



## Family perception of a telehealth program for people with cystic fibrosis during the COVID-19 pandemic in northeastern Brazil

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### TO THE EDITOR:

Cystic fibrosis (CF) is a chronic disorder that requires follow-up in a specialized service involving a multidisciplinary team.<sup>(1)</sup> Despite advances in treatment, many challenges remain related to adherence and delivery of care in different localities.<sup>(2)</sup> In the face of the COVID-19 pandemic, normal care activities were suspended to comply with lockdown recommendations, and alternative ways were needed to adapt care plans.<sup>(3)</sup>

Telehealth has been particularly helpful where access to care is difficult because of the need to travel long distances to a referral center.<sup>(4)</sup> It has been associated with improvements in efficiency and equal or greater patient satisfaction than have face-to-face visits.<sup>(5)</sup> Although the results are positive, few studies have been conducted in low-income countries.<sup>(2)</sup>

Bahia is a state located in the northeast region of Brazil with large geographical dimensions, placing 4th in the Brazilian ranking of number of CF diagnoses.<sup>(6)</sup> The state has two referral centers, both located in the capital, Salvador. Most people travel for many hours to attend clinical appointments. Incorporating remote assessments allows data to be collected more frequently in a person's natural environment in addition to reducing the burden of the number of in-person visits.<sup>(4,5)</sup> Therefore, this study aimed to evaluate families' perceptions of a telehealth program for people with CF during the COVID-19 pandemic in northeastern Brazil.

Until then, telehealth had not been used routinely. As a strategy for coping with the health crisis, a remote care program was carried out for individuals with CF between September of 2020 and October of 2021 through a platform of the *Universidade Federal da Bahia*.

Participants were recruited from the CF referral center. If they agreed with the care provided by the model, appointments were scheduled. Exclusion criteria were as follows: individuals who had comorbidities that limited their participation in the study, as well as the existence of behavioral or intellectual difficulties that did not allow remote interaction. This project included telemonitoring, individual and group telerehabilitation, behavioral/emotional support, and health education. Videos, webinars, and booklets were freely available.

At the end of the 12 months of the study, participant satisfaction was assessed using an adapted questionnaire (Telehealth Satisfaction Scale),<sup>(7)</sup> using Google Forms. A similar questionnaire was validated for use in Brazil in 2022.<sup>(8)</sup> The institutional research ethics board approved

the study (Protocol no. 4.237.807). All patients and/or guardians signed the free and informed consent form in addition to the assent form, when indicated.

This study enrolled 51 participants between two months and 21 years of age—median (IQR) = 76 (36-120) months—who were predominantly males (53%), and only 10 patients (20%) resided in the city of Salvador. In 70.6% of the sample, family income was up to three Brazilian national minimum wages, and 45% of guardians completed secondary education.

A total of 393 appointments were performed. There were two discontinuations, and pulmonary exacerbations occurred in 5 children (9.8%) during the study. Participants older than 14 years of age and parents/guardians of those under this age completed the questionnaire. The level of satisfaction with this model of care was high, and most participants rated as excellent the time and explanations provided by the CF team, as well as the privacy and convenience of telehealth; 51% of the participants rated the visual quality of the equipment, personal comfort, and ease of use of the telehealth system as excellent (Figure 1).

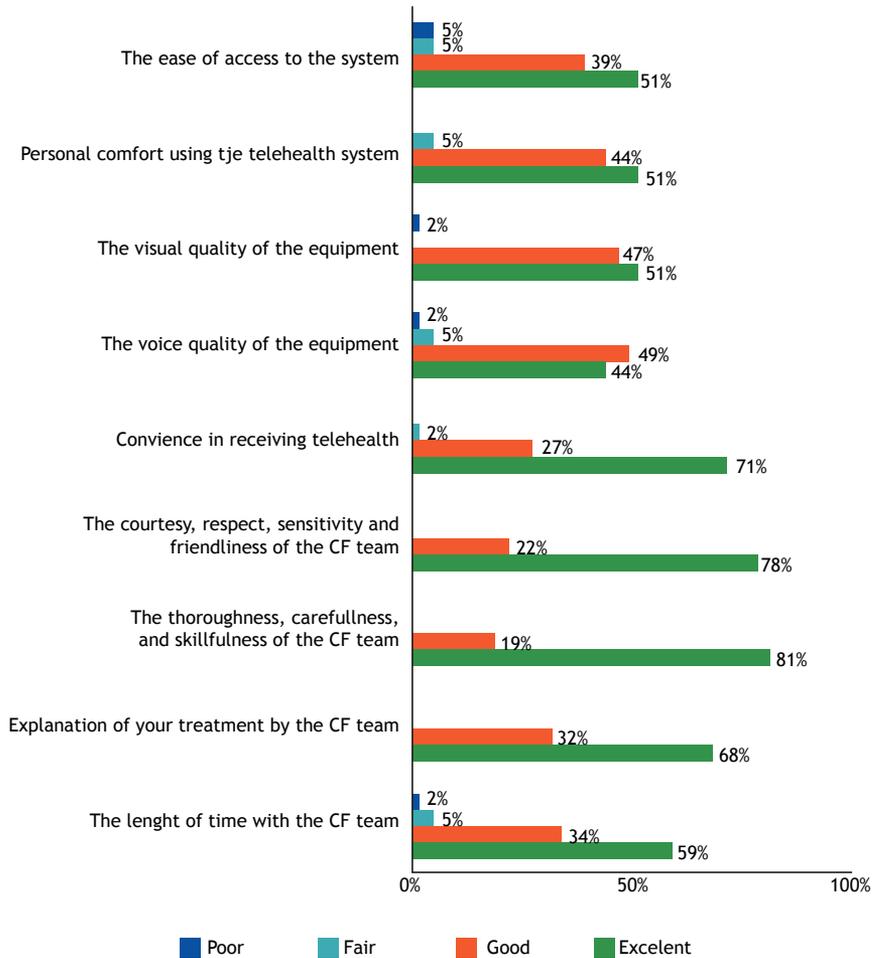
Considering the lack of in-person visits, 36.6% reported moderate concern about the lack of spirometry and throat/sputum cultures, while only 19.5% expressed a major concern about the lack of physical examinations. However, only 22% of participants had previous experience with remote care, and most stated that they would welcome the inclusion of telehealth in treatment routines.

This study reported on the experience of implementing remote care during COVID-19 in a referral center for people living with CF (PwCF) in Brazil. A high level of satisfaction with telehealth was observed. Given the critical timing of access to on-site services, most of the participants stated that they were not very concerned about absenteeism during routine. In addition, most indicated that they would like to receive some visits remotely.

Faced with the advent of novel therapies, particularly CFRT modulators, changes in the care model must address current challenges by adopting a proactive perspective. Previous studies reported that telehealth is feasible and acceptable to provide care for PwCF.<sup>(3,4,9)</sup>

Learned lessons in recent years have shown that the use of telehealth can continue in the post-pandemic period and reduce the burden on families. In addition, well-being and safety can be improved through a flexible telehealth model, and enhancing patient education and communication with the team of experts can be useful

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**Figure 1.** Responses to questions of the adapted questionnaire involving satisfaction with telehealth for people with cystic fibrosis followed at a referral center in Bahia, Brazil, 2020-2021.

to ensure the best clinical outcomes for PwCF and help address geographic disparities.<sup>(4,9)</sup>

Despite the huge benefits mentioned above, critical considerations must be made about telehealth for PwCF, as we cannot generalize the benefits to everyone. Individual needs as well as social and cultural contexts must be considered. Recognizing the potential of digital approaches and the opportunities to plan a hybrid care model can be crucial to ensure better outcomes.<sup>(9,10)</sup>

A limitation of this study was the small sample of individuals and the design used. However, considering the pandemic scenario, the authors developed a prompt response to overcome the imposed limitations. The strength of this study lies in the possibility of replicating it for other rare diseases.

In summary, a high level of satisfaction was found with telehealth, which played an important role in addressing the challenges associated with the COVID-19 pandemic. For the management of PwCF, digital approaches hold promise for the future. Their implementation can help improve quality of life, reduce costs, and expand support for people with chronic diseases.

This study highlights the possibilities of the use of affordable technological tools to provide care to the CF community, mainly in low-income countries where there is a scarcity of resources and limited access to referral centers. However, further research is needed to explore these outcomes and the standardization of technologies for clinical care.

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### AUTHOR CONTRIBUTIONS

AVBF: study design; data collection and analysis; and drafting and reviewing the manuscript. ELS and RTR: study supervision and manuscript revision. All authors approved the final version of the manuscript.

### CONFLICTS OF INTEREST

None declared.

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