Segregation of children with cystic fibrosis: difference in psychosocial impact between young children and adolescents

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Background: In 2005 the CF Centre Utrecht adopted a segregation policy in order to prevent cross-infections with P. aeruginosa. After years of intense contacts between CF patients, a lot of patients have difficulties adapting to the strict segregation rules.

Aims: To study the psychosocial impact of the segregation policy on children with CF who are admitted to the hospital, to compare differences in impact between young children and adolescents.

Methods: All patients admitted to our clinic for treatment of a pulmonary exacerbation and their parents receive a questionnaire. Outcomes will be compared between young children and adolescents with CF and between patients with first admission before and after the start of segregation.

Results: Patients will be included in this study until June 1, 2007. Results will be presented at the conference. Preliminary results indicate that young children do have less difficulties adapting to the segregation rules compared to adolescents.

Conclusion: There is a substantial psychosocial impact of segregation on children with CF. There is an indication that there are differences in impact between young children and adolescents with CF.

Patient assessment of a new intravenous infusion device

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Home treatment is common practice, especially intravenous therapy. Infusion devices are popular as they reduce dose error, infection risk and treatment time thus improving quality of life.

Aim: To assess the effectiveness and ease of use of an alternative elastomer infusion device (Eclipse®) introduced at this Centre.

Method: Patient satisfaction forms were given to all patients the first time they received the device. A stamped, addressed envelope was included and patients were asked to return the forms.

Results: All forms were returned (n = 48). 11 were partially invalid due to incorrect completion, therefore 37 forms were available for analysis. Sixteen (42%) reported that infusion time took longer than stated in the instructions – 3 to 15 minutes, 100% reported no problem with connection to their intravenous access, 100% reported no problem with priming the line. A scale of 1–10 was used to rate comfort (mean: 9, range: 4–10) and discreetness (mean: 7.8, range: 4–10).

Conclusion: The Eclipse® appears to be easy to use and popular with patients. Although a number reported longer than expected infusion times, some also reported shorter than expected infusion times. People with CF carry out demanding and time consuming treatment regimens, increasing with deteriorating health status. It is the responsibility of the CF Team to explore – in partnership with patients – alternative methods of administering treatment that may help to reduce this daily burden.

Feasibility and tolerance of percutaneous central catheters in children with cystic fibrosis (CF)

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Introduction: In CF, colonisation of airways by P. aeruginosa often requires prolonged intravenous antibiotics.

Aim: To evaluate the feasibility and tolerance of central catheters introduced by a peripheral vein (first Picc (BD)).

Study design: A prospective, descriptive study from 2004 to 2007.

Results: We included 23 children, aged 11.2 ± 4.9 years. During this period, 13/23 (56.5%) children underwent the procedure once, 7/23 (30.4%) twice and 3/23 3 times. The catheter was inserted successfully in 22 children. The overall duration of the procedure was 38.6 ± 16.1 minutes. The catheter was inserted in children’s ward room in 26.1% of cases, with inhaled analgesia (MEOPA) associated with local anaesthesia (EMLA patch) in 60.9% of cases. The operators encountered few difficulties (score 2.2 ± 2.1 out of a scale from 1 (no difficulty) to 10 (maximal difficulty)), the number of attempts was 1.6 ± 1.0 per child. There were no major side effects. We noted 2/23 cases, with a thrombosis of the catheter. The Ultrasound-Doppler scan performed at the end of the antibiotic course showed total permeability of the central veins in 92.3% (12/13) of cases. There were no cases of infection or venous inflammation. Satisfaction index of the operators and the patients were high, 9.1 ± 1.8 and 8.0 ± 1.2 (out of a scale from 1 (worst) to 10 (best)), respectively. 92.3% of cases received a continuous perfusion to maintain catheter patency.

Conclusion: Central catheters, introduced via peripheral veins are simple to use. The procedure can be performed in the ward, under local anaesthesia and sedation. These catheters are well tolerated and increase the comfort of children with cystic fibrosis.

The theory and practice of childhood attachment and family systems for disease outcomes and service utilisation in adult cystic fibrosis patients. Research findings from a mixed methodological study

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Previous studies in Cystic Fibrosis have identified the psychosocial correlates of the disease but factors impacting on patient clinical relationships, disease behaviors, and service use in are largely not understood.

Aims: The main objective of this research was to explore whether attachment and family relationship experiences from early childhood impact on disease management behaviour, and disease outcomes in cystic fibrosis patients.

Method: Qualitative and quantitative assessment measures were used to explore patient attachment style and family functioning in the context of objective markers of disease severity and occasions of service. Subjects were selected from a consecutive sample of inpatients in a 12 month period.

Assessment tools included three validated self report questionnaires, and a single qualitative semi structured standardised interview.

Data analysis: Statistical and thematic content analysis was undertaken to identify any association between early attachment patterns and disease outcomes.

Results: Within limitations of the sample size there was a definite trend between attachment type, disease outcomes and service utilization, demonstrating the relevance of the psycho-dynamic framework and attachment based assessment in chronic illness management. The study demonstrates trends to significance not inconsistent with previous studies in chronic illness and attachment, linking poorer physical and mental health outcomes and higher service utilisation with insecure attachment. Further research and interventionist studies are anticipated.