289 Time invested in the respiratory global care of CF paediatric patients

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Background: Respiratory therapy for patients with Cystic Fibrosis (CF) includes chest physiotherapy (CPT) and inhaled medications, as well as physical activity. In our center, patients are instructed in autogenic drainage as basis of any CPT. It is well known that daily respiratory therapy is time consuming; we aimed in our study to describe the time spent for CPT including nebulisation, cleaning of devices and physical activity.
Materiel and Method: Cross-sectional prospective study in a cohort of paediatric CF patients. A specific questionnaire was developed to look at the time spent on respiratory therapy over a 3 months period. Enrolled were all CF patients followed in our center between 6 to 16 years (Exclusion criterion was lung transplantation).
Results: Out of 40 enrolled patients, 22 participated (13 boys), aged between 7 and 15 (mean age 11 years). 20 patients (91%) had mild (FEV1 > 70%), 2 (9%) moderate disease (FEV1 > 60%). Patients spent about 2 hours a day (0.12–7.38 hours/day) in their respiratory care, including CPT (31%), nebulising (15%), cleaning (4%) and physical activities (50%). 40% of CPT is spent for nebulising, 42% for therapy by their own and 18% for therapy with a physiotherapist. Physical activity was conducted by a coach in half of the time (47%), the rest of the time alone (53%).
Conclusion: In regards of the results, it seems crucial to look in global way, searching to optimize the respiratory therapy (ratio time/efficiency) by maintaining the efficiency and a good compliance. The physical activity is important to promote in regards to reinforce the therapy in a more playfull way, apart from the the social aspect.

290 Effect of early physiotherapy intervention in CF babies persists at least till 12 years of age

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With improving prognosis for patients with CF and more intensive medical care for newborns and babies, new methods of physiotherapy started to appear throughout the world for this age group. Our method is one of them and is based on airway clearance and developmental kinesiology according to breathing patterns. It combines airway clearance techniques (ACT) with care of psychomotor development.
Study group consists of 19 children born during 94–97 longitudinally followed up for 12 years. Patients were diagnosed during the first year of age and treated by respiratory handling (RH) for ACT and Contact Stimulating Physiotherapy (CSP).
Control group consists of 26 patients, born in 89–97. They did not differ in age of diagnosis, ATB treatment and nutritional support, but their physiotherapy did not include CSP.
We compared development of pulmonary function tests (PFTs) of these two groups at the age of 8, 10 and 12 years by means of t-test. Patients treated by CSP generally did not suffered from obstruction of central and peripheral airways and achieved higher results in PFTs except of FVC. In control group slight decrease of PFTs, especially MEF25% was observed. At the age of 12 years FEV1 for study group is 94.5±15.3% pv vs 82.2±21.3% pv in controls and MEF 50% in study group 100.5±26.7% pv versus controls 76.8±30.9% pv ($p < 0.05$).
We think that CSP applied in early age improves intensive homecare mother's physiotherapy without crying and stress. Due to improvement of adherence to therapy it has a long-term effect and postpones obstructive bronchial symptoms. We consider CSP to be a suitable and adequate method for patients from newborn screening.
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291 A survey of weekend physiotherapy provision in UK adult CF units

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Background: The CF Trust Standards of Care (2002) state that all specialist centres should have qualified physiotherapy staff to provide treatment as necessary, throughout a 24-hr period.
Following evaluation of the CF weekend physiotherapy service in Manchester Adult CF Centre, we wanted to establish the provision in other CF units nationally, to benchmark against our service.
Method: A questionnaire was emailed to physiotherapy leads at adult CF units in the UK.
Results: 17 questionnaires were returned (response rate = 81%), all stating that a weekend physiotherapy service is provided to inpatients, staffed mainly by general respiratory physiotherapists (94%). The median number of inpatient beds is 10 (SD 7.09, range 28). Physiotherapists work a median of 3.5 hrs/weekend day (SD 2.45, range 7).
Only 47% offer a weekend physiotherapy input to all inpatients. For the remainder, criteria used to identify appropriate patients are condition-related (e.g. likely to deteriorate, palliative/terminal-stage care, awaiting transplant, benefit from weekday intervention) and/or patient-related (e.g. compliant, not independent with treatment).
The main modality provided at all units is airway clearance techniques (ACT), including adjuncts. 59% offer exercise, of which 40% stipulated only if part of ACT.
Discussion: The feedback from this survey highlights the variation in current weekend physiotherapy provision for CF inpatients in UK specialist adult centres, in terms of who provides the service, which patients receive input and what modalities are offered. The impact these differences have on a patient's progress/outcomes is unknown but could be explored in further investigations.

292 National survey on home-based physiotherapy for CF patients: the difficulties of care at home

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Context: In France, home-based physiotherapy is carried out by the patient, his parents, or by a home-care physiotherapist.
How are the sessions carried out at home? What are the difficulties encountered by the home-care physiotherapists, with the parents? With the patients? What are their needs? Their expectations?
Method: The Physiotherapy workgroup of the French CF Society conducted a survey of 400 home-care physiotherapists to answer those questions by a questionnaire.
Results: They show that main difficulties encountered are patient compliance with physiotherapist treatment, the variability of the patient's pulmonary and physical condition, the need before each session for a full assessment of the situation, taking into account the respiratory condition, muscular condition, fatigue of the patient. The quality of the relationship physio-patient (or, physio-patient-parents for young patients) directly affects the patient's adherence to treatment, his/her quality of learning and mastery of different techniques and the quality of everyday life.
Conclusion: The management of this chronic disease requires a specific clinical approach and treatment, but also and equally important a good psychological and a psycho-social approach of of the patient and family members who accompany his/her physiotherapy treatment throughout life. A so good quality of management will provide and maintain an optimal quality of life for the patient, his parents and siblings.