Evaluation of adherence to THC in patients with Cystic Fibrosis in a period of 2 years

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Cystic Fibrosis: Guidelines of Treatment

In Cystic Fibrosis (CF), the improvement of prognosis is due to a changed approach in the management of the patient.

Continuous monitoring of clinical status, the recognition and early treatment of respiratory complications represent at today the main criteria guiding.

In case of exacerbations, early initiation of antibiotic treatment helps prevent more serious complications, and limits the lung damage in the long term.

Early intervention allows also to use effectively less invasive antibiotic therapies.
Cystic Fibrosis: the Role of Telehomecare

In the Cystic Fibrosis Centre of Bambino Gesù Pediatric Hospital in Rome, since 2001 telehomecare (THC) has been activated in the follow-up of patients at home.

In a previous study we found, in THC patients, some positive effects, such as a decrease of outpatient accesses and increase of therapy cycles, and a trend toward higher stability of the respiratory function.

Cystic Fibrosis: The Problem of Poor Adherence to Treatment

In CF patients’ follow-up, the risk of poor adherence to daily treatments (medications, physiotherapy, nebulisation, insulin, etc..) is a fact by now well known.

From psychological perspective, THC represents a type of intervention that supports the patient in the course of illness making him feel thought, aided, surveyed in an active mode towards treatment.
The Aim of the Study

It’s long been known as the patient’s knowledge of the disease in CF contributes to increase adherence to treatment and decreases the mental barriers which can condition it in the negative.

In the present study we examined, in our CF patients followed at home, data related to adherence to telemonitoring for a period of 2 years, in the aim to improve the follow-up in terms of efficiency and appropriateness.
Methods

Currently, about 30 patients are included in the telehomecare program. In all subjects was given the clinical diagnosis of CF, confirmed by genetic study of the CFTR gene. Patients included in the program of telemonitoring are followed-up and treated with the usual protocols, similar to those that do not practice it.

Spirotel™ instrumentation is used as part of a system called Home Vivitel Control Service (www.vivisol.com), providing the data of a spirometry and nocturnal pulse oximetry and transmits these remotely.

A short questionnaire is administered based on the detection of 6 subjective respiratory symptoms, classified in 3 degrees (absent, medium, max) and then transmitted with the data.
Intervention Parameters

For Spirometry:
acute reduction in FEV1 >10% compared to the characteristic value for each subject in stable conditions (Ramsey e coll, 1992) and / or worsening of one or more symptoms.

For Nocturnal Pulse Oximetry:
desaturations <80% of the maximum value of haemoglobin oxygen saturation (SaO2), mean reductions in SaO2 and increments of T90.
## Results

**Balance of enrolment** (from feb, 15 2010 to feb,15 2012)

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>enrolled</td>
<td>37</td>
<td></td>
</tr>
<tr>
<td>active</td>
<td>25</td>
<td>67.57%</td>
</tr>
<tr>
<td>drop-out</td>
<td>12</td>
<td>32.43%</td>
</tr>
<tr>
<td>poor adherence</td>
<td>7</td>
<td>58.33%</td>
</tr>
<tr>
<td>died</td>
<td>4</td>
<td>33.33%</td>
</tr>
<tr>
<td>other</td>
<td>1</td>
<td>8.33%</td>
</tr>
</tbody>
</table>
## Results

### General Summary (from Feb, 15 2010 to Feb, 15 2012)

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>transmissions</td>
<td>536</td>
<td>730</td>
<td>831</td>
<td>2097</td>
</tr>
<tr>
<td>working days</td>
<td>226</td>
<td>257</td>
<td>248</td>
<td>731</td>
</tr>
<tr>
<td>adherence</td>
<td>8.78</td>
<td>9.62</td>
<td>13.03</td>
<td>mean 10.47%</td>
</tr>
<tr>
<td>spyrometry</td>
<td>658</td>
<td>1048</td>
<td>1060</td>
<td>2766</td>
</tr>
<tr>
<td>pulse oximetry</td>
<td>183</td>
<td>231</td>
<td>292</td>
<td>706</td>
</tr>
<tr>
<td>symptoms</td>
<td></td>
<td>322</td>
<td>709</td>
<td>1031</td>
</tr>
<tr>
<td>inpatients</td>
<td>12</td>
<td>15</td>
<td>49</td>
<td>76</td>
</tr>
<tr>
<td>phone calls</td>
<td>466</td>
<td>592</td>
<td>745</td>
<td>1803</td>
</tr>
<tr>
<td>contacts</td>
<td>451</td>
<td>523</td>
<td>679</td>
<td>1653</td>
</tr>
<tr>
<td>% contacts/trasm</td>
<td>71.64%</td>
<td>81.38%</td>
<td>mean 77.00%</td>
<td></td>
</tr>
</tbody>
</table>
Discussion : Criteria for Inclusion in THC

In CF subjects, the definition of criteria for inclusion in telemonitoring is difficult as there is no experimental data that ensure in the various expressions and clinical types significant differences about a better efficacy of the THC procedure.

On the other hand, since telemonitoring actually in Italy is not yet included in the essential basic assistance levels (LEA), its viability depends in the individual cases from voluntary resources provided by local health authorities.
The main cause of drop-out was poor or no adherence to individual treatment occurred during the period of inclusion (58.33%).
Discussion: Adherence to Treatment

The surveys were carried out at variable intervals, depending on the clinical condition of the individual.

We advised our patients to transmit at least 2 times a week, so that the optimum achievable adherence is 40% (2 transmissions/5 working days).

We got mean values of ¼ of the expected optimal value, with a slightly increasing trend over the years.
Discussion : Causes of Poor Adherence

1. CF patients are already burdened with a heavy load of continuous therapies, both medical and physiotherapy.

2. This result was obtained without the Centre has requested a detailed timetable of registration, limiting themselves only to indicate a general transmission rate (usually twice in a week).

3. Patients who dropped out reported in many cases, during THC, an increase in the subjective feeling of anxiety. We therefore sought to overcome this situation, leaving our patients essentially free to transmit, and the trend of increase in adherence over the years it is comforting.
Discussion: the Problem of Adherence

In CF has been suggested a complex approach to the problem of poor adherence to treatment.

Customize the intervention, in this case via telemedicine, is also a way to foster a good relationship with the patient (or caregiver), this condition to improve the mutual trust that must underlie the process of care.

Factors that could increase adherence to treatment may be an explicit and continuous encouragement, present and continuous support of family and caregivers and the introduction of strategies aimed at changing the habits of life and individual behaviour.
Discussion : the Problem of Contacts

We were able to establish immediate contact with the patient or family on an average of only 77 % of cases. The medium that we used usually to establish the contact was the cell phone.

When it was not possible to obtain an immediate contact, in all cases has been researched a contact in the hours or the day thereafter. These data certainly does not seem satisfactory and clearly indicate the need to improve the procedure, to ensure the best continuity of care.

The cell phone, in this case, although it has proved a valuable tool, has not always proved completely reliable.
Conclusions

The improvement of clinical outcome in FC necessarily passes through an improvement of the adherence to treatment.

More psychological and behavioral studies are needed in order to gradually remove the obstacles which still prevent a further improvement in long-term outcome.
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THANKS