



Telephysiotherapy during COVID-19: Difficulties and barriers individuals with cystic fibrosis and their family members

Telefisioterapia durante a COVID-19: Dificuldades e barreiras de familiares e indivíduos com fibrose cística

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ABSTRACT

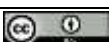
To describe difficulties and barriers for adherence to telephysiotherapy during the COVID-19 pandemic. Experience report, conducted with relatives and individuals with cystic fibrosis (CF) on internet, smartphone or computer, to receive asynchronous telephysiotherapy care in the form of folders and videos. All participants were required to complete an initial assessment, a quality of life questionnaire, and at end provide feedback about remote assistance and exercise frequency. Nine individuals participated in this study, and few completed all the stages. Five participants provided feedback regarding the offered assistance, and the majority of responses indicated difficulties in performing home-based physiotherapy. relatives and individuals with CF became overwhelmed with online demands, as routine activities were being conducted “on screen” during that period, which negatively impacted adherence to telephysiotherapy. These findings alert healthcare professionals to reflect on adherence aspects when offering this modality.

Keywords: Pediatrics. Treatment adherence. Rehabilitation. Physiotherapy. Telemonitoring.

RESUMO

Descrever dificuldades e barreiras para adesão a telefisioterapia durante a pandemia da COVID-19. Relato de experiência, realizado com responsáveis e indivíduos com fibrose cística (FC) via internet, celular ou computador, para receberem atendimento de telefisioterapia assíncrona, em formato de cartilhas e vídeos. Todos deveriam responder avaliação inicial, questionário de qualidade de vida e, ao final, feedback sobre a assistência remota e a frequência na realização dos exercícios. Nove indivíduos participaram do estudo e poucos concluíram todas as etapas. Cinco participantes forneceram feedback quanto à assistência oferecida e a maioria das respostas apontou dificuldades para realizar fisioterapia a domicílio. Responsáveis e indivíduos com FC ficaram sobrecarregados com as demandas *online*, visto que as atividades rotineiras estavam sendo realizadas “via tela” no referido período, o que impactou negativamente na adesão a telefisioterapia. Esse achado atenta para profissionais da saúde refletirem sobre aspectos da adesão ao oferecerem essa modalidade.

Palavras-chave: Pediatria. Adesão ao Tratamento. Reabilitação. Fisioterapia. Telemonitoramento.



INTRODUCTION

Cystic fibrosis (CF) is a hereditary disease, with important systemic and pulmonary manifestations, and requires multidisciplinary follow-up throughout life¹. Among the therapies for the individual with CF, respiratory physiotherapy is essential, with early and routine indication, which implies a lot of discipline and commitment from the family, especially in pediatric patients^{1,2}. In addition, for the treatment to be successful, all those involved in the assistance have to have knowledge of clinical aspects and the particularities of this health condition³.

In adverse situations, such as the pandemic caused by COVID-19, doubts and concerns have arisen regarding the management of chronic respiratory disorders, as is the case with CF⁴. Given the pandemic, there was a need to make telephysiotherapy feasible in Brazil, as an emergency therapeutic measure, aiming to maintain physical therapy assistance at a distance concerning sanitary measures of social isolation⁵. With the emergence of this new modality, home monitoring of individuals with CF became possible, which favored the continuity of the exercise routine and physiotherapeutic practices, controlling acute pulmonary exacerbation and the exposure of these individuals to the new coronavirus^{6,7}.

However, despite the advantages of telephysiotherapy, many challenges were faced in this remote modality to ensure patient compliance such as lack of materials for physiotherapy in the home environment, presence of other individuals in the residence, difficulty in handling electronic devices (mainly children and the elderly), insecurity about carrying out distance exercises, among others^{8,9}. Given the above, the present study aimed to describe the difficulties and barriers faced by caregivers and patients with CF in adhering to telephysiotherapy during the COVID-19 pandemic.

METHOD

This was a descriptive experience report, which included children and adolescents diagnosed with CF, aged between 3 and 15 years, and their guardians. The non-probabilistic convenience sample came from a university extension program at the University of the State of Santa Catarina (UDESC) and the Associação Catarinense de Assistência ao Mucoviscidótico (ACAM), both institutions located in Greater Florianópolis, state of Santa Catarina, Brazil. As an inclusion criterion, participants should have access to the internet, via cell phone or

computer, to ensure care through asynchronous telephysiotherapy.

Participants were contacted individually via the WhatsApp application and informed about the purpose of the research. After consenting to participate in the study, all those involved signed the ethical terms, and a survey of data was conducted in the medical records of the participants. The project was previously approved by the Human Research Ethics Committee of the UDESC (CAEE 80800217.4.00005361, opinion 4.153.930 of July 14, 2020).

Initially, an evaluation form was sent, with questions for individuals with CF and for their guardians, as well as a questionnaire to assess the quality of life (QoL), the Cystic Fibrosis Quality of Life Questionnaire (CFQoL), validated and translated into Brazilian Portuguese¹⁰. The CFQoL has 12 domains, namely: physical, body image, digestive, respiratory, emotional, social, nutrition, treatment, vitality, health, social role, and weight. The scores for each domain range from 0 to 100 and, in general, a score >50 is considered to indicate a good QoL.¹⁰

For remote physiotherapy, a WhatsApp group was created with the participants, through which educational materials were systematically sent - in the form of videos, images, and folders - whose content included aerobic and breathing exercises to be performed in the current week. In addition, the program's assistance team remained available to answer any questions regarding the shared guidelines.

The assessment of satisfaction regarding the service, as well as the verification of adherence to the assistance, was carried out by requesting feedback from the participants, which occurred after 2 weeks of follow-up. This feedback occurred by filling out a form developed by the researchers on the Google platform, which addressed aspects of the home physiotherapy routine and remote application of the contents oriented by the extension program. Personal data, perception of signs and symptoms, frequency of physiotherapy, execution of techniques, and characteristics of the home environment were also questioned in this form, which also included two open questions. One of these questions addressed their satisfaction with this joint action of the university program with ACAM, and the other questioned the clinical presentation of the individual with CF during social isolation (Box 1).

All data obtained were entered in an Excel spreadsheet and then tabulated in the Statistical Package for the Social Sciences (SPSS®) 20.0 software for Windows® for analysis. Descriptive statistics of the data were calculated, with the construction of tables and graphs, as well as an analysis of the responses provided by the participants.

RESULTS

Nine individuals participated in the study, three patients with CF and six guardians. Regarding the evaluation instruments sent, not all were completed by the participants. Figure 1 shows the documents answered and the respective percentages of responses. Of these, four participants did not return the feedback form, three only answered this form and only two answered the feedback and also the CFQoL.

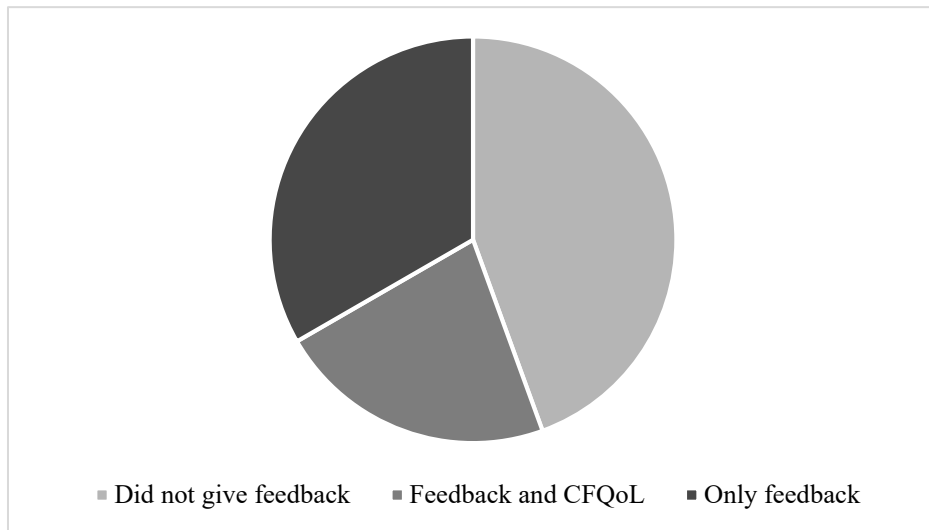


Figure 1. Assessment instruments and percentage of participants' responses.

Regarding the feedback on the proposed activities, five participants returned, four of whom were guardians (80%) - 3 women. Only a 10-year-old patient responded. When asked about the frequency of carrying out shared physiotherapeutic activities, one participant answered rarely (1 to 2 days a week), three answered occasionally (2 to 3 days a week) and one answered frequently (4 to 5 days a week). Figure 2 illustrates the objective responses given by guardians regarding satisfaction with the telephysiotherapy care model offered by the program.

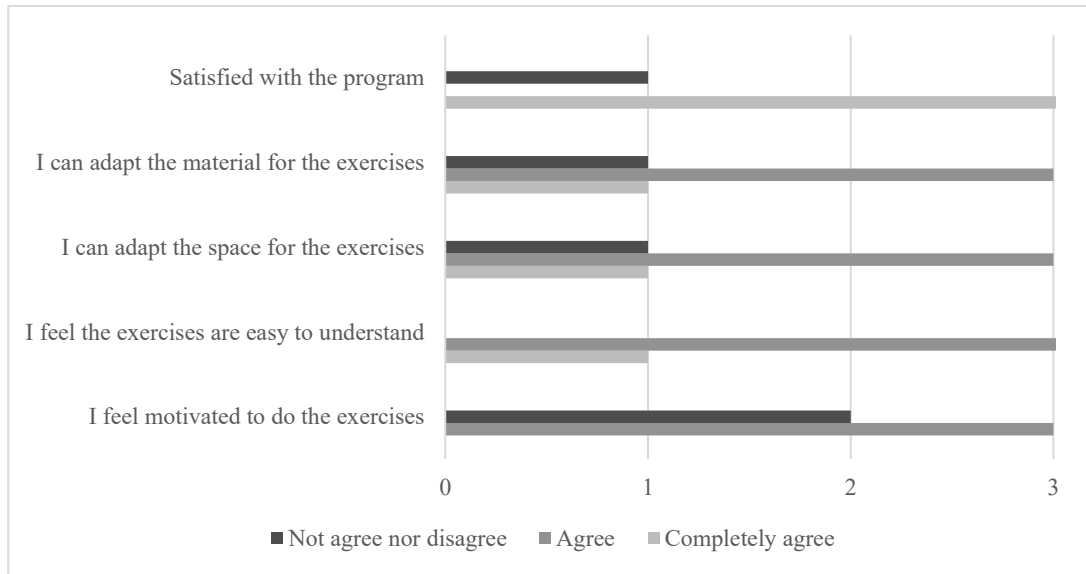


Figure 2. Feedback from participants on satisfaction with the telephysiotherapy care model.

In addition to the objective questions, four guardians answered the open questions, as listed in Box 1.

Box 1. Answers from guardians in the feedback of open questions requested through a form

QUESTION	ANSWERS
1. How do you feel about the joint action between the Brincando de Respirar program and ACAM? Has it made a difference in your routine? Feel free to write what you feel here.	G1: "It makes a difference, but the big problem is finding time to practice the activities. We usually end up executing the ones we are already used to, due to pure lack of time."
	G2: "It actually got easier for me because I work outside the home and I had difficulties taking my son to UDESC."
	G3: "I liked that it is a way of helping us with our little ones, as we are not able to have face-to-face meetings, it is a very good way for us to help and to be able to continue to make our little ones well."
	G4: "The partnership is essential, even though Acam is at the state level and cannot give due support to the project, which basically serves the greater Florianópolis."
2. Did you notice changes in terms of symptoms such as cough, secretions, and tiredness during his/her isolation period? If so, in what way?	G1: "Continues without coughing and secretion."
	G2: "No."
	G3: "No, she is still fine, thank God. She does a little exercise at home, and she's also doing rhythmic gymnastics which helps her a lot, thank God she's still doing great, she coughs when she finishes some activities and when she's just curled up, but she coughs very rarely."
	G4: "Yes, there was a reduction in the Physiotherapy routine. We even blame ourselves for being parents. But we have to intensify, because she is growing and increasingly has to adapt to Physio."

Subtitle: G1, G2, G3, and G4: Abbreviations for the term "guardian" were assigned to the actual patients/guardians, numbered in ascending order.

Only two guardians answered the CFQoL, G5 and G6. G5 reported that the child had no difficulty in performing vigorous activities, playing sports, climbing stairs, and carrying

heavy objects. For G6, her son showed little difficulty in these tasks. According to G5, the child always appears happy and full of energy and never appears to be worried, tired, angry, or irritated. In turn, the G6 child manifests themselves like this at times. Both answered that their children do not miss school due to health conditions or treatments and that they do not have walking difficulties or changes in body image.

Still, according to them, the children do not seem to feel withdrawn, lead a normal life, have fun regularly, do schoolwork, and usually do well at school. G5 also reported that her son practices sports without difficulty and recovers well from physical exertion, while G6 reported that her son never practices. According to G5, the treatment does not interfere with her child's daily activities and does not take much time, but they have difficulty with mealtimes. In turn, G6 considered these tasks difficult for her child.

Regarding aspects of symptoms, both reported that their children have difficulty gaining weight, but do not manifest shortness of breath and sleep interruption due to coughing. Children also do not have diarrhea, but manifest gas and problems with eating. The presence of a little yellowish secretion, coughing during the day, wheezing, and abdominal pain were described by G6, while G5 did not mention these symptoms, and reported that her child feels healthy and considers her health to be excellent.

DISCUSSION

Amid the pandemic, many chronic diseases were monitored by telephysiotherapy, characterized by the use of digital means of communication for physiotherapeutic interventions – care and education – remotely, either exclusively or as a complement to face-to-face monitoring⁷. In CF, telephysiotherapy emerged as a promising alternative for follow-up during this period, since the great challenge for health professionals was the continuity of physical therapy treatment due to the distance imposed by the pandemic context¹¹.

Therefore, the present study was justified by the demand of patients who required this care model, given the urgency to maintain physical therapy treatment for individuals with CF, since non-adherence to the management of this disease contributes to the extension of hospital stay, higher occurrence of pulmonary exacerbation, and loss of pulmonary function, which is the main cause of death.^{12,13,14}

In this way, we sought to gather information and feedback from patients and their guardians regarding this new modality of physiotherapy, aiming to improve the main

dissatisfactions and adapt the program to the profile of each individual, to facilitate adherence and contribute to the maintenance of QoL.^{13,14} Nevertheless, according to the results presented, few participants returned with the answers, which even compromised the conduction of the proposed method and the collection of research results.

A justification for this unsatisfactory participation of the analyzed sample may be the exhaustion caused by the presentation and interaction with so many technological demands during the pandemic, whether in the area of health or another family routine. In a recent study, Sanada et.al. found that screen time with infants increased significantly during the pandemic, from 4 to 7 hours a week, with emphasis on the use of televisions.¹⁵ Furthermore, the pandemic period was marked for excessive communication via WhatsApp groups, many videos on the internet, and information on social networks, which added to the nature of the research, which also included videos of exercises to be done at home, reading digital booklets and conversations on cell phones.

This profile of frustration-tiredness-discouragement in the pandemic was pointed out by Souza et al.¹⁶, who discussed the fact that it is still not possible to measure the impact that social isolation measures - associated with the pandemic - have had on the mental health of children and adolescents. Outside the pandemic, Feiten et al.¹⁷ already pointed out tiredness as one of the main reasons for not performing physiotherapy in this population, in addition to a lack of commitment.

Despite the results of this research and adherence to this therapeutic modality being a major challenge for health professionals^{9,10}, the implementation of technology in physiotherapeutic treatment was considered a great advance. This is because telephysiotherapy facilitates access to patients from different cities, contributes to better management of the demand from the health system, and even the routine treatment of individuals with different illnesses. Importantly, this care strategy requires special attention regarding respect and compliance with codes of ethics, consideration of the profile and eligibility of patients, maintenance of humanized care, and continuity of care, and it is necessary to invest in strategies to improve the therapist-patient relationship in this virtual format.^{18,19}

As for the QoL of the sample, although the two children analyzed had the same health condition, they refer to different routines, impressions, and characteristics. In this sense, the findings by Santos et al.²⁰ highlight the importance of assessing the QoL of individuals with CF, showing that they need continuous monitoring and information about the disease, as this creates a network of support, which facilitates both the life of the patient and their family

members.²⁰ In this context, and considering other aspects raised in the present investigation, some barriers can be highlighted about telephysiotherapy such as the impossibility of carrying out a complete evaluation of the patient; internet access limitation; difficult access to digital technology; compromised adherence to treatment; lack of adequate physical space at home and privacy to receive telecare; dissatisfaction with the remote model.^{9,13}

The excess demands via technology and the distance between therapist and patient in the pandemic seem to have contributed to the difficulty in adherence and continuity of telephysiotherapy treatment, as well as to effective participation in the research carried out. Telephysiotherapy was then a major challenge during the pandemic, as well as for other health professionals, but despite barriers and difficulties, it represented a possible, accessible, and safe therapeutic modality, which enabled the continuity of care for patients with CF and their family members assisted by the university extension program.

CONCLUSION

During the pandemic, caregivers and patients with CF were overwhelmed with the demands presented online, since all activities were being offered via screens in that period, characterizing a difficulty and/or barrier in adherence to telephysiotherapy. Thus, health professionals have to pay attention to these factors when opting for the remote therapeutic mode.

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