Adolescence and cystic fibrosis

Improving the median FEV1% by reinforcing Therapeutic Patient Education in the course of a quality improvement program

Valérie David Paediatrician - Centre of Reference for Cystic Fibrosis Nantes France
v david@chu-nantes.fr
Dominique Pougheon Bertrand - Centre of Reference for Cystic Fibrosis Nantes France

8-11 June 2016
39th European Cystic Fibrosis Conference, Base, Switzerland
Introduction

• Adolescence is a period at high risk for FEV1 decline

• As in all chronic diseases, adolescents with CF have more or less serious difficulties for treatment monitoring and have a drop in motivation to take care of themselves

• These difficulties may have a negative effect on their respiratory status.
Nantes CF Centre engaged in the QIP PHARE-M in 2011

• French QIP pilot phase:
  – implement and adapt the CF Foundation LLC QIP
  – explore synergies between TPE and QIP
  – in order to reinforce mutual efficacy

• Therapeutic Patient Education culture is our “pattern”:
  – TPE activities are an essential part of the process of care delivered in the Paediatric CF centre
  – Thus the Team engaged in PHARE-M to sustain the implementation of TPE activities
Interdisciplinary team: physician, nurses, physiotherapist, dietician, psychologist, social worker, art-therapist,

1 month: Diagnosis by neonatal screening

Individual diagnosis (Parents)

Individual diagnosis (Parents+children)

Individual diagnosis (parents+children)

At 16: valorisation of skills' acquisition

At 17y Questionnaire: « I am ready to transition to CF adult center »

At 18 y Transfer to CF adult center

Individual sessions integrated to classical follow

Group «6 m-2y»: Children's parents

Group «7-8 y»: Children+parents

Group «12-13 y»: Children+parents

Group «16-18 y» Adolescents + parents

Parent’s group for talk Twice a year

8-11 June 2016
39th European Cystic Fibrosis Conference, Base, Switzerland
Step 1: 5P analysis of the CF centre

Patient outcomes: median FEV1 in our center was close to the worst for patients aged 13-18 (French Patient Registry - data 2010)

→ Objective: Improve the median FEV1 % of adolescents aged 15-18 years by 5% in 4 years (from 78% to 83%)
Step 2: fishbone points out the need to pay more attention to the ado’s « body image »

**Patients**
- Adherence to treatments
- Self-esteem
- Nutritional status

**Professionals’ attitude**
- « Body image »
- Adolescents consultations without parents
- Empathy

**Pattern**
- Team trained and specialized in therapeutic patient education

**Knowledge & Practice**
- Identify exacerbations symptoms and define a personalized Action Plan in case of exacerbation
- Assess systematically results of treatments
- Propose education activities to develop self-management and psycho-social skills in respiratory and nutritional care

FEV1 for adolescents

8-11 June 2016
39th European Cystic Fibrosis Conference, Base, Switzerland
Step 3: display “Measures That Matter”

- A systematic multi-disciplinary review of every Ado’s situation allowed to fix priorities for education and health outcomes.
- Each Metric and its goal was assigned to a professional in the multidisciplinary team.

<table>
<thead>
<tr>
<th>Number of patients who:</th>
<th>Name of the professional</th>
<th>date</th>
<th>date</th>
<th>date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attended TPE sessions</td>
<td>nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have done the “Overall assessment of skills acquired”</td>
<td>physiotherapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have learned lung drainage</td>
<td></td>
<td>date</td>
<td>date</td>
<td>date</td>
</tr>
<tr>
<td>Regularly practise exercise</td>
<td>doctor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use an exacerbation plan</td>
<td></td>
<td>date</td>
<td>date</td>
<td>date</td>
</tr>
<tr>
<td>Discussed on topics including alcohol, tobacco, fertility and sexuality, motivation to treatment</td>
<td>psychologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Filled out a quality of life-anxiety-coping-depression questionnaire</td>
<td>dietician</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have learned the importance of high caloric intake</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have realised art –therapy (non-verbal expression)</td>
<td>art therapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient professional project, hobbies, social rights awareness</td>
<td>social worker</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Step 4: clinic visit process review

- Patient Installation In a BOX
- Evaluation (Nurse) → Evaluation (Physio)
- Consultation Psychosocial ou Consultation Dietician
- Consultation Physician
- TPE session
- Patient departure
- Box désinfection

Duration: 1h15

8-11 June 2016
39th European Cystic Fibrosis Conference, Base, Switzerland
<table>
<thead>
<tr>
<th>Patient</th>
<th>IDEC</th>
<th>KINÉ</th>
<th>PSY</th>
<th>DIET</th>
<th>A.S</th>
<th>Médecin</th>
<th>Stagiaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salle</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>IDE RC ETP</td>
</tr>
</tbody>
</table>

- 📌 = I am in the box
- 🟦 = I have finished and I call the next professional
The primary objective was met and even exceeded by the end of 2015, as the median FEV1 of patients aged 15-18 years reached 90%.

<table>
<thead>
<tr>
<th>Year</th>
<th>Median FEV1</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>75%</td>
</tr>
<tr>
<td>2012</td>
<td>86%</td>
</tr>
<tr>
<td>2013</td>
<td>87%</td>
</tr>
<tr>
<td>2014</td>
<td>82%</td>
</tr>
<tr>
<td>2015</td>
<td>90%</td>
</tr>
</tbody>
</table>

Other results:

Patient satisfaction with the creative and sports activities offered was high.
The team got involved immediately, cohesion around the project was strong, and the psychologist was heavily enlisted.
Conclusion

The monitoring of educational goals was enhanced in the course of the QIP. This helped achieve the objectives in terms of health outcomes and self-management for adolescents before transitioning to the adult program.

TPE and QIP, combined for the best, were able to improve the health indicators of CF Ados in our CF center.

As Bruce Marshall wrote in the British Medical Journal in 2014: « we suggest that the aggregate effects of these combined efforts — a widely available and transparent patient registry, benchmarking of best improvement practices, active involvement of patients and their families in improvement initiatives, and dissemination of improvement methodologies among CF healthcare professionals — may be transferrable to improving care for others with serious chronic illnesses »