

THE DUC-25: A SHORT-FORM QUESTIONNAIRE FOR MEASURING HEALTH RELATED QUALITY OF LIFE OF CHILDREN WITH A CHRONIC ILLNESS H.M. Koopman, N.C.M. Theunissen, A.G.C. Vogels, R.P. Kamphuis and G.H. Verrips, Department of Pediatrics, Leiden University and TNO Prevention and Health, Leiden, The Netherlands

The DUC-25 (age 6–16) is a generic 25-item self-report questionnaire. The instrument is designed to measure children's and adolescent's affective evaluation of different aspects of their daily functioning. The items of the DUC-25 (using a five-point visual analogue scale) cover four domains: physical, emotional, social and home functioning. The instrument allows for comparison of data about the child's functioning in life irrespective of diagnosis or disease. In a reference sample of healthy children ($n = 1092$) the DUC-25 proved to be understandable, internally consistent ($\alpha = 0.90$) and reproducible ($r = 0.89$). The four subscales showed homogeneity (α ranging from 0.75 to 0.76). Confirmatory factor analysis supported the preconceived scale structure. The results of the children's reports were summarized with the mean score and the standard deviation. The differences in mean between groups of children (8–11) with a chronic illness and the reference sample were tested with independent student's *t*-tests.

Table: Differences in mean – Scales DUC-25

<i>n</i>	DUC25	Emo.	Phys.	Soc.	Home
Arthritis (52)	-8.46*	-1.12	-4.33*	-1.07	-0.43
Astma (28)	-6.02*	-1.21	-1.89*	-1.49	-0.45
Celiac dis. (105)	-4.42	-0.88	-1.15	-1.22	-0.44
Celiac d. Adol. (41)	-9.83*	-1.89	-2.89*	-2.00*	-2.17*
Metabolic Dis. (20)	-7.22*	-1.66	-2.68*	-2.42*	-1.45*
Spinal Cord Inj. (16)	-1.48	+0.28	-0.60	+0.92	-0.23

* - Signif. LE 0. 05 (2-tailed)

Only the children with celiac disease (not the adolescents!) and spinal cord injury evaluated their HrQoL as equal to the reference group. Comparison of the mean of the 25 item scores also showed lower HrQoL for children with a chronic illness. On 24 of the 25 items children with a chronic disease reported less satisfaction. On more than 50% ($n = 13$) of the items the difference was significant. The scores also reflected what children feels important concerning their HrQoL. The family and the home seemed most important. School and sleeping were valued less positive. It is concluded that most of the children with a chronic illness report a lower level of quality of life compared with a reference group of healthy children.

HEALTH-RELATED QUALITY OF LIFE AND DISEASE SEVERITY IN PATIENTS WITH ALPHA-1 ANTITRYPSIN DEFICIENCY A.R. Knebel¹, N.K. Leidy², S. Sherman¹, ¹Clinical Center Nursing Department, National Institutes of Health, Bethesda MD; ²Center for Health Outcomes Research, MEDTAP International Inc., Bethesda MD

Alpha-1 antitrypsin (AAT) protein deficiency is an autosomal recessive genetic mutation that can lead to panacinar emphysema at an unusually early age, the third to fifth decade of life. The highest incidence of the *zz* mutation is found in Scandinavia, but the condition occurs throughout other Caucasian populations as well. Because this illness develops at the height of family growth and economic productivity, the impact on health-related quality of life (HRQoL) may be significant. Unfortunately, very little is known about HRQoL in this population. The purpose of this study was to describe the HRQoL of a sample of patients with AAT deficiency, examine the cross-sectional relationship between disease severity and HRQoL, and explore changes in lung function and HRQoL over time in a subset of these individuals.

Forty-five adults (30 men, 15 women) completed the Chronic Respiratory Disease Questionnaire (CRQ), pulmonary function tests (PFT) and six-minute walk distance (6-MWD) test; 20 subjects completed the CRQ and PFTs at 12 and 24 months.

Mean \pm SD age of the sample was 49 ± 8 years; FEV-1% predicted was $48\% \pm 12$. Baseline CRQ scores (possible range) were: dyspnea 17.5 ± 4.3 (5–35); fatigue 17.0 ± 5.46 (4–28); emotional function 33.1 ± 8.67 (7–49); and mastery 21.7 ± 4.65 (4–28). No relationship was found between PFT and CRQ scores ($r = .01$ to $.25$); a significant relationship was found between 6-MWD and fatigue ($r = 0.32$, $p < 0.05$). Although PFTs declined over 2 years ($p < 0.01$), no changes were observed in HRQoL ($n = 20$).

Results suggest persons with AAT deficiency face challenges to HRQoL that are not unlike those of older adults with chronic pulmonary disease. Further research is needed on the relationship between disease severity and HRQoL in this population.

This study was funded by the Clinical Center Nursing Department and conducted in cooperation with the Pulmonary / Critical Care Medicine Branch at the National Institutes of Health.