

FREQUENCY AND NATURE OF PATIENT-REPORTED OUTCOME CONVERSATIONS BETWEEN PHYSICIANS AND PATIENTS WITH CYSTIC FIBROSIS

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Abstract

OBJECTIVES: To describe the frequency and nature of patient-reported outcome (PRO) conversations between physicians and patients with Cystic Fibrosis.

METHODS: A random sample of de-identified patients with Cystic Fibrosis in the United States was selected from a large de-identified database of medical office visit transcriptions. Transcriptions were based on physician-dictated voice recordings detailing every individual patient encounter/visit. De-identified medical visit transcriptions were analyzed to evaluate the burden associated with Cystic Fibrosis, as depicted by PRO topics observed in patient-physician dialog in the real-world practice setting. Descriptive statistics are reported.

RESULTS: 333 transcriptions of medical encounters between 130 physicians (most commonly pediatricians 11%, internists 10%, pulmonologists 8%, general practitioners 8%, and surgeons 8%) and 183 patients over a 2-year period were evaluated (patient mean age: 31yrs; 27% <18yrs, male: 55%). Non-symptom related PROs, including quality of life and psychosocial impacts, were discussed by 50 patients (27%) (10% of patients <18yrs, 34% of patients ≥18yrs); the most commonly reported concerns were related to anxiety (n=16(9%)), depression (n=14(8%)), ability to perform daily activities (n=7(4%)), and work/school productivity (n=6(3%)). Symptom-related PROs were discussed by 108 patients (59%) (52% of patients <18yrs, 62% of patients ≥18yrs); the most commonly reported symptoms were cough (n=51(28%)), difficulty breathing (n=25(14%)), and difficulty gaining/maintaining weight (n=15(8%)).

CONCLUSIONS: PROs, as a function of disease burden, were routinely discussed by patients with Cystic Fibrosis. PRO discussions were observed more frequently among adult patients than the pediatric patients, and symptom-related PROs were discussed more frequently than PROs related to quality of life and psychosocial impacts. Modalities to alleviate this patient burden, including appropriate therapeutic interventions, warrant scrutiny.

Background

- CF has substantial impact on health-related quality of life (HRQoL) in terms of symptom interference in daily life (e.g., cough, difficulty exercising, maintaining weight), treatment burden, impact on ability to work, emotional and social well-being, and concerns about the future.
- Advances in clinical research are often reflected through improvements in patient reported outcomes (PROs) in CF (e.g., cough, emotional well-being, productivity, ability to perform daily activities).
- Characterizing the real-world interactions between CF patients and physicians in practice could help shed light on patients' real-world concerns/outcomes and focus future research efforts on areas that matter the most to patients.

Objectives

- To describe the frequency and nature of PRO conversations between physicians and patients with CF in real-world clinical practice.

Materials & Methods

Study Design

- An observational cohort study of a random sample of de-identified patients with CF in the United States, selected from a large de-identified database of medical office visit transcriptions over the period of Jan 2009 to Dec 2013.

Data Source

- Data from medical transcription services, used by thousands of physician practices, provided documented real-world evidence of treatment dynamics and clinical status/outcomes associated with patient care.
 - Physicians using medical-transcription services dictate details of individual patient visits and send the voice-recording-device to medical-transcription organization which processes voice-data and delivers electronic-files back to clinics; physicians review/revise/append the electronic-documentation and adds data to their patient-database-repository for future use.
 - Transcriptions detailing individual patient encounters are ideal sources for evaluation of real-world unaided PRO measures that concern patients.

Statistical Analysis

- De-identified medical visit transcriptions were analyzed to evaluate the burden associated with CF, as depicted by PRO topics observed in patient-physician dialogue in the real-world practice setting. Descriptive statistics are reported.

Results

- 333 transcriptions of medical encounters corresponding to 182 unique patients and 130 physicians were included in the analysis.
- Observed physician specialties:
 - The most common type of physician type was pediatricians (11%), followed by internists (10%), pulmonologists (8%), general practitioners (8%), and surgeons (8%)
- Patient demographics:
 - Mean age of patients: 31 years (73% ≥ 18 years)
 - Male: 55%
- PRO discussions were observed more frequently among adult patients than the pediatric patients

Figure 1. Most Commonly Reported Symptom-Related Concerns in Conversations between Physicians and Patients with Cystic Fibrosis

- The majority of patients (n=108; 59%) discussed symptom-related PROs with their physicians.
 - 28% reported issues with coughing
 - 14% spoke about difficulty breathing
 - 8% complained about difficulty in gaining and/or maintaining weight
 - 'Need for oxygen' and 'more or excessive sputum' were also reported by patients.

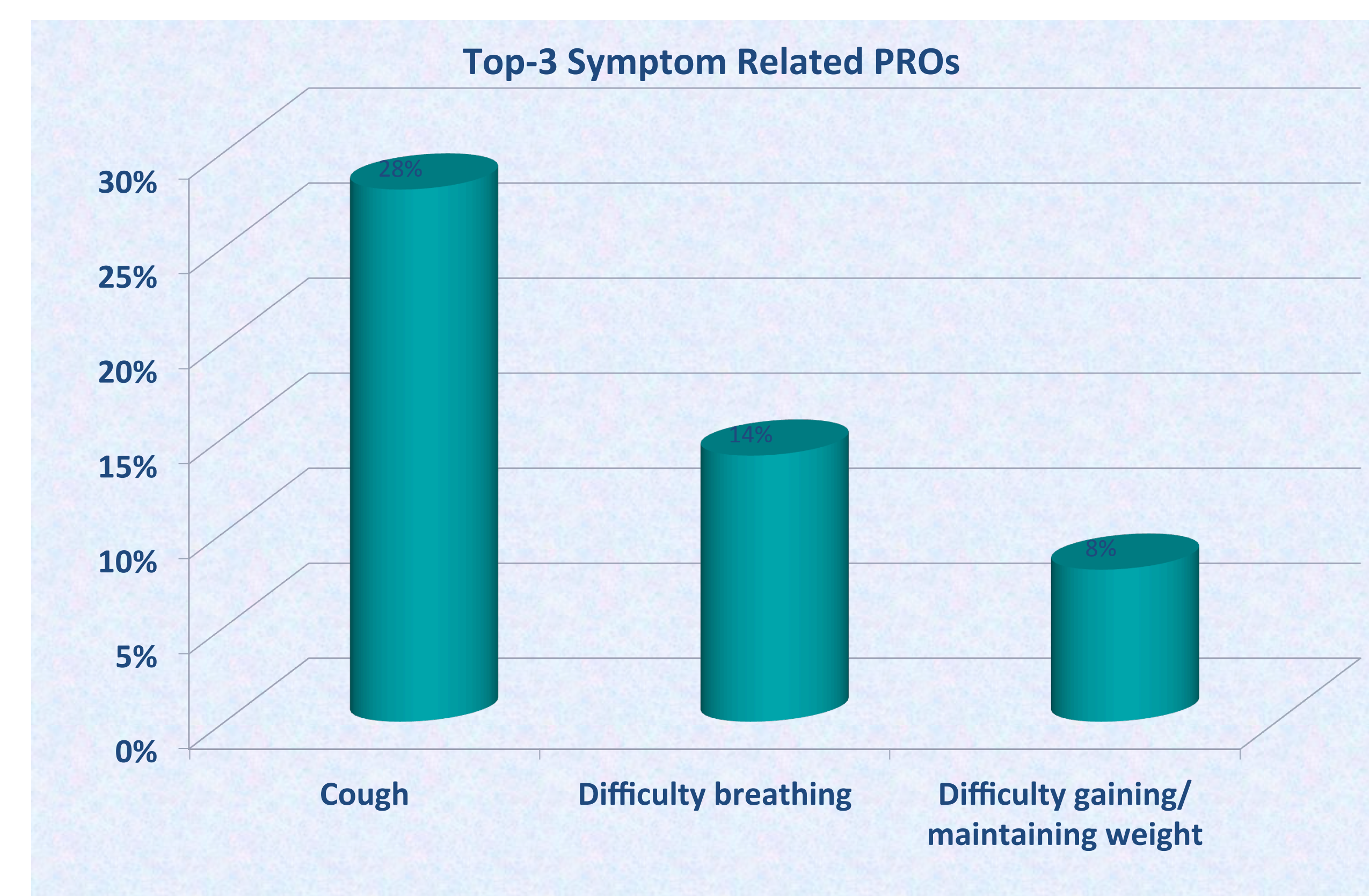
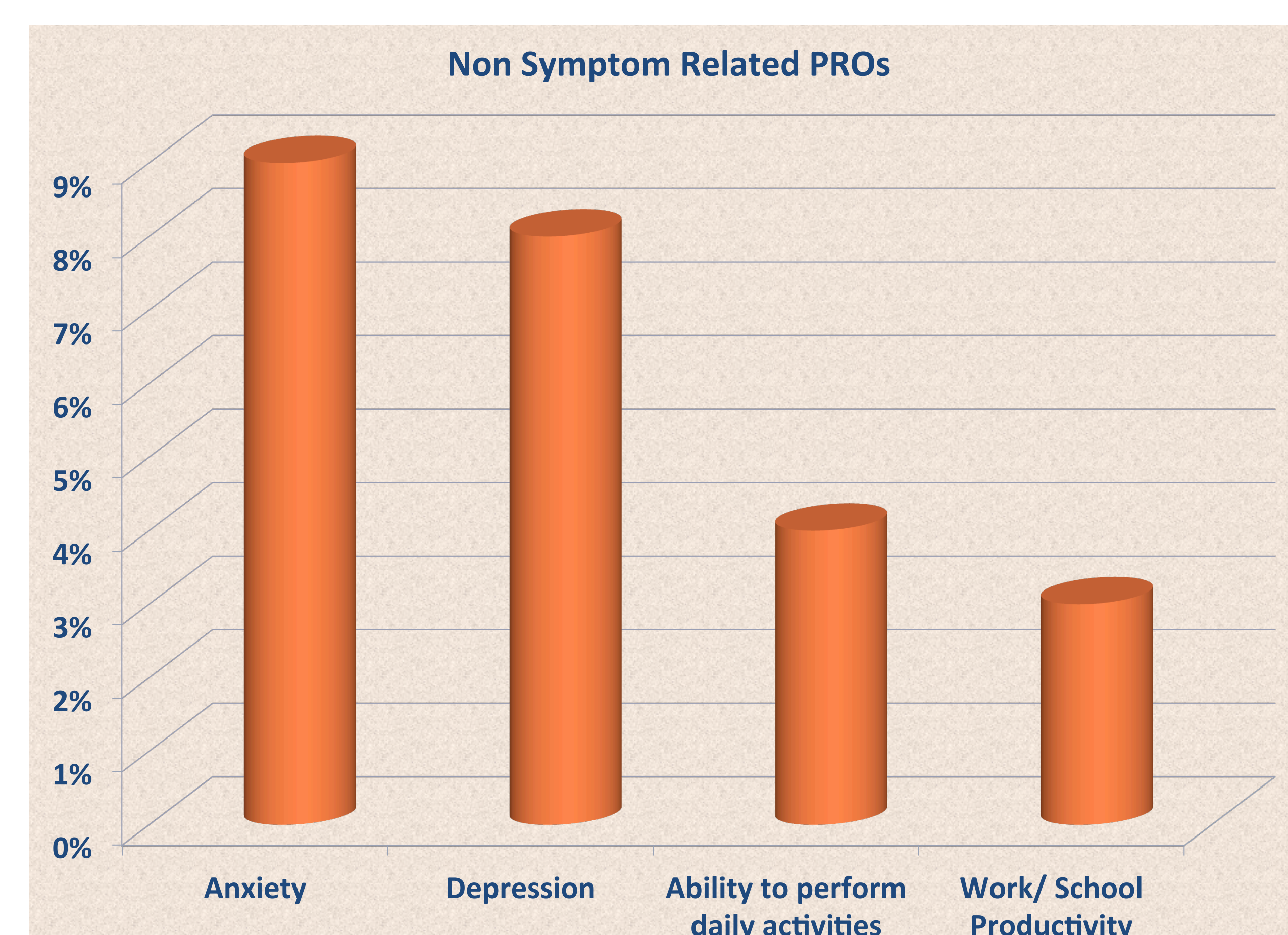


Figure 2. Most Commonly Reported HRQoL Concerns in Conversations between Physicians and Patients with Cystic Fibrosis

- Approximately 27% (n=50) of the patients discussed HRQoL-related topics, including psychological impacts of CF, ability to perform daily activities, and work/school productivity.
 - Anxiety (9%) and depression (8%) were discussed frequently by the patients
 - 4% complained about difficulty performing daily activities
 - 3% discussed impacts on work/school productivity
 - General QoL and concerns about family activities (i.e., not able to participate) were also reported by patients.



Conclusions

- PROs, as a function of disease burden, were routinely discussed by patients with CF in real-world clinical practice. PRO discussions were observed more frequently among adult patients than the pediatric patients, and symptom-related PROs were discussed more frequently than PROs related to HRQoL.
- Modalities to alleviate this patient burden, including appropriate therapeutic interventions, warrant further research.
- These PRO measures ultimately may be incorporated into routine clinical care to standardize symptom assessment and provide information regarding the need for specific clinical interventions to improve the quality of care delivered to these patients.