510 “Defeat Cystic Fibrosis” student project in Poland

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Between 2003–2005 medical students in Poland associated in the student's organization IFMSA-Poland were involved in the project “Defeat Cystic Fibrosis”

Aims: Increasing the knowledge about cystic fibrosis among students of Medical Universities, involve medical students in cystic fibrosis activity and help ill people.

Methods: Local actions and educative campaigns on Medical Universities, lectures about CF, open air events in big cities prepared and organized by medical students – members of IFMSA in Poland in cooperation with the Foundation MATIO between November 2003 and December 2005.

Results: During the III National Week of Cystic Fibrosis in April 2004 lectures organized in 7 of 11 Medical Universities gathered more than 500 listeners. 936 medical students from 8 out of 11 Medical Universities in Poland participated in CF knowledge assessment survey. The results of the knowledge analysis survey from Poznan University of Medical Sciences facilitated to start the first CF faculty classes for medical students in Poland. CF faculty on Poznan University of Medical Sciences allows to educate 60-120 students each year. In Wroclaw, where CF consultations with medical students took place, 80% of students declared to attend it again.

Conclusions: Increasing the knowledge about CF and involving future doctors in CF activity is one of possibilities to improve CF care. Well educated doctors who understand that CF is an interdisciplinary disease and perceive not only a patient, but a human being in ill person will better recognize problems of CF patients and this could also allow to inspire new people to help and act in the future.

511 Setting up a befriending service for young people with CF

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Social isolation in CF is common due to exhaustive treatment regimes and frequent hospitalization. The Cool Friends (CF) befriending Project was established in 2005 by the Butterfly Trust, which supports young people with CF in Scotland, in response to an identified need by the multidisciplinary team at the RHSC Edinburgh.

Aims: Provide support for young CF sufferers aged 10–16 who are socially and emotionally isolated.


Methods: Befrienders are recruited through advertising in local newspapers and community organizations. Interviews, Disclosure Scotland and references are undertaken. Befrienders are inducted on a training programme, which includes impact of CF, Child protection, listening skills, befriending and Butterfly Trust procedures. Befrienders are matched to clients who have been referred from the CF team at RHSC. Initial meeting occurs between the client, carer, co-ordinator and befriender. Thereafter future meetings are between client and befriender.

Results: 11 befrienders (9) have been inducted, 6 matched to clients (4m/2f, age 10–17). A further 2 clients have been referred but not yet matched. Nature and frequency of meetings between clients and befrienders varies according to needs. Requests have been made to extend this service to siblings of CF suffers, older CF clients and clients in other geographical areas.

Discussion: Formal evaluation of this project will commence next year through qualitative interviews with clients, parents and befrienders, to evaluate the worth of this project. Successful evaluation will lead to wider implementation of this initiative.

512 Is living with CF a painful experience?

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Introduction: Pain is commonly associated with chronic medical conditions. We felt it would be interesting to determine the size of the problem within our local CF population.

Methods: We devised a questionnaire regarding pain issues and completed this during an interview with the patient. Visual analogue scores (VAS) were employed for some questions.

Results: 30 patients were surveyed (mean age 23 years (range 16–40), M=14). Their perceived level of CF activity was assessed: 10 were very active, 14 moderately active and 6 sedentary. 10 are in employment, 4 in education and 16 unemployed.

Although 3 take daily analgesics and 12 at least weekly, 15 (50%) only experienced pain during exacerbations or not at all. The most prevalent was headache (n=9), followed by back (n=5) and joint pains (n=3), and 4 had been labelled as having arthritis. Mean intensity of pain (VAS) was 4.7 (range 3.1–8), with mean limitation of daily activities due to it 3.5 (0–8). 8 patients use NSAIDs, 6 codeine and 17 paracetamol; 13 had tried other medications. Analgesia efficacy mean VAS was 7.0 (range 3.1–10). Of those with frequent pain (>1 day per week), 10 (67%) had taken analgesia for >12 months. 5 had their pain control reviewed in primary care, 1 in hospital. Side effects of their current regime were reported by 4 patients. Only 5 had ever tried ‘alternative’ therapies for pain – 2 regarded them as more effective.

Conclusions: Our data suggests that around half our CF patients frequently experience pain. This can be associated with a marked limitation of activity in some cases. Analgesics are generally quite effective and well tolerated. Possibly we could do more to promote non-pharmaceutical interventions in those where conventional treatment is less successful.

513 Travelling with CF – heading for trouble?

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Introduction: Cystic fibrosis requires conscientious self-management and patients are prone to periodic deteriorations in health. We felt it would be valuable to assess their attitudes towards taking holidays, evaluate preparations undertaken, and identify problems encountered.

Methods: We surveyed a random sample of our CF population. A questionnaire was filled out during a one-to-one interview with a doctor or specialist nurse.

Results: 46 questionnaires were completed (mean age 24 years (16–40), mean % predicted FEV1 66 (52–139), F = 26). 37 patients reported taking >1 holiday/year. Although 31 (67%) felt that having CF had no bearing on their holiday planning, 28 patients carried a reserve antibiotic course, 8 along with steroids. Almost all arranged travel insurance: half reported difficulty obtaining cover and half had accepted cover excluding CF-related illness. Only 1 had experienced breathing difficulties during a flight, but 5 have required medical assistance overseas. 22 say they manage their CF on holiday as well as at home, with physiotherapy being most frequently neglected in the remainder.

Conclusions: Patients with CF generally plan well for holidays, and despite widespread concerns they rarely encounter problems. However, their travel insurance cover is often inadequate. Many patients are also unaware that they can apply for travel grants.