373* Non-adherence as coping strategy of young adult patients with CF. A qualitative study

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Objectives: Lack of adherence is not only an essential reason for deterioration of the physical state of CF-patients, it also interferes with the caregiver-patient relationship and is frequently seen as irrational, incomprehensible and dysfunctional behaviour. Our study aims to understand relevant attitudes and experiences of young adult CF-patients with respect to coping behaviour and caregiver-patient relationship and to explore the relation between these factors and treatment adherence.
Methods: 12 semi-structured interviews were performed with patients (age 17–24 years). The interviews were audio-taped, transcripted and evaluated. Data analysis was computer-aided by the ATLAS.ti software.
Findings: The study reveals a lot of clinically relevant information; e.g., avoiding the treatment (taking medicine, visiting the doctor, diagnostics, ...) serves as a function to avoid the burdening realisation of (the extend of) the illness. E.g. *Going to the hospital regularly is indeed a confirmation that I'm in a bad shape ... that's something I don't want.*
In fact, the relationship to the caregivers was shown to be a very supporting and moderating factor to handle these burdening feelings; e.g. patients over all desire respect, solicitousness and encouragement.
Conclusions: The findings provide a better comprehension of emotional aspects concerning non-adherence. Non-adherence to medical treatment is not only a dysfunctional behaviour but can be very reasonable to sustain emotional well being. This strengthens the importance of the psychological and social role of the caregivers and reveals significant clues how to support our patients better and to improve treatment adherence.
Supported by: Novartis.

374* Improving self efficacy in adolescents and young adults with cystic fibrosis (CF)

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Background: Encouraging patients with a chronic disease such as CF to actively manage their own condition may be effective, especially during adolescence when adherence to treatment can diminish.
Aim: To facilitate self-management, via a mentorship system which develops relationships between patients with CF and their health professionals, augmented by telephone and IT tools, aiming to improve quality of life.
Method: A randomized, controlled pilot study of an education and behavioural adaptation program designed to enhance self-management in adolescents aged 12–19 with CF. 46 participants were randomised to 1 of 3 groups for 6 months with a further 6 months follow up: standard care (controls; N = 15), standard care + phone mentoring (M; N = 16), or standard care, phone mentoring + IT tool (M + IT; N = 15) which facilitated electronic self reporting of daily symptoms. Primary outcomes included the Stanford Self-Efficacy scale and CFQ-R. Secondary outcomes were spirometry and height and weight z-scores. Outcomes were re-assessed at 3, 6, and 12 months. Qualitative data were also collected from 10 intervention participants and mentors.
Results: No clinically meaningful improvements were detected between groups.
Conclusions: The trial provided an important opportunity for mentor training and refinement of IT tools, but did not produce short-term improvements in these particular outcomes for adolescents measured using these methods.
Supported by: CF Australia & RCHF Brisbane.

375 The Use of Patient Held Drug Information Cards to improve adherence: a questionnaire survey

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Introduction: We have previously presented a pilot study of the use of these drug information cards at the ECF, Prague 2008 (*Journal of Cystic Fibrosis* 2008; 7(Suppl 2):S102). The previous study showed that the drug cards were found to be useful in educating our CF patients. In this study we developed the use of these cards in CF patients perceived to have poor compliance with medication, or who had recently joined the service (transition and new diagnosis).
Study design: We performed a questionnaire, comparing different responses in the patient group perceived to have poor compliance, compared to those who had newly joined the team (new diagnosis or transition), or those who had been given the cards at the general CF clinic. The aim of this study was to see if there were different perceptions of these cards by patients in these different patient groups.
Method: We developed a series of small (9 x 5 cm) cards which included simple, relevant information about 11 of the commonly used CF drugs. This information was tailored to the use of each medication in Cystic Fibrosis. The Drugs included: Pulmozyme, Creon, Alendronate, Azithromycin, Colistin, Flu Vaccine, Insulin, Omeprazole, Salbutamol Inhaler, Seretide Inhaler and Ursodeoxycholic Acid. The cards were designed to provide concise information delivered in terminology that was easily understandable and relevant to CF, and was not intended to replace the package insert information. The drug information cards were introduced to CF patients during outpatient visits, home visits and in-patient stays. The patients were then surveyed 6 weeks after initial use of these cards and asked about their views related to aiding compliance and education.
Results: The results of the questionnaire survey will be presented.

376 Totally implanted venous access devices (TIVADs) in children with cystic fibrosis: Pilot satisfaction survey

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Background: TIVADs are commonly used in children with CF with difficult venous access and a number of studies have demonstrated safety and a reasonable functional lifespan in such subjects. However there are limited data reporting how children with CF perceive their TIVAD.
Aims: To determine what children and adolescents with CF think about their TIVAD and how having such a device affects their quality of life.
Methods: Families of twenty children with CF attending the Leeds Paediatric CF Centre who had a TIVAD (either PORT-A-CATH® or P.A.S. PORT®) inserted between 1993 and 2006 were invited to participate. A structured questionnaire was answered by the child/adolescent, with parental help if required.
Results: 20 children with mean age 11.6 years (range 4–16 years) participated (9 male). All 20 subjects reported that having a TIVAD had improved their quality of life. 7 (35%) reported that having a TIVAD affected what clothes they chose to wear, and 14 (70%) described that the TIVAD did sometimes cause pain or discomfort. 5 (25%) reported that the TIVAD affected their body image or caused embarrassment. 4 (20%) reported difficulty wearing a seat belt, and 2 (10%) that the TIVAD affected their sleep.
Conclusions: Children and adolescents with cystic fibrosis who have required TIVAD insertion all report that the device improved their quality of life. This is despite the majority reporting that the TIVAD sometimes caused pain or discomfort, and commonly affected clothing choices. This information will be of use when counselling children, adolescents, and their parents prior to TIVAD insertion.