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465

CONSTRUCTION OF A DISEASE SPECIFIC QUALITY OF LIFE QUESTIONNAIRE FOR CYSTIC FIBROSIS. B. Henry¹, C. Grosskopf², P. Aussage¹, JM. Goehrs², R. Launois³, and the French CFQoL Study Group.
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Prolonged life with Cystic Fibrosis (CF) leads now to focus on enhancing Quality of Life (QoL) of young and adult patients. Generic instruments such as the Nottingham Health Profile (NHP) prove helpful when assessing major intervention outcomes, but are restricted to adults and usually insensitive to progressive health changes under long term treatment. We report on a 3-year French development program of a set of disease-specific QoL questionnaires for assessing multi-dimensional treatment impact in CF pediatric and adult patients. Nine domains of QoL impairment with Cystic

Fibrosis were first identified from literature and interviews with experts and CF associations, and operationalized through items derived from 44 interviews with pediatric and adult patients. Two extensive questionnaires were designed, one for teenager / adult patients, the CFQoL - 14+, and one for child assessment by parents, CFQoL Parent coupled with a short-form child questionnaire to be administered to 8-13 year old patients. For item reduction, 534 questionnaires were completed by patients and parents enrolled in 24 hospitals and analysed using descriptive statistics and factorial analysis. Principal Axis Factoring retrieved the 9 hypothesized factors for the CFQoL - 14+: 5 are « generic » dimensions, namely *physical*, « *role* » (school - job), *psychic/emotional*, *energy/fatigue*, *social*, and 4 are « specific » i.e. *eating disturbances*, *body image*, *embarrassing symptoms* and *treatment burden*. A module on intensity of symptoms and an integrative general health perception construct have been added for studying relationships with QoL dimensions. Factorial structure of the CFQoL Parent is very close to that of the CFQoL - 14+ except for the psychic/emotional and social health. Parents used as proxies are limited to behavior or conduct descriptions (mood, irritability, antisocial attitudes etc.), whereas questions on subjective perception (anxiety, depression, social restrictions) must be answered by the child himself. The initial validity of the scales was established through Multitrait analysis : all item-scale correlations were superior to 0.4; test of item discriminant validity achieved success rates of 85 to 100% for both questionnaires. Internal consistency was good: all Cronbach alpha coefficients but one exceeded the acceptable standard for group-level comparison (>0.7). Clinical validity was pre-tested by comparing QoL profiles among the different groups of severity and analysing QoL score correlations with respiratory symptom intensity. Both instruments were found to be discriminative. A validation study is under way to further assess the reproducibility, validity and sensitivity of the three CFQoL questionnaires. New and valuable information should also be brought on child assessment methodological issues, particularly on how to deal with dual informant evaluations.