431 Psychological particularities in children with cystic fibrosis

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Aim: To point out the psychological particularities in children with cystic fibrosis (CF), family relationships and the elaboration of a methodological set of their psychological support.
Materials and Methods: The examination of psychological particularities of the given sick children, the test of family relationships and of their influence upon the disease evolution, the elaboration and implementation of a methodological set for psychological support of the sick children and family environment were performed. In the frame of this research 19 children with diagnosis of CF have been interviewed as well as their mothers. The conversation, observation, the analysis (MMPI, 16 PF – Cattell, Leary, State Trait Anxiety Inventory, the projective test, PARI, the test of family relationships, the sentences fulfillment, self-appreciation of social importance of the disease, the family picture) methods were used in group of study.
Results: After processing of the results we obtained a high anxiety, aggressive tendencies, inhibition, emotional rigidity, phobias, negative thinking in children; in mothers – hyper-protection, the phobia of loosing the child, the sexuality inhibition, mother dependence, and familial conflicts – divorces. All these serve as causes for the elaboration of a methodological set of a psychological support. This set is based on the supportive psychotherapy which includes especially some techniques from the cognitive-behavioral therapy: strategies focused on the problem through strategies of avoidance and active behavioral strategies.
Conclusion: the intervened changes in the life of children with CF are the limitation of physical and psychical capacities in the normal activity, ambient and relational changes, with major influence in the affective sphere.

432 Impact on lung function and body mass index (BMI) when CF patients become parents

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Background: With improvement of survival, an increasing number of CF patients, become parents. During the pregnancy women with CF can be less intensive treated due to anxiety of possible adverse effects on the foetus. After the birth, parents are at increased risk of viral infections transmitted from the child. Furthermore the risk of decreased adherence to the treatment after the child birth can be a problem. We wanted to investigate a possible negative impact of these factors on lung function and BMI in a population a CF patients who became parents.
Methods: All CF patients chronically infected with *P.aeruginosa* followed in the Copenhagen CF centre, who had become parent during the last 10 years, were included. Men and women were studied separately. Lung functions and nutritional data were collected from visits in the clinic in the year prior to pregnancy and in the first 2 years after birth of the child. Results were compared using a paired Students t-test.
Results: 13 patients were included (7 males). In the female group, FEV1 changed from a median of 62.5% (range 36.1–91.4) in the year prior to pregnancy to 57.5% (range 27.9–90.1) in the first year after childbirth ($p < 0.04$) and to 58.1% (range 29.1–75.1) in the second year after childbirth ($p < 0.02$). In the male group, median FEV1 was 73.7% predicted (range 35.1–95.4) in the year prior to pregnancy. In the first year of the child, FEV1 was 68.3% (range 32.9–88.3) (n.s.) and in the second year, FEV1 changed to 66% (range 36.1–81.3) ($p < 0.001$). We found no change in BMI in either group.
Conclusion: Becoming a parent can have a negative impact on progression of CF lung diseases. The possible explanation can be less intensive antibiotic treatment, increased risk of viral infections and reduced adherence to the treatment. Further analysis on larger groups of patients is needed.

433 The Italian Caregiver Quality of Life Cystic Fibrosis (CQOLCF) Scale: initial validation

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Aims: Taking care of cystic fibrosis (CF) patients might represent a condition of distress, burden and concerns. The aim of the study was to: 1) translate the original Caregiver Quality of Life Cystic Fibrosis (CQOLCF) Scale (Boling W. et al., 2003) into Italian and 2) to psychometrically evaluate the Italian version of the CQOLCF in the Italian population.
Methods: The linguistic validation of the CQOLCF followed the international guidelines by Guillemin et al. and by the MAPI Research Institute, suggesting the "forward-backward-forward" translation. Once the Italian CQOLCF was created, 15 CF caregivers were interviewed and asked to indicate the clarity of each item and the risk to misunderstand the questions. The administration started on January 2008 and will include all those subjects (at least 200), identified as the CF family caregivers (>18 years), attending the CF Unit with their loved one (with a confirmed diagnosis of CF). They will be asked to complete: informed consent, anagraphic sheet, CQOLCF, Short-Form Health Survey 36 (SF-36), CES-D and State-Trait Anxiety Inventory (STAI Y1-Y2). The physician will be asked to assess the clinical-medical variables for each CF patient cared by the CF caregiver: FEV1, BMI, pancreatic status, infections, on a waiting list for a transplant.
Results: the Italian CQOLCF resulted to have a good face validity and was positively accepted by all the subjects recruited. Future analyses on the statistical properties of the CQOLCF will explore internal consistency, concurrent validity, test-retest validity and disciminatory ability.
Conclusions: once fully validated, the CQOLCF might be a valid tool in research and clinical practice with CF caregivers.

434 Challenge of Living with Cystic Fibrosis (CLCF): psychometric validation

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The Challenge of Living with Cystic Fibrosis (CLCF) questionnaire aims to assess the impact of new interventions on caregivers in clinical trials. This PRO was developed with CF professionals and parents with action research methods and is designed to capture the experience of bringing up a child with CF from 1 year post diagnosis to 13 years. We report the instrument's validation with n = 300 caregivers examining floor and ceiling effects and internal reliability. Concurrent validity assesses the CLCF's correlation with the Cystic Fibrosis Questionnaire (CFQ) and clinical severity indexes (FEV1% predicted, Chest X-ray and Schwachman Scores). Divergent validity tests the instrument's ability to distinguish between: (i) age groups, (ii) presence/absence of pseudomonal airways infection, and (iii) genotypes. Caregivers of younger and older children differ in the way they administer enzymes – caregivers of younger children spent more time [median (95% CI) difference in minutes per day: 9.59 (2.20)]. This corresponded to the ease with which caregivers thought they were managing this task and suggests an age-specific profile. Respondents report that completing the CLCF is useful to reflect on their experience and to record how they are coping with this complex challenge. It offers a framework for caregivers to raise any difficulties and has potential as a clinical tool at annual review as well as a research tool in clinical trials.