

12th International Congress on Early Onset Scoliosis | November 15-16, 2018| Lisbon, Portugal

Relationship Between Subjective Health Related Quality of Life (HRQoL) Outcomes and Objective Pulmonary Function Testing

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Disclosure Slide

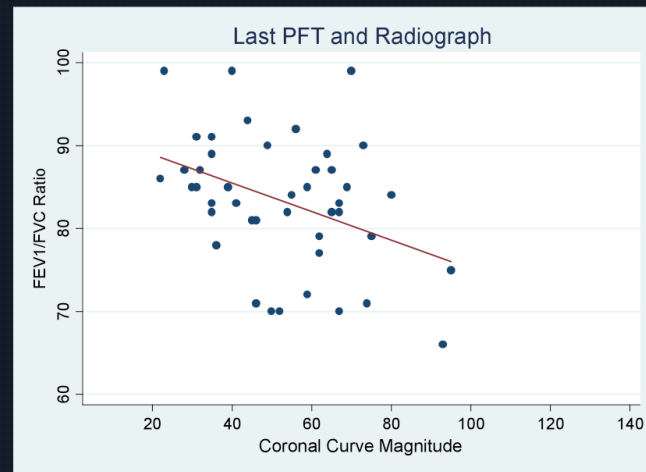
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Introduction

- Pulmonary function is compromised with progressive spinal deformity in EOS
- Pulmonary function has traditionally been assessed via spirometry, but cannot be obtained in some children (**too young, cognitive delay, trach dependent**)
- EOSQ-24 pulmonary function domain (PD) was initially validated with limited pulmonary function testing data to anchor the instrument



Purpose and Hypothesis

Purpose:

- To investigate the association between the EOSQ-24 PD score and forced vital capacity (FVC)

Hypotheses:

- Higher scores in FVC are associated with higher PD score in EOSQ-24
- EOSQ-24 PD scores can be used a surrogate for spirometry



Methods & Design

- **Multi-Center, retrospective, cross-sectional study**
- **EOS patients who underwent PFT and had their parents complete an EOSQ-24 questionnaire within 180 days of each other at any stage of treatment**
- **EOSQ-24 includes a Pulmonary Domain**
 - ✧ Two questions
 - ✧ Pertaining to shortness of breath
- **FVC % predicted obtained by spirometry using arm span**

EOSQ Pulmonary Domain

Pulmonary Function: During the past 4 weeks

5. How difficult has it been for your child to cry/babble/speak (appropriate for age) without experiencing shortness of breath?

Difficult

Somewhat Difficult

Neutral

Somewhat easy

Easy

6. How often has your child experienced shortness of breath during activities?

All of the time

Most of the time

Some of the time

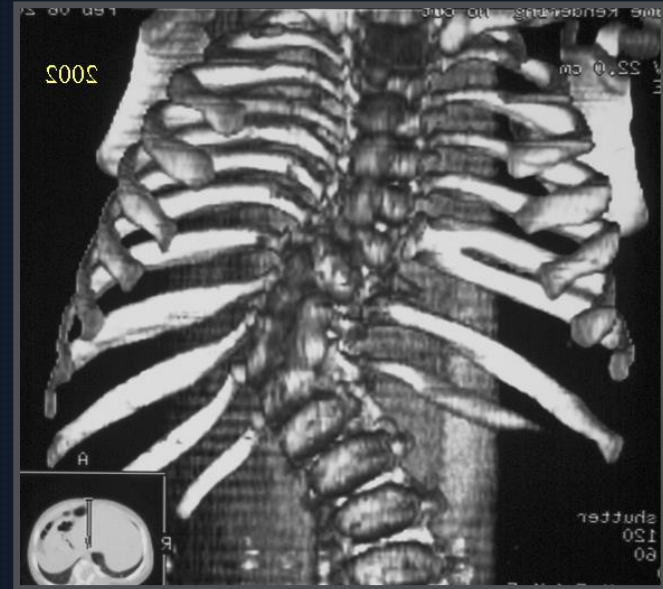
A small amount of
the time

None of the time

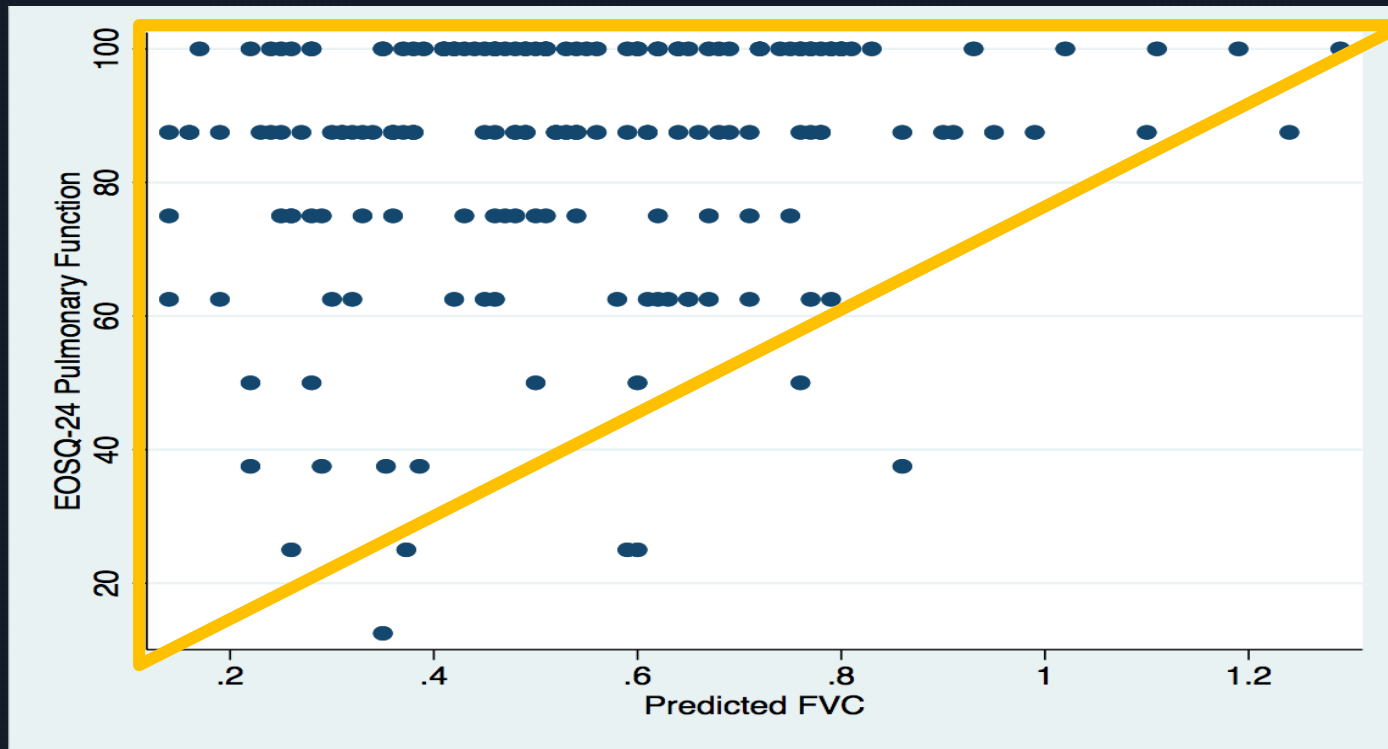


Baseline Characteristics

- **176 patients**
 - Mean age: 10.4 years
 - Male: 44% Female: 56%
- **Etiology:**
 - 33% congenital/structural
 - 27% neuromuscular
 - 26% syndromic
 - 14% idiopathic



PFD scores had wide variance at lower FVC % predicted values (<50%). As PFD scores increase, a simultaneous decrease in variance occurs with few exceptions



Conclusions

- **Lower PD scores more often when FVC% is $< 40\%$**
- **Children adapt to mild to moderate restrictive lung disease as reflected higher HRQoL scores**
- **Increased variability in HRQoL in moderate to severe restrictive (FVC $<50\%$) lung disease reflects limits on adaptation**
- **EOSQ-24 PD does not substitute for PFT's**

Thank You!!

