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Original Article

Evaluation of Mobile Phone-based Tele-monitoring of Cystic Fibrosis Patients during the COVID-19 Pandemic: A 3-year Experience in Iran

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Abstract

Background: Telemedicine has been used for cystic fibrosis (CF) in a wide range of signs and symptoms even before the COVID 19 pandemic, however, little is known about the health consequences and use of specific health care for cystic CF. This study aimed to evaluate the evolution of clinical trends and data related to mobile based monitoring activities in CF patients at home for 3 years. **Methods:** This is a semi experimental single group study. Forty five CF patients under 7 years' old who were referred to the Masih Daneshvari Hospital between 2018 and 2021 were selected. A mobile phone_based customized Short Message Service (SMS) application used to monitor patients. Remotely monitored variables included the amount and color of sputum, cough, wheezing, and shortness of breath at rest. SPSS using Chi square and Friedman tests. **Results:** The condition of patients based on the number and type of cough increased sputum, decreased appetite, fatty stool, fever and dyspnea, headache, noninvasive ventilation, and drug comfortably remained almost unchanged in the study of the 1st, 2nd, and 3rd years, and the studied parameters did not show a significant difference ($P > 0.05$). Of course, the number of outpatient visits decreased significantly (*P* value: 0.02). The respiratory rate and arterial oxygen saturation variables were almost the same in three consecutive annual measurements (*P* values: 0.544 and 0.639, respectively). **Conclusion:** Telemedicine is a method that is useful in the follow up of chronic diseases such as CF and improves the quality of life and reduces the deterioration of lung function; therefore, there is less need for invasive treatments in the long run, and a fundamental change in referral motivation brings to the hospital.

Keywords: Cystic fibrosis, home care, telemedicine

Introduction

Cystic fibrosis (CF) is a systemic genetic disorder that affects 30000 people in the United States[1] and at least 70,000 worldwide.[2] CF is caused by the abnormal function of cystic fibrosis transmembrane conductance regulator (CFTR). Dysfunction of CFTR leads to systemic changes in the viscosity of the mucosa and involvement of several organs, often affecting the lungs, pancreas, and liver.[3] Due to its progressive nature and multisystemic manifestations, this disease requires lifelong multidisciplinary care.[4] In CF, because lung involvement with infection and chronic

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inflammation leads to progressive lung disease and early deaths due to respiratory failure; therefore early detection of acute lung infections or CF flares can restore and improve lung function.[3] The survival of these patients has increased rapidly over the past three decades, largely due to the development of effective and new drug therapies and advanced invalid clinical care provided by CF foundation centers.[5] The CF care model prioritizes regular periodic screening with an interdisciplinary team in CF care in which treatment and care programs are updated in collaboration with CF people and their families. Unfortunately, in many reputable CF centers, regular screenings were discontinued during the COVID-19 epidemic, and the need for rapid change in screening approaches and remote health care was strongly felt.[6] Current and future challenges of meeting patient care needs by specialized centers require new models of care delivery. Technology-based solutions to challenge the availability of regular care and screaming teams are considered possible solutions to the problem. Telemedicine provides telecommunication health-care services using telecommunication technology. Telemedicine can be offered in a variety of ways, including A: A virtual visit is a simultaneous (live) interactive encounter between the patient and the caregiver and B: Chat-based interactions are an online connection to a mobile application to transfer health-related data for further diagnosis or treatment planning. C: Remote patient monitoring: Collection and transfer of data to a provider or health-care team for chronic disease management. D: Save and send: Data transfer for patients' health assessment and subsequent diagnosis.[7] Telemedicine may allow frequent contact with the health-care team. It has the potential to improve access to specialist care, and it can reduce the cost of receiving care by meeting the needs of patients and their families traveling; it may reduce exposure to epidemics such as COVID-19 and getting infections, and it may help improve patient interaction and adherence to treatment.[8] Outpatient management of chronic disease must go hand in hand with time; the best example of discovering the value of telemedicine in the treatment and care of CF patients. Several studies have examined the effectiveness of remote health in a CF care model. A study in Western Australia found that telemedicine is very convenient for CF patients located at long distances from the nearest specialist center to minimize costs and improve access to health care.[9] In studies, television has been used successfully to improve physical activity and nutrition in patients with CF, and its use to monitor forced expiratory volume in the first second (FEV1) and side effects have significantly reduced the cost of clinical tests.[10,11] Telemedicine is also a good way to assess the respiratory symptoms of anxiety and decreased lung function before and after transplantation in CF patients.[12] Rural living showed great potential cost savings and high levels of patient satisfaction with telemedicine.[13,14] However, another study raised concerns about poor patient acceptance of the virtual model and showed no effect on pulmonary function after 5 years of telemedicine interventions.[15] With the onset of the COVID-19 epidemic in 2019, there has been a major shift in virtual care to facilitate social distancing, allowing clinics to redistribute resources to meet other medical care needs and promote infection control. These changes in service delivery, coupled with regulatory changes, have enabled rapid admission to telemedicine at CF centers around the world.[16] It should be noted that telemedicine is not a substitute for the main medical process but as a complement to face-to-face counseling and interaction to promote health and self-management. Telemedicine has the potential to promote faster patient recovery and lower health-care costs through frequent visits in virtual clinics and remote monitoring by strengthening previous interventions, reducing hospitalization, and easing discharge from the hospital.[17] Even before the COVID-19 pandemic, there was considerable interest in using telemedicine to manage the disease, and there is a strong and growing body of articles on the subject. Studies have evaluated the use of telemedicine in adults and children. Since studies on this subject are heterogeneous in the studied population, the method of using telemedicine and the evaluated results can make it difficult to draw conclusions and generalize.[8] Telemedicine policies have been introduced to reduce the prevalence of coronary heart disease-related CF patients, and as a result, several organizations are working diligently to transfer care from outpatient clinics to telemedicine clinics. However, the COVID-19 epidemic has led to more attention being paid to telemedicine, revealing the benefits of this method.[18] Since the effect of telemedicine on the population of CF patients in Iran has not been studied, to study the evolution of the clinical trend, data related to the remote monitoring activity of CF patients at home have been followed for 3 years; hope that different dimensions will be useful.

Subjects and Methods

All procedures performed in this study were in accordance with Helsinki declaration and its later amendments or comparable ethical standards. Ethics endorsement was made by the Ethics Committee of National Research Institute of Tuberculosis and Lung Diseases (NRITLD), Shahid Beheshti University of Medical Sciences University of Medical Sciences (Code of ethics: IR.SBMU.NRITLD.REC.1394.216).

Study design

In this one-group semi-experimental study performed by pre-and post-test methods for 3 consecutive years from January 2018 to May 2021 in Iran, 45 CF patients were referred to the pediatric clinic and emergency department of Masih Daneshvari Hospital as a referral center of CF in Iran and were selected by the convenience sampling method. Inclusion criteria were being under 7 years of age and parents' willingness to participate in the study. Exclusion criteria were lack of access to the patients during the study for any reason or patient death.

Research setting

A mobile phone_based customized Short Message Service (SMS) application used to monitor patients. This panel was a software system for receiving, sending, and processing SMS

based on the number, date, and text of SMS and reporting in an Excel file without the need for special hardware and equipment. To use the SMS panel, doctors only needed to access the internet and log in to the panel system. After registering the patients' mobile numbers in the system, the physicians sent a text message to each patient, which included the parameters required for remote patient monitoring, and the patients sent the information to the panel after receiving the text message and taking the necessary measures. The information was stored in the panel and was visible, categorized, and reviewed by the doctor. To use this app, patients only had to have an internet-connected mobile phone with the ability to receive and send SMS. Any operating system or platform was usable. Patients (or parents) recorded the symptom score in a text message three times a week and sent it to the research physician. The text messages were reviewed by the research physician on the same day and recorded in the forms related to each patient. In case of the need to follow each symptom, it should be addressed to the pediatric pulmonologist and instructed accordingly. Patients were monitored by this method for 3 years, and analysis was performed based on the 1st, 2nd, and 3rd years.

Data collection

To collect the data, a checklist was prepared that included variables such as the amount and color of sputum, cough, wheezing, and resting dyspnea. A table was designed to rate each of these symptoms and determine the threshold of symptoms that needed to be followed.

Data analysis

Data analysis in this study was based only on respiratory symptoms recorded before using the SMS panel in the 1st year and then in the 2nd and 3rd years. Data were analyzed using SPSS version 23 (IBM Corp., Armonk, N.Y., USA) software, and the findings were analyzed using Chi-SQUARE and FRIEDMAN tests. SPSS software version 23 was used, and a significance level of <0.05 was considered.

Results

In this study, 45 patients were included to monitor CF at home through telemedicine. The Chi-square test showed that the condition of patients based on the number and type of cough, increased sputum, decreased appetite, fatty stools, fever and shortness of breath, headache, noninvasive ventilation (NIV), and drug comfort remained almost the same in the 1st, 2nd, and 3rd years and the parameters did not show significant differences ($P > 0.05$). However, the number of outpatient visits decreased significantly ($P = 0.02$) [Table 1].

The variables "respiratory rate" and "arterial oxygen saturation level" were almost the same in three consecutive and annual measurements (respectively, $P = 0.544$, $P = 0.639$) [Table 2].

The two variables of arterial blood oxygen saturation and respiratory rate were slightly based on the mean rank, so that the mean arterial blood oxygen percentage shows that in the 1st year of study, the percentage of arterial blood oxygen in patients was the highest (mean rank: 2.03), and in the 3rd year, it was the lowest (mean rank: 1.87). The average patient respiratory rate shows that the highest number of breaths was reported in patients in the 1st year (mean rank: 2.13), and the lowest number of breaths was reported in the 2nd year of study (1.80).

Table 1: Frequency and frequency percentage of qualitative variables

Variables	Frequency (%)			*P*
	Year 1	Year 2	Year 3	
Number of coughs				
Low	33 (73.3)	30 (66.7)	30 (66.7)	0.902
High	12 (26.7)	10 (33.3)	10 (33.3)	
Type of cough				
Dry	6 (13.3)	0	0	0.123
Has sputum	39 (86.7)	45 (100)	45 (100)	
Increased sputum				
No	0	0	0	-
Yes	45 (100)	45 (100)	45 (100)	
Decreased appetite				
No	30 (66.7)	30 (66.7)	24 (53.3)	0.685
Yes	10 (33.3)	10 (33.3)	21 (46.7)	
Fatty stools				
No	36 (80)	36 (80)	36 (80)	>0.999
Yes	9 (20)	9 (20)	9 (20)	
Fever				
No	36 (80)	42 (93.3)	45 (100)	0.146
Yes	9 (20)	3 (6.7)	0	
Shortness of breath				
No	36 (80)	39 (86.7)	36 (80)	0.859
Yes	9 (20)	6 (13.3)	9 (20)	
Headache				
No	39 (86.7)	45 (100)	45 (100)	0.123
Yes	6 (13.3)	0	0	
NIV				
No	45 (100)	45 (100)	45 (100)	-
Yes	0	0	0	
Drug comfortable				
No	0	0	0	-
Yes	45 (100)	45 (100)	45 (100)	

NIV: Non-invasive ventilation

Discussion

The results of our study showed that the amount and frequency of study variables, i.e., number and type of cough, increased sputum, decreased appetite, oily stool, shortness of breath, headache, NIV, drug comfort, arterial oxygen level, and respiratory rate, in 3 consecutive years did not significantly change in their values and frequency in the measurement and evaluation sessions; in other words, telemedicine intervention and care were effective in keeping the patients' condition constant and preventing him from deterioration, and home monitoring helped improve the respiratory function of patients who were compatible with this method. The use of

Table 2: Differences in patient's status in three consecutive years in the variables of respiratory rate and arterial oxygen

Variables	Time of measurement	Number	Average	SD	Minimum	Maximum	Mean rate	*P*
Arterial oxygen level	Year 1	45	92.93	4.92	82	98	2.03	0.639
	Year 2	45	93.20	4.05	85	98	2.10	
	Year 3	45	92.93	4.92	82	98	1.87	
respiratory rate	Year 1	45	27.26	7.34	9	34	2.13	0.544
	Year 2	45	27.20	5.61	18	38	1.80	
	Year 3	45	27.26	7.61	18	42	2.07	

SD: Standard deviation

telemedicine in CF has been evaluated in several studies. Most of them are small feasibility studies that assess participants and heterogeneous outcomes. Cox *et al*. evaluated eight telemedicine studies related to CF and found that telemedicine was possible in these patients, and they were willing to use it and had no concerns about data transfer and adverse effects.[19] Grzincich *et al*. pointed out that remote monitoring is useful in the assessment of the health status of CF patients;[20] in a study by Murgia *et al*., patients undergoing telemedicine showed a significant improvement in lung function compared to those treated in the traditional way.[21] In the study of Sears *et al*., home spirometry was generally accepted by patients under remote monitoring, and the quality of FEV1 measurement was good; the participants stated that immediate access to lung function indicators was a useful complement to their self-care.[22] Numerous studies have shown that the implementation of telemedicine in the field of COVID-19 is possible for stable clinical patients and those with access to the minimum appropriate technology. In the context of the COVID-19 epidemic, telemedicine is likely to become the standard method for monitoring patients with chronic disorders and ensuring their disease control without the risk of exposure to COVID-19 infection.[6,8,18] Running a telemedicine screening program during the COVID-19 epidemic at a CF multidisciplinary clinic through a standard process using only one SMS panel is a practical and sustainable procedure that can be used by other multidisciplinary programs. Following the COVID-19 epidemic, Compton *et al*. transferred all screenings required for adults with CF at the University of Virginia from outpatient clinics to telemedicine clinics through WebEx (Cisco Systems, San Jose, CA). Patients were contacted on their preferred platform before scheduled screenings, and triage was performed in the following cases: (1) identify patients eligible for multidisciplinary distance therapy, (2) identify patients who need to be visited immediately at the clinic due to acute needs, and (3) identify patients with a stable condition who should be specified the next time for their visit. Eligible patients at the telemedicine clinic were followed up by telephone due to lack of access to technology. A total of 63 patients were visited during 4 weeks; of these patients, 20 changed their shifts (20%). In addition, two (3%) were visited in the clinic for acute needs, and 38 people (60%) were visited by a multidisciplinary team through telemedicine.[18] The results of a study by Solomon *et al*. on the use of telemedicine during the COVID-19 epidemic in CF centers showed that most people had at least one remote visit. Ninety-one percent reported using telemedicine as easy, and 66% reported similar quality or higher than face-to-face care. One-third (34%) expressed the highest tendency for remote care in the future. Forty-five percent (212 people) wanted telemedicine fifty percent or more. Adolescents were more likely than parents to visit remotely (64% vs. 36%). Respondents who considered telemedicine to be of similar or higher quality were more likely to seek telemedicine in the future than those who considered it to be of lower quality (96% vs. 50%).[6] In the present study, the decreases in the number of outpatient referrals was statistically significant ($P = 0.02$).

Grzincich *et al*. reported that remote monitoring has been useful in the evaluation of patients' health status and reducing CF workloads.[20] The results of the present study in this respect contradict the results of the study of Bella *et al*., in which they observed an increase in the number of hospitalizations from the preintervention period to the follow-up period. This discrepancy may be due to the effect of changing follow-up protocols for the care of patients with CF during their study period. The results of the study of Bella *et al*. also show that remote monitoring programs may not be well accepted by patients with CF, and its use appears to generally increase access to health care without having clear effects on pulmonary function.[15] Adaptation to the remote monitoring method was a significant issue in the present study, and 25% of the subjects were unable to continue remote evaluation. Bella *et al*. reported that approximately 29% dropped outpatients in their study; they justified the noncompliance of patients with remote monitoring methods with an interesting reason. According to them, some patients are accustomed to transferring data only in good condition, and in case of illness, they will go directly to the hospital. In the case of uninvited patients, they also have the advantage in terms of quality of life that they have some tools at home that allow them to stay in touch with the center, and this is a situation for greater comfort, which is significant; thus, when planning for such studies, it is necessary to consider compliance figures.[23] CF requires lifelong multidisciplinary care to manage pulmonary and extrapulmonary manifestations. The average age of people with CF is increasing, and the number of adults with CF is expected to increase dramatically in the coming years. The patients have better results when managed in specialized centers, but access can be limited. Remote and technology-based care solutions may help overcome and improve barriers to access. Telemedicine has

been used for CF in a wide range of symptoms before the COVID-19 pandemic and is generally accepted by patients and providers. However, there is conflicting information about the health consequences and use of specific health care for CF and related diseases, so future studies will address the health consequences, cost, remote health burden, and operational barriers needed.

Conclusions

The average survival age of people with CF has increased in developed countries, and the number of adults with CF is expected to increase dramatically in the coming years. New and innovative models of health-care delivery to meet the growing number of patients with complex medical needs while maintaining health outcomes are needed to meet this demand. More routine care may be provided remotely in the future, and the goal of plans should be to improve the quality of life and reduce the burden of care. Not all patients have access to technology, and ways must be found to eliminate this inequality. As efforts continue to advance outcomes for people with CF and expand patient-centered care models, telemedicine may help meet patients' needs and improve interaction and outcomes. While telemedicine is promising, costs, additional burden on the patient and provider, and barriers to availability must be considered.

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Conflicts of interest

There are no conflicts of interest.

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