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Cystic Fibrosis Questionnaire (Dutch version): a health-related quality of life measure for children with cystic fibrosis (CF) and their parents

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Cystic Fibrosis Questionnaire (CFQOL) is a valid tool to measure disease-specific health-related quality of life in CF children (Quittner, *J Pediatr Psychol*. 2003). The aim of this study was to administer CFQOL to parents of 20 CF children, to search for correlations between items and to relate items to clinical data. The age of patients ranged between 7 and 20 years with median FEV1 93% of predicted (range: 40–128). Eleven CFQOL items were evaluated (median score, range): 'physical': 89 (44–100), 'emotion': 80 (40–100), 'vitality': 67 (40–93), 'school': 78 (22–100), 'eating': 67 (0–100), 'body image': 89 (22–100), 'treatment burden': 44 (0–100), 'health': 67 (33–78), 'respiratory': 78 (17–89), 'digestion': 67 (33–100), 'weight': 67 (33–100). The higher the score, the more successful the child was in that area. Significant inverse correlations were found between each of the items 'physical', 'vitality', 'respiratory' and age. Each of the items 'physical', 'vitality', 'eating', 'digestion' correlated significantly with the item 'respiratory'. Other correlations were found between 'digestion' and 'physical' and 'weight' and 'body image' ($P < 0.05$). Item 'body image' was significantly lower in the group of patients with underweight compared to patients with normal weight. The items 'physical symptoms' and 'respiratory symptoms' were significantly lower in the group of patients who need intravenous antibiotics compared to patients who do not need such treatment. **Conclusion:** CFQOL in CF patients provides a comprehensive assessment of how this disease affects daily living in several areas of functioning, including physical, emotional and social. Significant correlations between items were found and differences between groups of patients were shown.

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Validation of the Italian version of the Cystic Fibrosis Quality of Life Questionnaire (CFQoL): pilot studyF. Gobbi¹, F. Lupi², A. Miano¹, F. Monti², E. Iacinti³, D. Petrolini³¹Centro Regionale Fibrosi Cistica-Ospedale Bufalini, Cesena, Italy, ²Università di Bologna-Facoltà di Psicologia, Bologna, Italy, ³Centro Fibrosi Cistica, Parma, Italy

Introduction: Health-related quality of life (HRQoL) measurement is important in determining the impact of disease on patients. Generic HRQoL measures have been employed with patients with cystic fibrosis (CF) in Italy but these may not be sufficiently specific. The aim of this work was to validate in Italy the Cystic Fibrosis Quality of Life Questionnaire (CFQoL; Gee, L., Abbott, J. et al., 2000), a disease-specific HRQoL measure for adults and adolescents with cystic fibrosis. **Method:** The CFQoL has been translated into Italian and then completed by 76 CF patients. The factorial structure was assessed by applying two Principal Components Analysis, with varimax rotation. The test-retest procedure was employed to test the external reliability and, in order to verify the concurrent validity, the Short Form 36 item (SF-36) Health Related Status questionnaire was administered in parallel. **Results:** Averages, standard deviations, item-total correlations, Cronbach Alpha and Guttman Split-half coefficients were calculated and confirmed a very good internal reliability (Alpha = 0.651–0.908). The factorial structure is essentially similar to the original one even if a few items do not show strong correlation with their factor. Test-retest reliability was found to be robust (Pearson $r = 0.691$ – 0.944 at 15 days) and the concurrent validity demonstrated to be good too ($r = 0.470$ – 0.860). By using cluster and discriminatory analysis, the measure was found able to divide patients with different levels of disease severity into different groups. **Conclusions:** In the pilot study the Italian CFQoL demonstrated to have good statistical properties and, when fully validated, it will be useful in clinical trials and longitudinal studies.

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Health related quality of life in children with Cystic Fibrosis: assessment of agreement between parents and children

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Aim: To investigate the degree of agreement between parents and their children with Cystic Fibrosis (CF) on health related quality of life (HRQoL). **Method:** 36 parents and their child completed the Dutch version of the Cystic Fibrosis Questionnaire Revised (Quittner, 2003, Klijn, 2003). The following dimensions were assessed: physical condition, emotional state, body image, eating, treatment, respiratory digestion. Higher scores indicated a better HRQoL. Paired t-test and intra-correlation coefficients (ICC) were presented. **Results:** Children reported higher QoL than parents on the dimensions physical condition, emotional state, body image, eating and treatment, indicating fewer problems in these areas. Moderate agreement between parents and children was found on the dimensions respiratory digestion and body image ($r = 0.50$, $r = 0.41$ and $r = 0.40$ respectively). Agreement levels between parents and children on physical condition, emotional state and treatment were low ($r = -0.01$, $r = 0.01$ and $r = 0.18$ respectively). The agreement level on the eating dimension was very high ($r = 0.75$). Age and gender analysis showed that older children (age 11–13) reported better QoL in terms of eating than younger children (6–10) and girls reported better QoL in terms of eating than boys. **Conclusions:** In concordance with previous studies agreement was found on symptom related issues (respiratory and digestion). Parents and children agreed strongly on the eating dimension and disagreed most on the treatment dimension. This supports the need for working together with the family to establish treatment schedules that take into account the needs of the illness as well as individual differences in perceptions of the illness and its impact on QoL.

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The Continuum of Maturation with Cystic Fibrosis: Home and Away

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How easy is it for young CF adults to attain emotional maturity? We look at physical and psychological issues and view life as a continuum involving a number of developmental tasks to be negotiated (Erikson, 1963). CF brings additional factors such as responsibility for medication, relationships and perhaps parenthood, treatment decisions, disease progression, transplant, and death. Data on 42 adult patients completing the CFpsychQ as part of their annual review were collected. Patient characteristics gave information about living status: alone (grp 1), with partner (grp 2), at home (grp 3). Groups 1 and 3 differed significantly on age, BMI, and levels of family involvement. Patients living alone were more likely to be older, have a higher and lower levels of family involvement. There was no difference between the groups in their FEV¹ status. We note however that despite parental and patient assessment that physical maturity and independence are gained, adult emotional autonomy is often not fully realised. Young adults with CF are increasingly wishing to take the mantle of independence yet expect to be able to return to the parental home for care and support, regardless of their own responsibilities as a partner or parent themselves. Our concentration on the physical aspects of care may result in an emphasis of the importance of continual staged emotional development. Do adult and paediatric sectors need to work together more closely to evolve an integrated physical and psychological model of care over the continuum? We plan to monitor changes in living status over time and a comparison with a group of healthy matched individuals is planned.

Erikson, E. (1963) *Childhood and Society*, New York: Norton.