Development of a Feedback Report to Track CF Child and Parent Proxy Health-Related Quality of Life (HRQOL) and Key Physiologic Measures

MJ Detzer, P Robichaud, T Kneeland, H Quinton, L Feenan, W Boyle, HW Parker, L McCormick , GT O'Connor, A Olson

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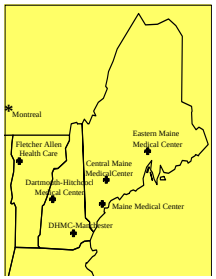
The Northern New England Cystic Fibrosis Consortium



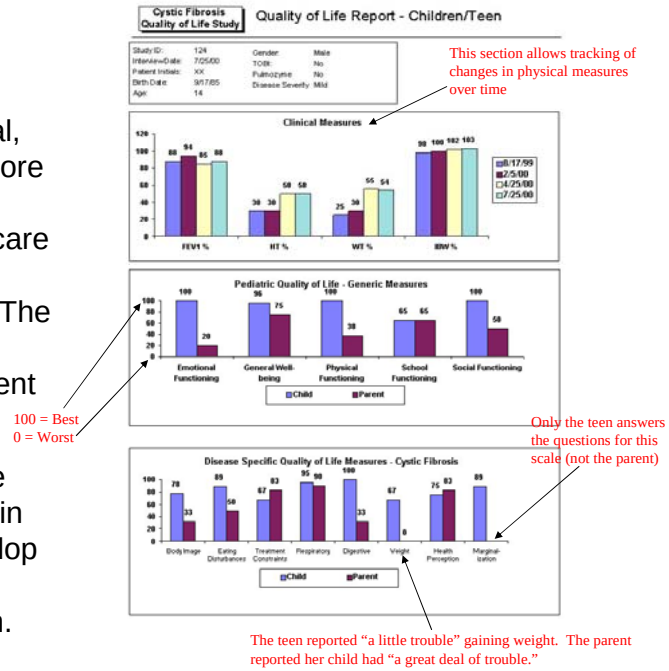
The NNECFC is a regional, voluntary consortium of more than 80 clinicians and researchers from the CF care centers in Maine, New Hampshire and Vermont. The mission of the group is to improve CF care and patient outcomes.

Goal

The purpose of this study was to measure generic and CF disease-specific HRQOL in the pediatric CF clinic setting and to develop a data feedback report of HRQOL and physiologic measures for the clinical team.

Methods

Thirty-one children aged 8 to 17 years completed the PedsQL (version 3.0), a validated, generic pediatric HRQOL tool, at outpatient visits. Selected subscales from the Cystic Fibrosis Questionnaire (CFQ) were used to assess disease-specific symptoms. Parents completed a proxy version of both tools. A one-page feedback sheet was developed to graphically display HRQOL subscales for the current visit and key physiological data (FEV1, weight- and height-for-age percentiles, ideal body weight) from current and previous clinic visits to track changes over time. Spearman's rho was used to calculate correlation due to small sample size.



HRQOL Correlations for Child/Parent

Pediatric Quality of Life Generic Measure	
Emotional functioning	.34
Physical functioning	.55
School functioning	.47
Social functioning	.54
General well-being	.57

Cystic Fibrosis Questionnaire Selected Disease-Specific Subscales	
Body Image	.37
Eating disturbances	.56
Treatment constraints	.47
Respiratory	.24
Digestive	.12
Weight	**
Health perception	**

** these subscales completed by teens only (n=8)

Patient characteristics

Median age:	12 years (range 8 to 17)
Severity based on FEV1:	90% mild; 10% moderate
Median height percentile:	30 (range 5 to 95)
Median weight percentile:	28 (range 5 to 95)

Results

Standardized on a 0 to 100 scale, mean PedsQL subscale scores ranged from 76.3-82.4 for children; 74.5-82.3 for parents. CFQ subscale means ranged from 53.3-93.5 for children; 65.5-88.7 for parents. Correlations between children and parent ratings were moderate for PedsQL scales (range .34-.57) and low to moderate on CFQ scales (range .12-.56), supporting the need for assessing both perspectives for HRQOL assessment.

Conclusions

- HRQOL data can be successfully collected during CF clinic using brief validated tools.
- Clinicians find a one-page summary including both HRQOL and key physiologic measures useful for patient management.
- PedsQL and disease-specific subscales from the CFQ are useful in detecting differences in child and parent perceptions in HRQOL.
- Low child/parent correlations were noted in the CF specific subscales characterizing respiratory and digestive symptoms.
- Low to moderate correlations seen in the HRQOL domains indicate the importance of assessing both children and parents.