, but also for personal development, discipline and socialization.

Instituto Remo Meu Rumo (IRMR) is a Brazilian non-profit organization established in 2013 that provides rowing and canoeing to children and adolescents with physical disabilities on a regular basis. Among participants' conditions are CP but also myelomeningocele, Down syndrome, spinal cord injury, autism spectrum disorder, among others, including typical development children, in a truly inclusive environment. An interdisciplinary health care team of physical educators, physical therapists, a psychologist and a social worker have a daily routine to improve function and prepare children and adolescents with disabilities for rowing and canoeing and all the beneficial effects of this activity.⁵

The need for social distancing in order to avoid the dissemination of the coronavirus infectious disease 2019 (COVID-19) resulted in the suspension of IRMR activities and also school activities⁶⁻⁸ leading to physical, psychological and social damage to this population, a situation which is already considered a secondary effect of the pandemic.⁸ According to WHO, in relation to social distancing, adolescents and their families should be encouraged to count on sports and carry on with positivity and, in the face of setbacks, maintain routines, discourage bad habits, maintain calm, stress control and resilience when confronting COVID-19 and its consequences.⁹ This was approved by the Ethics Committee for Analysis of Research Projects (CAPPesq) (number CAAE: 00995518.0.0000.0065)

TELEHEALTH

As an immediate strategy by switching to remote assistance, IRMR was able to maintain activities through the work of its multidisciplinary team, minimizing the effects of social isolation during

the COVID-19 pandemic. This was especially important for this population considering their vulnerability in the face of isolation situations.⁴ In order to keep the NGO's participants active and happy, a series of instructional videos with proposed activities was delivered via the social media platform WhatsApp. The content of the videos included physical, psychological, and cultural cues as a measure to improve resilience when coping with this unique situation. Recommendations were addressed to participants and also their families with topics such as exercise, posture, emotional balance, quality of sleep and reading.

Additional advice aiming to help participants adapt to this new scenario¹⁰ was in the form of a booklet called "Guide to Good Practices - COVID-19", which was developed in digital format. This served not only as a guide to individual measures for prevention of the spread of the coronavirus, but also about quality of life within the current social demands, such as economic instability and the emergence of eventual financial impact challenges.¹¹

After 4 months of remote assistance, a cross-sectional survey was developed utilizing an internet-based application to assess client satisfaction about the multidisciplinary instructional videos (Table 1). The survey consisted of nine multiple-choice questions and one open question. Through that, it was possible to appraise participants and their caregivers' perception of the service provided by the team, enabling better decision-making in order to improve services. Out of 104 participants receiving assistance, 81 answered the survey. The median age of the respondents was 13.43 years (ranged 9 to 19), 37% were female and 67% were Caucasian. The social media platform initially chosen by the participants was WhatsApp at 66%, Zoom 18% and other social media 16%. When asked about forming groups

Table 1. Telehealth and telerehabilitation in a sports non-governmental organization for children and adolescents with physical disabilities during quarantine of coronavirus infectious disease 2019 (COVID-19) pandemic.

Variables	Physical disabilities participants (n=81)
Socio demographic	
Age, years	13.43 (9-19)
Female sex	30 (37)
Caucasians	54 (67)
Telehealth	(n=81)
Social Media Platform Preferred	
Whatsapp	53 (66)
Zoom	14 (17)
Other social media	14 (17)
Preference to group virtual visit	65 (80)
Adherence to instructional videos	
1 to 3/week	44 (70)
≥ 4/week	18 (30)
Perception of activities as enjoyable	
Telerehabilitation	53 (85)
Perception from the Physical Therapy Team	
Virtual visit assiduity	31 (84)
Technical difficulties	10 (27)
No help from household members during visit	
Decrease in pain	13 (35)
Perception from participant or caregiver	
Readiness to perform activities	31 (84)
More independence in ADLs	26 (70)
Mood improvement	29 (78)
Sense of worthwhileness	33 (90)

Results are presented in n (%), median (minimum-maximum values). ADL (Activities of Daily Living).

according to affinity and age to attend online visits for physiotherapy, physical education, social work and psychology, 80% agreed with this proposal since they were feeling lonely and 20% did not agree because they were busy with other tasks, such as schoolwork. After videos were sent, the majority of the participants (76%) reported they were able to perform what was proposed in the instructional videos. Of those participants that were performing the activities (n=62), 34% reported they were doing it once a week, 36% two to three times, 8% four to five times and 1%, 6 times. The participants were asked if they felt better with the help offered in the IRMR videos and 83% of those who carried out the activities said "yes" (Table 1).

In the open question about what participants thought to be most beneficial to them in online health services, answers revealed that the majority of children and adolescents were grateful for the team's commitment and suggested for more incentives to adhere to activities, and asked for advice about family issues, schoolwork, motivation, resilience and positivism during the COVID-19 quarantine. A few families displayed anguish and seemed overwhelmed with the housework, financial difficulties and the psychological burden on their children and adolescents due to social isolation.

TELEREHABILITATION

One of the important goals when managing children and adolescents with motor disabilities, in physiotherapy treatments, is gaining autonomy when performing daily tasks. Interestingly, telehealth and telerehabilitation have improved convenience delivering care in familiar environments. On the therapist's side, it became an opportunity to understand the patient's home lives and settings, particularly relevant during the COVID-19 pandemic quarantine/lockdown. In our experience, several objects available in the participants' homes could be used, such as broomsticks, chairs, beds, carpets, walls, balls, pillows and plastic bottles, allowing therapies without the need for further expenses on the part of the families during this pandemic. There was a clear demonstration of creativity, effort and synergy between the IRMR team and the participants when performing the therapy.

Another positive effect of virtual physiotherapy care was making it possible for family members to be more involved in the therapy being delivered. A survey involving stakeholders of the telerehabilitation program at IRMR was conducted. From the physiotherapist perception, out of the 37 participants who assiduously attended physiotherapy virtual visits, 27% reported technical difficulties or the lack of someone to assist them, keeping in mind that 35% of the participants were alone during the appointments. When there was somebody at the house, at least 49% of the participants received direct help from them. Participants reported an 11% decrease in pain from the beginning to the end of the activities, and even in those where the pain persisted, there was a perception of analgesia in about 10% according to the analog visual scale. During the virtual visits, there was an average of 7 different therapeutic interventions per appointment, such as massage therapy, analgesia, recreational

circuits, strengthening exercises for upper and lower limbs and stretching among other techniques. There was no complication during visits. Everyone received some type of guidance at the end of the appointments, such as continuing the activities during free time, reinforcing the need for engagement to obtain better results. Virtual physical therapy assistance from the perspective of participants or caregivers was evaluated in a survey: 83% of participants reported they carried out activities spontaneously, on their own initiative, not perceiving activities as boring; 70% declared greater independence on a daily basis; 78% showed a better mood after the start of activities; 70% reported more will after the start of activities; 67% described carrying out everyday tasks as being easier; 77% informed lower levels of pain after starting activities and 90% of those who carried out the activities considered the online visits worthwhile (Table 1).

Telehealth and telerehabilitation, in our experience, was an important initiative that ultimately benefited children with impairments and challenges, and their families during quarantine. It is imperative to continue to find new ways forward on developing solutions for better care to people in social isolation. Even after the COVID-19 pandemic, a hybrid form of assistance would be of great benefit to a large number of individuals that have less access to health care. Actions such as those could be implemented in the public health system improving the care of children and adolescents with physical disabilities and increasing the health-related quality of life for pediatric chronic conditions populations and their caregivers. Future multicenter and multidisciplinary studies will be necessary to clarify these issues and challenges in a large population.

CONCLUSION

This was an innovative and relevant initiative and remotely assisting people with disabilities has proven to be very effective in giving the patients assisted a perception of continued, lowering barriers of isolation, minimizing contagion for patients and healthcare workers, diminishing physical inactivity and the risks of chronic diseases, until their return to full social life after the COVID-19 pandemic quarantine/lockdown.

Funding

This study was supported by grants from Lei de Incentivo ao Esporte (LIE) SLIE 1915361-99 Ministério da Cidadania – Secretaria Especial do Esporte LIE 11.438/2006, Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq 303422/2015-7 to CAS), Fundação de Amparo à Pesquisa do Estado de São Paulo (FAPESP 2015/03756-4 to CAS) and by Núcleo de Apoio à Pesquisa "Saúde da Criança e do Adolescente" da USP (NAP-CriAd) to CAS.

ACKNOWLEDGMENTS

We gratefully acknowledge the work of Sueli Felizardo Costa, Gabriel Menezes Santos, Tauana Vieira Lenha Verde e Thiago Rodrigues and counseling from Lúcia Bruni Queiroz.

AUTHORS' CONTRIBUTION: Each author contributed individually and significantly to the development of this article. PMG: intellectual concept and article writing. MFL: data analysis and article writing. FGLG: data analysis and article review. DAS, CAM and JMB: data collection and article review. NAS: data analysis and article review. CL and RMM: work coordination and article review. CAAS: writing and reviewing the article and also supervising the intellectual concept of the article.

REFERENCES

1. World Health Organization. International classification of functioning, disability and health (ICF). Geneva: World Health Organization; 2001. Available from: <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>.
2. Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Dev Med Child Neurol*. 2017;59(1):16-25.

3. Rosenbaum P, Gorter JW. The 'F-words' in childhood disability: I swear this is how we should think! *Child Care Health Dev.* 2012;38(4):457-63.
4. Bundy DAP, Silva N de, Horton S, Jamison DT, Patton GC, editors. *Child and adolescent health and development*. 3rd edition. Washington (DC): The International Bank for Reconstruction and Development / The World Bank; 2017. pp. 113-29.
5. Gomes FGL, Laurentino MF, Grangeiro PM, Sá CSC. Avaliação funcional de crianças e adolescentes com paralisia cerebral praticantes de remo indoor. *Rev Assoc Bras Ativ Mot Adapt.* 2019;20(2):13-26.
6. Loades ME, Chatburn E, Higson-Sweeney N, Reynolds S, Shafran R, Brigden A, Linney C, et al. Rapid Systematic Review: The Impact of Social Isolation and Loneliness on the Mental Health of Children and Adolescents in the Context of COVID-19. *J Am Acad Child Adolesc Psychiatry.* 2020;59(11):1218-39.
7. Silva CA, Queiroz LB, Fonseca CB, Silva LEVD, Lourenço B, Marques HHS. Spotlight for healthy adolescents and adolescents with preexisting chronic diseases during the COVID-19 pandemic. *Clinics (Sao Paulo).* 2020;75:e1931.
8. Safadi MAP, Silva CAAD. The challenging and unpredictable spectrum of COVID-19 in children and adolescents. *Rev Paul Pediatr.* 2020;39:e2020192.
9. Choi KR, Heilemann MV, Fauer A, Mead M. A second pandemic: mental health spillover from the novel coronavirus (COVID-19). *J Am Psychiatr Nurses Assoc.* 2020;26(4):340-43.
10. Lim M. Achieving resilience during COVID-19: psycho-social risk & protective factors amidst a pandemic in adolescents. *Oxford: Mental Health Research Matters;* 2020.
11. Tisdell CA. Economic, social and political issues raised by the COVID-19 pandemic. *Econ Anal Policy.* 2020;68:17-28.