



Telemedicine and Telenursing as Valid Tools in the Treatment and Prevention of Chronic Conditions such as Cystic Fibrosis in the Current and Future Health Scene

A Federici, B Corona, F Cicchetti, JM Discalzo, R Maione, D Gargano, S Bella*

Cystic Fibrosis Center, Bambino Gesù Children's Hospital, IRCCS, Rome, Italy

*Corresponding author: Sergio Bella, Cystic Fibrosis Center, Bambino Gesù Children's Hospital, IRCCS, Rome, Italy

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Abstract

Objective: To observe telemedicine as an innovative resource in the current and future health scenario, in particular for the treatment and prevention of chronic conditions, thus improving patients' quality of life patients, and regarding telenursing as a valid approach to nursing health care.

Keywords: Telemedicine; Remote monitoring; Telenursing; Cystic fibrosis; Chronic condition; Health care

Materials and Methods

A telemedicine project involving chronic patients suffering from a genetic disease, was analysed. The project has been conducted by Doctor Sergio Bella (the creator of the project) in the cystic fibrosis unit of the Bambino Gesù Children's Hospital for more than 20 years. In particular, it is about remote monitoring of patients with cystic fibrosis, a multi-organ chronic disorder that mainly affects the respiratory and digestive system. It is caused by an altered gene, the CFTR (Cystic Fibrosis Transmembrane Regulator), that determines the production of thick mucus. This mucus clogs the bronchial tubes and leads to recurring respiratory infection. It may cause a blockage in the pancreas and block the tubes that carry digestive enzymes from your pancreas to your intestines. This can result in digestive disorders [1]. The most serious complication of cystic fibrosis is lung damage. Other organs infections and inflammations are the major cause of morbidity in patients with cystic fibrosis. In Italy, about 200 new cases are estimated today [2], with no distinction between males and females. However, thanks to the constant therapeutic advances, the average age of the population suffering from cystic fibrosis is increasing significantly. Together with treatments and scientific findings, healthcare is of fundamental importance. For several years now, especially during the pandemic situation we have been living, telemedicine has been a precious form of care, and can provide a valuable ally for the treatment of chronic diseases like cystic fibrosis. As previously mentioned, in the

Cystic Fibrosis Center of the Children's Hospital Bambino Gesù in Rome, there is a home telemonitoring service. At first, just a few patients joined the project, while today, 60 people, aged between 10 and 50, are involved in it. This service involves: from the comfort of their home and in the middle of their daily life, patients have to take a lung function test called SPIROMETRY. This is a non-invasive and painless test able to evaluate many respiratory parameters related to respiratory system functionality. Spirometry measures the air volumes both in terms of quantity, meaning the air "within" the patient's lungs, and in terms of bronchial capacity, to allow the correct airflow within the respiratory system. Spirometry is carried out using a spirometer, a medical device that measures parameters, connected to a mouthpiece. The patient closes his lips tightly around the mouthpiece, and performs a cycle of full, normal and forced respiration. The test lasts a few seconds but it must be carried out correctly, with a good posture and a good respect of the times. So, an optimal compliance by the patient is required. The most important values of Pulmonary Function test are:

FVC: the total volume of air exhaled forcefully, following a full inhalation

FEV1: the volume of air that was exhaled into the mouthpiece in the first second after a full inhalation

The FEV1/FVC Ratio, also called Tiffeneau-Pinelli index: PEF, FEF2575%, OTHERS.

In addition to spirometry, patients can monitor both their heart rate and their blood oxygen saturation levels by using a pulse oximeter. Sometimes, a blood glucose control is required as well.

The frequency of measuring these values can vary from patient to patient, depending on their needs and their pathological conditions. However, a minimum measurement frequency of twice a week is required.

Once the values are collected, patients send their data to their reference centre by using some technological systems such as tablets, cable, Bluetooth or wireless connections. When the data sent by patients are received, the nurse responsible for the remote monitoring will start a data verification. Data will be saved in a database, located in specific folders, and evaluated together with the doctor coordinator of the project. These steps seem simple, but they are necessary and fundamental to a good remote assistance. There are two essential phases: conversation between the doctor and the nurse to discuss about their patients' conditions, considering patients' parameters and current state of health, and establish a treatment plan if needed; and daily phone contact between nurse and patient or care-giver. Telephone conversation between patients and nurses makes it possible to connect with patients, giving them the possibility to voice their needs from many points of view. And it is a useful and fundamental instrument the healthcare professional has available for this kind of healthcare, in order to listen to patients' needs, their distress calls, and evaluate if they need to be monitored in a hospital. Telehealth is one more tool that we have available, and it represents the future, but it will never be able to replace the visit to a doctor. In this specialized center for the treatment of cystic fibrosis, an investigation was conducted to assess the effectiveness of remote monitoring programs in patients. Comparing acute pulmonary exacerbations, it has been noted that adolescent and adult patients belonging to the CF center of the Bambino Gesù Hospital who are not followed through the dedicated home telemonitoring service show an increase in *Pseudomonas Aeruginosa* infections and a greater decrease in respiratory function. The use of telemedicine in CF is therefore an effective system not only in monitoring the disease but also as a treatment strategy, in the context of an evolving multidisciplinary model. As advantages, telemedicine can reduce the number of *Pseudomonas Aeruginosa* lung infections and the greater stability of respiratory function over time [3].

Result

This form of remote nursing care, called telenursing, is a focal point for telemedicine. Despite certain differences existing in the telematic relationship between nurses and patients, the nurse function remains the same, and it probably has a more peculiar

feature as it is necessary to establish a relationship of openness and trust with patients, in the effort of removing "barriers" that people normally experience when working through digital means of communication. Nurses are still sanitary educators who promote healthy lifestyles, listen carefully and constantly to their patients, and have the duty to adhere to their own code of ethics, even if apparently the method of implementing their mission changes. With telenursing, we practice the promotion of self-care, more than what we do in hospital departments with healthcare. Patients are able to listen to themselves, their needs and requirements, because they are the first listeners and evaluators of their condition, and it is they who will decide what to share with the medical staff and what not. Training and education for nurses are fundamental to establish the main requirement of doctor-nurse/patient relationship: trust. Nurses become coaches. In the healthcare sector, telecoaching can be introduced, like manager and executives are doing in other sectors. The possibility to assist patients by using a computer or a smartphone is revolutionizing Italian health care. According to ALTEMS (Alta Scuola di Economia dei Sistemi sanitari) most of the solutions adopted to remotely assist patients (there are approximately 180 digital solutions) are dedicated to chronic and fragile patients, regardless of coronavirus.

Conclusion

In the Italian health scenario, great possibilities for telemedicine can be seen. In the Lazio Region Official Gazette, a reimbursement for teleconsultation benefits was recognised for the first time today [4]. Telemedicine, in the case of chronic diseases such as cystic fibrosis, is a valuable ally to improve patients' quality of life and to early detect acute pulmonary exacerbations [5].

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