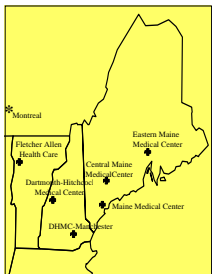


A Feedback Report to Track CF Adult Health-Related Quality of Life (HRQOL) and Key Physiologic Measures

P Robichaud, MJ Detzer, T Kneeland, HB Quinton, LM Feenan, WE Boyle, WP Parker, GT O'Connor
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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.

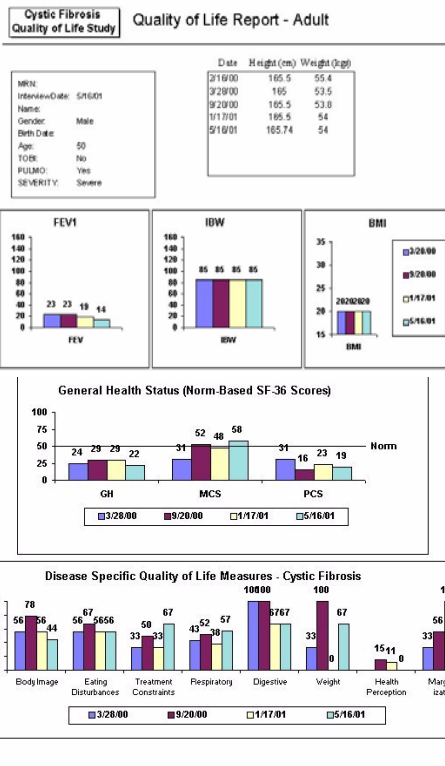
The mission of the group is to improve CF care and patient outcomes.

Goals

- Collect HRQOL data from CF adults.
- Provide a feedback report to the clinical team using a graphical display of 1) scored HRQOL measures and 2) key physiologic data showing changes over time.

Methods

- 52 adults participated
- Subjects completed QOL questionnaires during outpatient visits for 22 months.
- SF-36 was used to assess overall health compared to population norms. CFQ was used for disease-specific symptoms.
- Staff entered data on a laptop computer.
- Computer calculates IBW, BMI, SF-36 and CFQ subscale scores.
- Computer graphs these measures and FEV₁ for the current and previous 3 visits.



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- Useful summary to share with the team and the patient.
- Tool to track changes over time.

Patient Characteristics

n=52

Male	46%
HS grad	86%
Employed	67%
Median age	26 (range 18-62)
Mild disease*	25%
Moderate disease*	51%
Severe disease*	24%

*based on FEV₁

Results

HRQOL Baseline Visit Subscale Scores

SF-36 healthy population norm = 50 (SD=10)

	Median	Range
Physical score	44	19-64
Mental score	51	16-65
General health	42	5-100

CFQ 0=most trouble; 100= no trouble

	Median	Range
Body image	67	0-100
Eating disturbances	100*	22-100
Treatment constraints	67	17-100
Respiratory	57	10-100
Digestive	83	17-100
Weight	67	0-100
Health perception	62	8-92
Marginalization	67	0-100

*48% reported some eating disturbances; 52% reported none

Conclusions

- HRQOL data can be successfully collected from CF adults during outpatient clinic visits.
- Structured HRQOL interview and feedback sheet summarizing HRQOL and key physiologic measures improves communication with the patient about treatment and disease burden.
- The availability of a feedback sheet with a graphical display of key physical measures and HRQOL summary scores over time improves clinical information and is an aid to better patient management.