386 The impact of psychosocial and socioeconomic factors on health status in children with cystic fibrosis

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Aim: The study objective was the investigation of psychosocial variables affecting the disease trajectory in patient diagnosed with cystic fibrosis (CF). In addition, we analysed the impact of socioeconomic status on patients' health status.
Method: Between 2000 and 2009 all patients treated at the CF Centre at Innsbruck Medical University and aged below 18 (n = 103) were included in the study and assessed longitudinally. As measures of physical health status we recorded lung function values and body mass index (BMI). Psychosocial status was assessed using the Cystic Fibroses Problemchecklists (CFPC) and Hospital Anxiety and Depression Scale (HADS). Lung function and BMI were recorded quarterly. Psychosocial and sociodemographic variables were collected annually at routine examinations.
Results: Our results suggest a strong association between mother's marital status and lung function (mean FEV1: single parent 82.1% vs. parent with spouse 96.2%). In addition, we found an impact of mother's educational status on lung function (mean FEV1: compulsory school 79.6% vs. university degree 98.6%). We did not find any significant association with BMI and psychosocial variables.
Conlusion: A strong impact of education and marital status on the child's health status was found, although in Austria treatment costs are fully covered by general health insurance and all patients receive the same treatment. We conclude that it is essential to turn attention to the parent's marital and educational status. To be able to prevent a negative impact, further research is necessary to investigate how these factors affect lung function.

387 CF care through the patient's eyes – development of a disease specific questionnaire measuring patient satisfaction with CF services

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Background: The patient's experiences are important for developing the best possible care for chronically ill patients. As general patient surveys do not cover specific aspects of multi-professional care, we aimed to develop a disease specific questionnaire for CF patients and parents.
Methods: Expert interviews were carried out in 2 centres, and focus group discussions were conducted in 3 centres with 7 adult CF patients and 13 parents of children with CF. Audio tapes were used to extract relevant themes. Pilot questionnaires for parents and adult patients (⩾18 y) were mailed to participants from 4 CF centres, and responses were analysed to establish the modified final versions.
Results: Based on focus group discussions new items were identified which were not part of general Picker questionnaires on patient satisfaction, e.g. hygiene, multi-professional staff, accessibility, and support by the centre. The pilot questionnaires were mailed to 389 participants, with response rates of 83% and 69% in parents and adults, respectively. 22% of subjects provided suggestions to improve the questionnaires. Most respondents were satisfied with their care, although room for improvement was identified, e.g. insufficient information on side effects of drugs, or delayed information on test results.
Conclusion: We have developed CF specific questionnaires to investigate patients' and parents' experience and satisfaction with care. These can be used for quality improvement measures and benchmarking.

388 The impact of pulmonary exacerbation on the challenge of living with cystic fibrosis

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Background: We have developed and undertaken preliminary validation of a questionnaire tool to measure the challenge of living with cystic fibrosis (the CLCF questionnaire). This parent reported outcome has been developed in partnership with families and has a number of components including measures of time and effort.
Aim: To use the CLCF questionnaire to examine the impact of pulmonary exacerbation on the challenge of caring for a child with CF.
Method: Parents of children with CF aged ⩽13, at least one year post diagnosis, were enrolled. They completed the CLCF during a period of stability and pulmonary exacerbation (PEx), defined by two or more classical symptoms of PEx. The number of minutes per day undertaking treatment tasks and the average effort expended in treatment tasks were compared at the two time points.
Results: Thirty-two families enrolled into the study, and 13 completed the CLCF at both time points. Nine of the thirteen parents reported an increased treatment time during their child's pulmonary exacerbation, one reported no change, and three reported a fall in treatment time ($p > 0.05$). The median (IQR) increase in treatment time was 53 minutes (−16.5, 101.5). There was no significant change in effort. However, there was a correlation between the within person difference in minutes per day and the within person difference in average effort ($p = 0.024$).
Conclusions: The results indicate that parents experience an increased time demand during PEx, and that the concepts of time and effort are related. This study provides further evidence to support the face validity of the CLCF as a tool for measuring the burden for families of caring for a child with CF.

389 What defines a pulmonary exacerbation? The perceptions of children with cystic fibrosis

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Background: There is no standardised definition of a pulmonary exacerbation in cystic fibrosis (CF). In attempting to achieve standardised criteria it is important to identify patient-reported indicators. Interviews with adults suggest that they report symptoms of an exacerbation in different ways according to disease severity. This work reports on interviews with children employing similar methodology.
Methods: Interviews were undertaken with 26 children with CF (aged 8–15 years) who had experience of pulmonary exacerbations. They were asked to report symptoms experienced during a pulmonary exacerbation in two ways: the first symptoms they become aware of, and how they subsequently recognised when they were improving. Purposive sampling ensured representation of key variables including age, gender, in/out-patient, large/small CF unit, FEV_1% predicted, BMI, nutritional status, microbiology, and recorded exacerbations in the past year. Interviews were taped, transcribed verbatim and the data analysed thematically.
Results: A range of systemic and respiratory symptoms were reported. For many children the onset of an exacerbation was primarily characterised by 'cold' symptoms, tiredness, and changes in cough and sleep. When describing their improvement from an exacerbation the children tended to focus initially on activities they were now able to perform (e.g. playing, school work).
Conclusion: These preliminary data suggest that child-reported indicators of a pulmonary exacerbation tended to map onto those reported by adults with mild disease. Validity checks on these results are required prior to their contribution to the development of standardised criteria.