348 How well are cystic fibrosis patients coping in the real world? A snapshot of socioeconomic, education and home circumstances

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Objectives: As CF patients live longer into adulthood, many are leading independent lives and engaging in active socioeconomic and educational pursuits. To study this further, we took a snapshot of socioeconomic, academic and personal circumstances of our cohort of CF patients.
Methods: Using a structured questionnaire, we surveyed 92 consecutive adult patients (mean age 28 yrs [range 18–66], 45 female) attending our large CF unit.
Results: Whilst 16 achieved a University degree, 20 had attended College, 14 obtained A levels and 28 GCSEs, 14 had not received any formal educational qualifications. 19 and 18 were in part time and full time employment respectively, but 34 were unemployed and 3% classed themselves as disabled. A further 12 were full/part-time students and 5% were full-time home-makers. 83% received some form of state benefit (the commonest being disability living allowance [89%], followed by income support [22%] and incapacity benefit [19%]), and 42% were on multiple benefits. Among the 20–34 year age group, 33% of females and 62% of males were living with their parents, as opposed to the national average of 18% and 29% respectively for the general population.
Conclusion: Although CF patients are engaging in more academic and employment activities, there still remains a significant difference in the proportion of patients who leave their family home and live independent lives compared to the general population. Low socioeconomic status is associated with worse outcomes for the CF population, and it is therefore important to provide sufficient support to maximise the chance of these patients to lead independent lives and become economically productive.

349 Understanding of adolescents about their living with cystic fibrosis

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Objectives: To understand how adolescents deal with cystic fibrosis (CF) and how they realize their actual life and future.
Methods: A clinical-qualitative method was used with semi-structured interviews with open questions: (1) How is CF for you?; (2) Do you have any special need due to CF?; (3) How do you see your future?. Thirty-one adolescents (10–19 years old), being 13 males and 18 females were interviewed. A qualitative analysis of the answers led to: (1a) Subjective view about dealing with CF such as fear of death, being abandoned by a partner and people's opinion. Shame, anguish, anger and tiredness were also found. (1b) Suffered losses view: loss of school life, routine, friends and freedom. (2a) Real necessities: needs of adjusting to a tight routine to treatment, taking drugs daily and time required to prepare special diets. (2b) Psychological needs: equability and social acceptance. (2c) Understanding needs: about the disease and its knowledge by the society. (3a) Expectations regarding to CF: uncertainty and insecurity about future, changed plans after diagnoses and hope of cure. (3b) Personal plans: Having a family, studying and working. Ten subjects answered that they do not think about future.
Conclusion: The understanding of the studied categories how to deal with CF contributes to psychosocial processes, making possible future investigations and therapeutical proposes which can ease the disease impact, leading to a better treatment compliance and also a better quality of life for adolescents with CF.

350* Parenting adolescents with cystic fibrosis: an interpretive description of the adolescent point of view

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Background: Decreases in disease-related physiological and quality of life parameters are often seen in adolescents with cystic fibrosis. The aim of this study was to identify the types of parental support that adolescents with cystic fibrosis find helpful in terms of preventing these decreases.
Methods: Sixteen Danish adolescents with cystic fibrosis, aged 14 to 25, participated in the study. Two focus group interviews were carried out, one for 14- to 18-year-olds and one for 19- to 25-year-olds. Individual interviews were conducted with three subjects. Using interpretive description strategy, we conducted a secondary analysis of the interview data.
Results: The adolescents wanted their parents educated about the adolescent experience. They wanted their parents to learn a pedagogical parenting style, to learn to trust the adolescents, and to learn to gradually transfer responsibility for the adolescents' medical treatment.
Conclusion: Parenting an adolescent with cystic fibrosis is a challenge, and the adolescents felt that their parents need to learn skills to help the adolescents better manage their disease. These findings indicate that health professionals may need to educate parents about the best ways to help their adolescents with cystic fibrosis.

351 Developing a self-assessment transition tool for young people with cystic fibrosis

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Objectives: This project aimed to develop a self-assessment transition tool for young people to focus education and information giving and to ensure that the process of transition and the point of transfer to adult services is well-planned, smooth and not anxiety-provoking.
Methods: The tool was designed after case reflection following a critical analysis of the literature and in consultation with all members of the CF team. The tool was "proof-read" by young people in our clinic to check for readability. The tool included sections such as medications, diet, physiotherapy, equipment, fertility, smoking and so on. Each section includes key statements such as "I understand the best order in which to do my inhalers, nebulisers and physiotherapy". The young person decides if he/she needs help or further education in this area which guides the member of the CF team in their information giving and teaching of self-care skills. The tool was commenced at age 14 and continued at regular intervals until finished or transfer to adult services. At this point both the young person and the CF nurse complete an audit form to help evaluate the tool's effectiveness.
Conclusion: Early audit information suggests that this tool is producing positive benefits for the young person during the transition process with the aims being partly or wholly met. For example, young people stated that the tool helped them increase their self-confidence in the clinic setting. As more audit forms are completed, the tool will be updated according to suggestions made or where aims are not met. The anticipated conclusion is that this modified transition tool will become part of our ongoing transition practice.