



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference
November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



The transition of care in Cystic Fibrosis

Caterina Teodori
Dirigete Psicologo Psicoterapeuta
A.O.U. Meyer Firenze



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference

November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



The clinical manifestations of cystic fibrosis are characterized by:

- Chronic respiratory diseases
- Pancreatic insufficiency
- Nasal polyps
- Cystic fibrosis-related diabetes (CFRD)
- In men, atresia of the vas deferens



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference

November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Historically, CF has been a pediatric disease: affected children did not survive beyond childhood.

Currently, improvements in diagnosis and treatment over the last 60 years have allowed CF patients to survive into adulthood.

- In Europe, America, and Canada the median survival for CF patients is around 40 years and the median age of mortality is around 30 years.
- Predictive models claim that a child born today who is diagnosed with CF will have a life expectancy of over 50 years.

The progressive increase of the median survival will result in a significant increase in the number of adults with CF over the next decade.

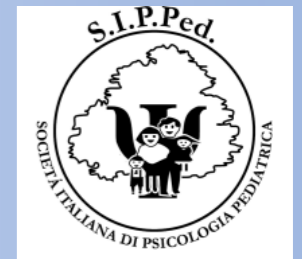


Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference
November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Adult patients with CF have different clinical and psychological needs than those seen in children. The pathology takes on more complex characteristics:

- Some morbidities become more frequent: FC-related diabetes, liver disease, osteoporosis, kidney failure, infertility and depression.
- Complications of the disease are also more frequent: severe hemoptysis, pneumothorax, appearance of multi-resistant bacteria.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference
November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



→ Developing care centers for adults with CF, along with transferring in them adolescent patients, has become both a medical and a management necessity. It requires a multidisciplinary team that can identify and manage every aspect related to both the disease and other areas of the subject's life (eg. school education, integration into the world of work).

In the medical field, the **transition** is defined as an *intentional and planned passage of adolescents with chronic pathologies towards a care center for adults, aiming at a full take-over, through the provision of appropriate services and with a guarantee of continuity of care.*



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference
November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Starting age of the transition phase

- The starting age of the transition phase is between 16 and 18 years.
- The period of transition from the pediatric care center to the adult center should be from the age of 18 to the age of 21.

The expected result of a valid transition process is to transfer 90% of adult patients by the age of 21.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference
November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Crucial elements in the transition development:

- The training path of the patient in the period preceding the transition must be carried out with competence, correct information and appropriate communication models by all the operators of the two centers involved in the transfer.
- The *interaction* between various professionals continues throughout the entire transition process. The pediatric team, which is in charge of the patient since birth, will be able to assist the adult team in identifying the critical points and strengths of each subject, aiming at a taking-over process as personalized as possible.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference

November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Evaluation of suitability for the transition

- The evaluation of the patient's availability to transfer is essential and involves an assessment of the patient's medical knowledge, the ability to autonomously manage the therapeutic program and the patient's psychological propensity to perform the transition. The role of the psychologist is essential.
- Use of validated evaluation questionnaires for CF, such as the “Transition Readiness Assessment Questionnaire (TRAQ)”, which assesses whether the patient is able to look after himself, to manage his own appointments, to take drugs correctly, to interact with the medical staff of the FC Center, to be autonomous in daily life activities.

The patient's age alone was not sufficient to establish eligibility for the transition in an adult CF center.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference

November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Critical issues

1. The critical issues of the adolescent period, during which the transition program is inserted, could delay the regular activation of the program itself due to a lower therapy adherence, the possible clinical pulmonary deterioration, the existence of complications such as diabetes and depression.

In chronic patients, personal independence is the goal of the physiological transition from adolescence to adulthood, which is achieved also through awareness of the disease and the acquisition of independence and autonomy, not only in the social context but also in terms of care and every aspect of pathology.

→ Patients with CF must develop greater self-awareness, organizational skills, sense of responsibility and self-management skills.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference
November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



2. The family-centered pediatric model, which foresees an active involvement of parents, caregivers, and patients themselves in the planning of treatments and decisions to be made, and that encourages the sharing between parents and patient, **is not sufficient to increase the independence of a teenager approaching an adult care system.** In the management of the adult patient, patient-centered care determines a direct responsibility of the patient himself.
3. The deep bond that the patient has established with the pediatric team could constitute a psychological barrier.
4. Fear that the adult FC center is not sufficiently competent.

Staying in the pediatric center together with children with CF could strengthen immaturity, a refusal of accepting the passing of time, and would inevitably remove the idea of death.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

**2nd S.I.P.Ped. International Conference
November 7 – 9, 2019**

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Aspects related to fertility / sexuality

Both the pediatric centers and the adult centers must deal with the problems inherent to sexuality / fertility with the patients, also making use of specialized consultancy dedicated to this field.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference

November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Organizing the transition

- Careful and accurate planning is the prerequisite for an effective transition of young CF patients, which also includes the preparation of the family, the pediatric team and the adult team. The adult center must take on the expectations of the patient and his family.
- Transition projects must be shared by both centers.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference

November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



The international literature on the subject shows that the most important factors in the success of the transition for young CF patients are:

- Meetings in which both the pediatric team and the adult team are present;
- Visiting the adult service before making the transition;
- Arranging the first appointment at the adult center autonomously;
- Concentrate the visits of these patients in dedicated spaces and in defined days or time slots, avoiding mingling with patients of old age or with complications, which may create disturbance and estrange the young patient.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference
November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Transition preparation procedure

- The transition is mentioned at each visit once a year from childhood; children and their families approach the transition as an expectation.
- Psychological preparation begins around the age of 14. It includes: encouraging independence in managing one's health and in relations with CF staff, supporting the patient and family members to deal with problems related to adolescence, recognition by staff of changing attitudes to illness and its management, providing information about adult CF centers and care services.
- Every year, for every patient between the ages of 16 and 18 who meets the criteria of the transition, two visits to the pediatric center will be scheduled at the same time by the adult doctor responsible for the transition project together with the pediatrician.



Transition times.

Supporting the child and adolescent's transitions in Pediatric condition

2nd S.I.P.Ped. International Conference
November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



Tools and methods for the self-management of the pathology

Improving the health status of CF patients should support the expectation of living an adult life with the potential to have a family, a marriage, a job. Both for the grown-up child and the adolescent, **the promotion of self-care in an early stage, in addition to the action and presence of the parents**, provides the possibility of increasing awareness of the need to self-manage, to understand why each therapy is prescribed and therefore to emphasize the need for independence.