What do children with CF know about their illness?

P. Goodhart, Dept of Clinical Psychology, Royal Brompton Hospital, UK

Background: Children are increasingly seen as active participants in their medical care. Information can be targeted and communication enhanced if a child's existing knowledge is established.

Aim: To develop a tool to access children's understanding of CF. To examine how knowledge of CF develops and whether family or illness factors may contribute to this.

Method: Questions from the perspective of a (fictional) child with CF were developed. The author together with the CF team, patients and parents, designed the questions. Subjects included: the nature of CF, treatment requirements, genetics, the future and emotions associated with CF. The questionnaire was then tested with patients (n=23, 4-18yrs). Mental age was assessed using the BPIVS and adherence with the MCIST. Parents completed the FES. Health and demographic data were collected. Data were analysed by the author and two independent raters to produce a knowledge score.

Results: Using the Pearson correlation coefficient where (p=0.01), knowledge of CF was positively correlated with age (r=0.94) and mental age (r=0.90). There were no associations between knowledge and health, and no correlation with adherence. Qualitative material provided insights into individual coping, e.g., the impact on life expectancy was known by all over 14 years and strategies for coping were spontaneously presented. Gaps in understanding and a desire for more information on fertility and illness progression were evident in this group. The booklet was well received by participants.

Conclusion: This is a tool that successfully accesses children's knowledge of CF. It has been clinically useful and has potential for further research. It will be adapted to card format and distributed to CF teams in the UK.

Home intravenous (iv) antibiotic (ab) treatment: education to achieve complete patient autonomy

I. Delvaux1, J. Birchall1, G. Jaccoume2, C. Knoop1. Departments of 1 Chest Medicine and 2 Pharmacy, Adult Cystic Fibrosis Unit, Hôpital Erasme, Brussels, Belgium

Most CF centers now offer home iv ab treatment. In order to increase the compliance to treatment and to preserve the patient's life as much as possible, we developed a new approach to patient education which emphasizes patient autonomy. The purpose of this poster is to describe our approach.

Patients who desire home iv ab are equipped with a subcutaneous central venous catheter. They are educated concerning hand hygiene, connection/disconnection of elastomeric disposable antibiotic pumps (and/or preparation of iv ab in babybotters if needed) and flushing of the subcutaneous device, in some cases patients are educated to insert/change the needle of the subcutaneous reservoir. The hospital pharmacy prepares the antibiotic pumps under sterile conditions for 72 to 96 h, these are stocked at home in the fridge and the patient self-administers treatment. The patient is seen at least twice a week at the outpatient clinic during the course and can gain access to his CF team 24/24 h by phone. All steps of the treatment are moreover described in a booklet and described/illustrated by photography on our internet site. Education is checked at least once a year. At present, we have educated 25 patients according to this strategy of whom 23 have achieved complete autonomy for home iv ab. There has been no major adverse event and only a few minor adverse events.

Adult CF patients educated in this way may now choose from several options whenever an iv course is needed: (1) treatment at home, (2) a combination of hospital/home treatment, (3) hospital treatment if needed. We believe that this type of education has improved adherence to treatment/autonomy/quality of life substantially for these patients. A belief confirmed by the patients.

School and CF in France: a cohort study between 1999 and 2003

R. Popa1, A. Nourry1, S. Ravilly2, G. Bellis1, 1 Institut National d’Études Démographiques, 2 Vaincre la Mucoviscidose, Paris, France

Aims: To study primary school attendance in CF patients and measure impact of various clinical factors on academic success or failure.

Methods: Based on data collected every year by the French CF Observatory (Observatoire National de la Mucoviscidose), a cohort of 102 CF children (mean age 6 years) was followed during 5 years (length of the primary cycle) from 1999 to 2003. During this period various indicators of state of health have been tested (age at diagnosis, FEV1, colonisation with P aeruginosa, IV antibiotics, nebulised and oral treatment) to study their impact on academic success or failure.

Results: At the end of the study period, 77% of the cohort was at their normal school level, whereas 23% had repeated a year or more. This proportion is slightly higher then that observed for the same age group of children in France (20%). Compared to CF children in their normal class age group, those who had repeated a year were more frequently (p < 0.05) colonised with P aeruginosa (50% vs 28%) and received more frequent IV antibiotics (46% vs 24%).

Conclusions: Primary school success in CF patients is comparable to the national population in France. Despite these encouraging results, the cohort study has highlighted that a progressive worsening of their state of health tends to favour repetition of classes. These results need to be confirmed on a larger scale and over a longer period of time.

Extramural care of the specialist CF social worker

A. Tijtga1, M. Hamddan1, I. De Schutter1, E. De Wachter1, K. De Rijcke2, A. Malfroot1, 1 Dept. of Paediatrics, Respiratory Medicine and Infectious Diseases, CF Clinic, Academic Hospital AZ-VUB Brussels; 2 Belgian Cystic Fibrosis Association, Belgium

Introduction: CF patients, children and adults come to the multidisciplinary CF centre for medical and psychosocial care. The social worker helps with practical and emotional issues, and non-medical interventions, mostly for financial problems. However social assistance must also be offered outside the centre.

Methods: a 6 months project was started offering extramural social care.

Results: 25 interventions were done at the patients or the parents request: 15 school (1 day care centre) visits to give age-appropriate information about CF to the classmates and the teacher, using educational material; 6 home-visits to provide practical and emotional help, 4 patients asked help to accompany them for a referral visit to the transplantation or the rehabilitation centre.

Conclusion: All interventions of the social worker outside the centre illustrate the different obstacles for social integration of the CF patient in the modern society: in children to better cope with their disease in normal school life, in adults to contribute to their independency and to facilitate vital decisions outside the centre. Supported by the Belgian Cystic Fibrosis Association

10. Nursing – Psychosocial issues