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# Video Call Educational Program for Cystic Fibrosis Adolescents

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## Abstract

Airway clearance technique (ACT) and inhalation therapy (IT) are essential in cystic fibrosis (CF) lung disease management. We here present our experience with a video-call educational program, which could maintain or improve adherence in adolescents. A 6-month program was offered to adolescents: a physiotherapist would monitor their ACT and IT home program via scheduled video-calls. A structured form evaluating patients' independence and awareness during a session would be filled in at the start and after 6 months. After informed consent was obtained, subjects filled in a questionnaire about their expectations and a satisfaction questionnaire at the end of the program. Student's t-test for paired data was performed for quantitative evaluation of the variables considered in forms filled during video calls. Eleven CF subjects were enrolled; most of them adhered spontaneously, as they expected to improve technique and receive helpful advice. About 301 educational video-calls were performed, 75% being the scheduled calls. Two patients dropped out. In the end, better awareness and self-management in ACT and IT was evident, and patients showed better performances ( $P < 0.01$ ), reporting they received helpful advice. Video-call education is a simple and feasible tool which could be useful to support adherence to ACT and IT in CF adolescents.

**Keywords:** adherence, patient education, telemedicine

## 1. Introduction

Adherence to “time-consuming” therapies in chronic patients is a well-recognized issue to overcome.

Low adherence has been described in adolescents suffering from diabetes mellitus [1] and reported in almost 50% of patient prescriptions for respiratory physiotherapy in cystic fibrosis (CF) [2] as well as more recently in prescriptions for drugs targeting cystic fibrosis transmembrane regulator (CFTR) protein function [3].

CF patients from adolescence to adulthood are at risk of their clinical condition worsening, due to several issues: a claim of autonomy (self-management), refusing therapies or parents' authority, and a misunderstanding or low perception of the treatment necessity and efficacy.

It is imperative for CF Centres to ensure awareness, knowledge, and autonomy in adolescents.

A recent review [4] focused on the existing evidence base regarding adherence interventions in adolescents with CF. Among potential strategies to improve

adherence, it was suggested to identify social media tools for online support; some preliminary positive experiences have been reported with online educational video. The German Airway League made available video clips about “Correct Inhalation Therapy for Patients with Cystic Fibrosis.” This gives the opportunity to CF adolescents to obtain, independently of time and location, autonomously, and in a time-saving manner, information on correct inhalation treatment [5].

An educational video was recently made available to parents of babies who resulted positive at the newborn screening program for cystic fibrosis [6], as an adjunct to help with genetic counseling. This study demonstrated the effectiveness of an educational video in improving parents’ knowledge.

We employed a novel face-to-face monitoring of home inhalation therapy (IT) and airway clearance technique (ACT), with a video call survey and educational program, with the aim of assessing awareness of CF adolescents and helping them to improve their knowledge and adherence. Here we present our preliminary experience.

## **2. Methods and patients**

CF adolescents, regularly followed up at our CF Centre, were invited to participate in a 6-month program designed to offer online support during home IT and ACT. All patients in the age range 12–18 years were offered enrollment in the project.

The primary endpoint of the study was the feasibility of the online video call program and its acceptability. Feasibility was determined by percentage of adherence (more than 75% of eligible patients), acceptability by the number of contacts for planned calls (more than 50%), and dropout of enrolled patients (less than 20%).

A secondary endpoint was to assess its efficacy in improving patients’ knowledge of therapies (preparation, sequences of IT/ACT) and autonomy in performing respiratory therapies and in cleaning devices, by means of score assigned during video monitoring.

Approval for conducting the study was received by the local ethics committee. Informed consent was obtained from subjects who agreed to participate and from their parents. All patients completed a Q1 questionnaire (see *Appendix*) to investigate their expectations toward the project.

Six touch screen tablets and internet connections were provided to adolescents who did not have access to one.

At the start, all subjects underwent their routine complete functional evaluation (spirometry, 6-minute walking test, MIP/MEP (muscle inspiratory and expiratory pressures)). All have their personalized therapeutic plan (IT and ACT), and during the 6-month program, they received a supervision of their physiotherapy program every 2 months at scheduled clinical visits.

A respiratory physiotherapist, via online video call, monitored, in the early afternoon, the adolescents’ home program performances two times a week for 6 months, following each personal therapeutic plan. The scheduled time for each connection was 30–45 minutes; this time was available to monitor both IT and ACT, to answer questions and correct errors.

At the start and end of the study, the physiotherapist filled in a form for each subject, evaluating their independence and awareness during a session. Three issues were assessed, with a total of different items: (a) Does the patient know why, when, and with which drugs to perform IT (3 items)? (b) Does the patient know how to properly prepare the devices (9 items)? (c) Does the patient know to clean and disinfect used devices (2 items)? For each item, a score between 0 and 5 was

assigned (0, severely insufficient; 5, excellent). The scores (maximum, sufficient) for each issue were (a) 15, 9; (b) 45, 27; and (c) 10, 6 (see *Appendix*).

With regard to the question “How do you perform ACT?,” the physiotherapist, after evaluation of each performance, gave a personalized educational intervention based on deficiencies identified during the video call, giving suggestions and advice and answering questions.

At the end of the study, a Q2 satisfaction questionnaire (see *Appendix*) was filled in by subjects, to evaluate agreement and acceptability of the project and to give their suggestions.

A descriptive analysis of the data collected was performed. A Student’s t-test for paired data was performed to assess improvement in scores at the end of the study.

3. Results

Thirty CF patients aged 12–18 years, regularly followed at our CF Centre, were eligible. Participation in the study was offered to all. All but one accepted to participate (97%), and 11 subjects (5 M) on a first arrived basis were enrolled.

The baseline characteristics of the study population are summarized in **Table 1**.

Patients	Sex	Genotype	Respiratory microbiology	Age	FEV <sub>1</sub> %	Mip%	Mep %	6' walking test (m)
1	M	F508 del/ G542X	<i>Staphylococcus aureus</i>	13	72	54	58	690
2	M	F508 del/ G542X	<i>Pseudomonas aeruginosa</i>	15	51	86	72	720
3	M	1717-1G > A/ N1303K	<i>Staphylococcus aureus</i>	13	104	66	63	720
4	F	F508 del/F508 del	<i>Staphylococcus aureus</i>	11	94	91	98	605
5	M	F508del/F508 del	<i>Staphylococcus aureus</i>	16	69	78	54	591
6	M	F508del/ 1898 + 1GA	<i>Staphylococcus aureus</i> <i>Pseudomonas aeruginosa</i>	16	94	108	83	660
7	F	W1282X/ R785X	<i>Staphylococcus aureus</i>	11	98	136	114	690
8	F	F508del/ N1303K	<i>Pseudomonas aeruginosa</i>	16	69	151	149	570
9	F	F508 del/F508 del	<i>Non-tuberculous Mycobacterium</i>	16	56	128	87	Not done
10	F	F508del/ G673X	<i>Achromobacter xyl.</i> <i>Staphylococcus aureus</i>	13	61	167	95	557
11	F	F508del/ W1282X	<i>Staphylococcus aureus</i>	12	79	118	96	695
Mean				13.82	77.00	107.55	88.09	649.80
SD				2.04	18.11	36.01	27.52	62.96

**Table 1.**  
*Clinical characteristics of the study population at the baseline visit.*

All subjects have a confirmed CF, and all presented pancreatic insufficiency, age ranged between 11 and 16 years. Seven subjects had moderate respiratory disease ( $FEV_{1pp}$ : 51–79%); four had normal function ( $FEV_{1pp}$ : 94–104%). Chronic *Pseudomonas* infection was present in three. All presented a 6-minute walking test within the normal limits (range 557–720 meters).

Airway clearance technique consisted of the use of PEP Mask in all of them.

In the 6-month program, 301 educational video calls were performed, which is 75% of the scheduled calls.

Their mean duration was 45 min (range 30–60 min). Each subject received a video call at least twice a week.

During the study period, two subjects dropped out ( $n^{\circ}9$  and 10; 18%), because of school commitments in the afternoon.

Regarding questionnaires filled in by subjects at the start (Q1) and at the end (Q2) of the project, Q1 (filled by 11 subjects) shows that eight adolescents were pleased to participate in the project, considering it an opportunity to maintain frequent contact with physiotherapists (in four cases) and a way to monitor their home program (in five). Nine subjects adhered spontaneously, but four did it for pleasing parents, and only one boy was forced by them. All subjects considered ACT very important to maintain their health, and their main expectations were to improve technique and receive helpful advice (six subjects) and have the opportunity to demonstrate their independence (two of them).

The Q2 questionnaire (filled in by nine subjects) shows that ACT was considered important in spite of the effort it requires. All of them were pleased to be enrolled in the study as it was a good opportunity to monitor the way they perform ACT; they have received helpful advice (reported by five of them) or have maintained contact with physiotherapists (by four). Four of them felt emotionally supported.

### 3.1 Results from forms filled by the physiotherapist

**Issue A.** *Does the subject know why, when, and with which drugs to perform IT and ACT* (possible score for each patient: 0–15)? At the start, 4 out of 11 adolescents did not know the reason for which they must perform the IT/ACT, and they did not perform both the IT and the ACT correctly. At the end, the final scores showed a greater awareness of why airway clearance is important and have shown a better understanding of IT in all subjects but one (mean score at start 6.5 (range 2–13), mean score at end 9.6 (range 5–14), ( $P < 0.01$ )).

**Issue B.** *Does the subject properly prepare his/her IT and device* (possible score for each patient: 0–45)? At the first evaluation, almost all were already able to prepare and assemble the devices; at the final one, all subjects were able to prepare and assemble the devices (mean score at start 29.5 (range 13–43), mean score at end 35.8 (range 25–43), ( $P < 0.01$ )).

**Issue C.** *Does the subject clean and disinfect his/her devices after therapy* (possible score 0–10)? None but one subject was autonomous in device cleaning and disinfection, leaving this duty to parents, both at the start and end (mean score 2.2 in both evaluations, NS).

The initial assessment of appropriateness in the execution of IT/ACT shows that seven subjects kept a right posture during IT/ACT and respected the correct sequence of drugs, but after the educational intervention, all of them performed the entire sequence IT / ACT appropriately.



## 4. Discussion

Our preliminary experience on a limited number of CF adolescents shows the possibility to perform an educational program by means of online video call. This program was designed to offer online support during home IT and ACT by a respiratory physiotherapist, with the aim of improving knowledge and adherence to respiratory physiotherapy in CF adolescents.

Recent reported experiences on an educational program on inhalation therapy [5] or newborn screening [6] with online video clips do not provide any kind of personal relationship between those who produced the media available online and the CF patient, differently by our program.

New technologies such as video call using smartphones or tablets are used on a daily basis by adolescents; thus we hypothesized that introducing educational programs in their life using these technologies might result in better outcomes. To the best of our knowledge, our study is the first educational program to use online video calls provided by an experienced physiotherapist to monitor IT/ACT. This program gave the opportunity to CF teenagers to develop personal contact with the respiratory therapist in their own homes, beyond the scheduled visits at the specialist center. Our work proved the feasibility of an educational video call program, where adolescents accepted online supervision for their daily IT/ACT and attended 75% of the planned calls.

The main problem we faced was the timing of the video calls, scheduled in the afternoon. In fact, 2 out of 11 patients had to abandon the project because of the video call time coinciding with commitments to school.

ACT monitoring and individualized educational interventions in the short term seem to lead to positive results, such as increased knowledge and better adherence to prescribed therapies by the end of the project.

Patients agreed to receive video calls and maintain frequent contact with the physiotherapist, and the program seemed to improve their autonomy in the management of IT and ACT.

With this study, we have also verified how an aspect of daily care, cleaning, and disinfection of IT/ACT devices is not taken into account as a personal task by teenagers but is constantly referred to one of the parents (usually the mother). An explanation could be also the desire of parents to be sure of the adequacy of cleaning or to be still present in the care of their teenage children.

Since the acquisition of personal autonomy also involves care (cleaning and disinfection) of the tools necessary for the execution of airway clearance, we will implement educational programs on this aspect of care.

The main positive effects of this project were the CF care team showed both the willingness and capability of using modern technologies to communicate with young people and improvement in knowledge, self-management, and autonomy in CF patients.

After the study ended, as a result of the project and in response to our patients' requests, video calls were made available during intravenous home therapy for pulmonary exacerbations, as patients recognized its usefulness in improving adherence.

Making additional resources available to patients outside the CF clinics, at their own home, resulted to be beneficial in reducing the feeling of loneliness during ACT daily performance and may, therefore, promote motivation and ameliorate adherence.

This pilot study has some limitations, including the low number of patients and its short duration. It is well known that educational interventions must be repeated

in time, with scheduled follow-up calls to maintain their efficacy. However, the primary outcome was to test the feasibility of an educational program via video calls, and this has been achieved, thanks to a rethinking of the CF health services model, which was delivered to patients' homes via online video calls.

The bias of the study is the very small number of patients.

In the future, further studies are needed to explore feasibility/acceptability with a larger number of subjects and clarify the duration needed to maintain positive results in the long term and its usefulness during home therapy for pulmonary exacerbations.

In conclusion, our pilot experience verified the feasibility and acceptability of an online video call educational program designed to improve knowledge and self-management of CF adolescents.

ACT monitoring and educational interventions, performed by video call, significantly improved our patients' ability and knowledge, promoting their adherence to ACT/IT and awareness of the need for greater adherence to the therapeutic program. Their independence has also been promoted. Video call educational programs could be a helpful therapeutic tool in the CF scenario.

#### **4.1 Psychological comment**

The design of this study also arises from the deep consideration of the psychological aspects related to the adolescent world of our age and in particular to the portion of the adolescent world that must live with a chronic disease caused by the presence of cystic fibrosis.

This is particularly true and relevant in a perspective that strongly supports the goodness and efficacy of the treatment being facilitated by the personalization of the therapeutic plan, modulated according to the characteristics and specific resources of the patient it is addressed to.

The current adolescent generation is embodied by the so-called "digital natives," namely, children and teenagers who have grown up hand in hand with the increasingly intensive use of the Internet, in an age where the use of technology breaks deep into everyday life, with a dramatic surge in virtual relationships that change and significantly influence the profile of contemporary adolescents.

Adolescence is a complex age with difficult specific-phase tasks to perform, even more so for the chronically ill adolescent, whose emotional world is permeated by difficult balances.

Girls and boys dealing with the disease are progressively confronted with aspects of themselves and of their pathology that binds them to a condition of dependence and fragility. This condition acquires anti-evolutionary meaning, in stark contrast with the increasing search for emancipation, autonomy, and self-affirmation.

Parents, in turn, are mainly concerned about their children's health and survival and often tend to limit their autonomy, with an excessive overprotection and control over the care and daily life of their children, thus possibly producing results that are quite opposite to their expectations, i.e., poor adherence to the prescribed therapy and onset of risk behaviors.

Therefore, respiratory physiotherapy represents an extremely delicate and meaningful moment for adolescents with cystic fibrosis, as it is a constant reminder of their chronic condition: they are chronically ill individuals who depend on a treatment they would most like to avoid. Physiotherapy inevitably turns into a battlefield where parents and children fight every day, causing distress and strain on both sides.

In light of these considerations, the project aiming at promoting the improvement of physiotherapy through video calls is even more relevant because it pursues multiple objectives.

On the one hand, it allows a personalized educational intervention aimed at supporting the improvement of techniques and skills by adolescent patients, taking advantage of technology and the Internet, which directly provide a familiar common language, appreciated by the youth and able to abolish distance.

On the other hand, the operator has the opportunity to walk into the homes of children and parents, albeit virtually, reducing the sense of loneliness and supporting the fatigue that adhering to such demanding regimens involves, especially during adolescence, thus encouraging a gradual autonomy, which is a fundamental objective both for the treatment and for the adherence to the therapies as well as for the growth and for the psychological well-being of our patients.

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## **A. Appendix**

1. Questionnaire #1
2. Video Call Educational Program (Evaluation Form)
3. Questionnaire #2

### **A.1 Questionnaire # 1**

Dear boys and girls, we ask you to fill this questionnaire before the beginning of the study.

The aim is to understand your expectation about this project. The questionnaire is anonymous; fill only your age and gender.

Thanks for your collaboration.

Dr. Padoan and Physiotherapists.

#### **1. Are you happy to be involved in this study?**

- ☐ Yes
- ☐ No
- ☐ Indifferent

#### **1a. If you answered “yes,” please explain why:**

- ☐ It is a way to monitor my physiotherapy.
- ☐ I like the technology.
- ☐ I am happy to receive support in my home treatment.



- ☐ I like the idea to receive support by the physiotherapist.
- ☐ I want to receive a tablet.
- ☐ I think that this project improves my adherence to the treatment.
- ☐ Other, please explain.....

**1b. If you answered “no,” please explain why:**

- ☐ Hospital visits are enough, I do not want to be checked at home.
- ☐ These scheduled calls limit my freedom.
- ☐ I do not like using computer.
- ☐ I think to do physiotherapy correctly so I do not need help.
- ☐ I think that physiotherapy is not such important for my health.
- ☐ Other, please explain.....

**1c. If you answered “indifferent,” explain why:**

- ☐ I do not know if this project could be useful for me.
- ☐ I do not understand what the project consists in.
- ☐ Other, please explain.....

**2. I have agreed to participate in the project:**

- ☐ Deciding by myself without any advice.
- ☐ Because my parents forced me.
- ☐ I decide alone with the awareness that this choice is the best for my parents.

**3. To maintain your health, do you think that physiotherapy is:**

- ☐ Very important.
- ☐ Not so important.
- ☐ Not important at all.
- ☐ I know that it's very important for my health but I do not want to perform it.
- ☐ Other, please explain.....

**4. Why do physician and physiotherapists involve you in this project? What do you think?**

- ☐ Because they do not believe that I perform my daily physiotherapy
- ☐ Because they believe that I do not correctly perform it
- ☐ Because they want to help me to feel good
- ☐ Because they want to control me
- ☐ To make my parents happy
- ☐ To help me to become autonomous and responsible for my therapy

**5. What do you expect from this project?**

- ☐ Being able to perform physiotherapy better than before.
- ☐ To receive advice and useful information.
- ☐ To receive support during my therapy.
- ☐ To prove that I am able to do things well.
- ☐ To please my parents, so that they “stress” me less for physiotherapy.
- ☐ To feel supported even emotionally.
- ☐ To waste time that I could use to do something else.
- ☐ To “earn” a tablet.
- ☐ I do not expect anything in particular.
- ☐ Other, please explain.....

**6. Do you want to tell us something else?**

.....  
**Your age .....**  
**You are**

- ☐ Male
- ☐ Female

**A.2 Video Call Educational Program (Evaluation Form)**

*Evaluation Date:.....*  
*Patient’s first and last name: .....*  
*Sex of the patient: ♂ Male   ♀ Female   Age of the patient .....years.*  
*The following assessment is:*

- ☐ *Initial*
- ☐ *Intermediate (3 months)*
- ☐ *Final*

A. Knowledge of therapy

	0	1	2	3	4	5
1. Does the patient know why he/she had to do respiratory physiotherapy?						
2. Does the patient know the correct sequence of respiratory physiotherapy (nasal lavage-bronchodilators-hypertonic/Pulmozyme/mucolytic-physiotherapy-antibiotic therapy)?						
3. Does the patient know the drugs he/she takes by aerosol (short-acting bronchodilators, bronchodilators and long-acting corticosteroids, oral steroids, antibiotics, Pulmozyme/hypertonic/mucolytic, etc.)?						

Legend:

5 = *Excellent*; 4 = *Good*; 3 = *Discrete*; 2 = *Sufficient*; 1 = *Insufficient*; 0 = *Severely insufficient*.

Educational notes (e.g., acknowledgment of need for education in a given area or on a specific aspect, etc.):

.....

.....

.....

.....

B. Execution of respiratory physiotherapy session

	0	1	2	3	4	5
1. Is the patient able to prepare the necessary material for the execution of the physiotherapy session (Lavonase, compressor, nebulizer ampoule, PEP Mask, or other devices)?						
2. Is the material clean and in good condition before the session?						
3. When performing the aerosol, does the patient choose the correct interface?						
4. If the patient uses the PEP Mask, is he/she able to fit the various components (mask, resistor, valve) in the correct way?						
5. If the patient uses the PEP Mask, does he/she employ the correct resistor?						
6. Does the patient respect the correct timing during the airway clearance technique?						
7. Does the patient perform FET or cough?						
8. Is the patient able to produce sputum?						
9. Is the patient's posture correct during the session of respiratory physiotherapy?						

Legend:

5 = *Excellent*; 4 = *Good*; 3 = *Discrete*; 2 = *Sufficient*; 1 = *Insufficient*; 0 = *Severely insufficient*.

**Educational notes** (e.g., acknowledgment of need for education in a given area or on a specific aspect, etc.):

.....  
.....  
.....  
.....  
.....

**C. Cleaning devices**

	0	1	2	3	4	5
1. Does the patient clean the devices?						
2. Does the patient disinfect the devices?						

**Legend:**

5 = *Excellent*; 4 = *Good*; 3 = *Discrete*; 2 = *Sufficient*; 1 = *Insufficient*;  
0 = *Severely insufficient*.

**Educational notes** (e.g., acknowledgment of need for education in a given area or on a specific aspect, etc.):

.....  
.....  
.....  
.....  
.....

*Signature of the physiotherapist.*

.....

**A.3 Questionnaire #2**

Dear boys and girls, this short questionnaire follows the project “Monitoring of Respiratory Physiotherapy Through Video Call in Adolescents.” The aim is to know what you think about the project and its utility and receive suggestion from you.

The questionnaire is anonymous; fill only your age and gender.

Thanks for your collaboration!

Dr. Padoan and physiotherapist.

**1. Are you happy to have been involved in this project?**

- ☐ Yes
- ☐ No
- ☐ Indifferent

**1a. If you answered “yes,” please explain why:**

- ☐ It was a way to monitor my physiotherapy.
- ☐ I love the technology.

- ☐ I was happy to receive support in my home treatment.
- ☐ I liked the idea to receive support by the physiotherapist.
- ☐ I wanted to receive a tablet.
- ☐ I thought that this project would improve my adherence to the treatment.
- ☐ Other, please explain.

**1b. If you answered “no,” please explain why:**

- ☐ Hospital visits were enough, I did not want to be checked at home.
- ☐ These scheduled calls limited my freedom.
- ☐ I do not like using computer.
- ☐ I thought to perform physiotherapy correctly so I did not need help.
- ☐ I thought that physiotherapy is not such important for my health.
- ☐ Other, please explain.....  
.....

**1c. If you answered “indifferent,” please explain why:**

.....  
.....

**2. What do you think about your respiratory physiotherapy?**

- ☐ It is very important.
- ☐ It is not so important.
- ☐ It is not important at all.
- ☐ It is very important to feel better but I do not want to perform it.
- ☐ Other, please explain.....  
.....

**3. What do you think about your involvement in this project by the physio-therapist?**

- ☐ Physiotherapists did not believe that I perform my daily physiotherapy.
- ☐ Physiotherapists believed I do not perform correctly my daily physiotherapy.
- ☐ Physiotherapists wanted to make me feel better.
- ☐ Physiotherapists wanted to control me.



- ☐ Physiotherapists wanted to make my parents happy.
- ☐ Physiotherapists wanted to help me to become autonomous and responsible for my therapy.

**4. What do you think at the end of this project?**

- ☐ I'm able to better perform physiotherapy.
- ☐ I received advice and useful information.
- ☐ I proved my ability to perform physiotherapy.
- ☐ I pleased my parents.
- ☐ I felt supported even emotionally.
- ☐ I wasted time that I could use to do something else.
- ☐ I did not learn anything.
- ☐ Other, please tell us.....  
.....

**5. Do you want to tell us something else?**

.....  
.....

**Your Age .....**

**You are**

- ☐ Male
- ☐ Female

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