„I´ll do it myself!“

Pavla Hodkova¹, Jan Machala², Dominika Rankova¹, Helena Uhlirova¹
¹) University Hospital Motol, Prague, Czech Republic, ²) University Hospital Brno, Czech Republic

Objectives

- Psychological support for children and adolescents with CF and their families
- To help the patients (children) to perform the medical regimen independently, and overtake the responsibility for the medical regimen through the various steps in family and patient counselling
- Involvement of physicians and nutritional nurses into the project to unite the whole CF team
- The project was drafted as a pilot version, so one of the main objectives is to identify which steps work as well as which ones do not

Audience

- Children and adolescents with CF at the age ranging from 0 to 18 years
- The audience is divided into the 5 groups according to the developmental stages
- The parents of these children
- The CF team members
- The project currently involves 23 patients and their parents, divided among four researchers

Impact

- Elaboration of educational and communication strategies in the therapeutic process
- Improvement of general communication in families – identification of functional and nonfunctional patterns and search for those that do work and bring benefits
- Children are more focused on the treatment regimen and their role in it
- Parents reflect on their role in the regimen and the independence of their children
- In consequence, the counselling reduces anxiety in both the children and the parents
- Investigation and recognition of abilities and independence level of children in different age groups shows great significance for the whole CF team

Challenges

- Timetable of meetings and telephonic interventions
- Non-participation of fathers, even after explicit invitations
- The long distance between some patients and CF centers
- Establishment of long-term work alliance with some patients
- Fluctuating motivation and bad cooperation of some participants
- Misunderstanding of possibilities and limits of project of some participants

Deliverables

- Education in the medical regimen can be conducted in any age group, provided that it is adapted for the development stage of the child and the situation in the family
- The work with younger children should be conducted mainly in form of play (Play Therapy techniques) and rehearsal, older children respond better to conversations
- Discovery of new important topics such as selection of type of high school, perspective of lung transplantation, how to tell the partner about CF, topic of death etc. These topics can be talked over in safe therapeutic environment
- It is very important to hold educational hours separately and not as minor part of physical examination
- Educational processes have to be monitored and continuously cultivated

This information has to be communicated to the whole CF team.

Contact: jan.machala@fnbrno.cz, 00420532234649, 00420532234574