

# **The Early Onset Scoliosis 24 Item Questionnaire (EOSQ-24) Reflects Changes in Quality of Life and Parental Burden after Growing Rod Surgery**

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# Disclosures

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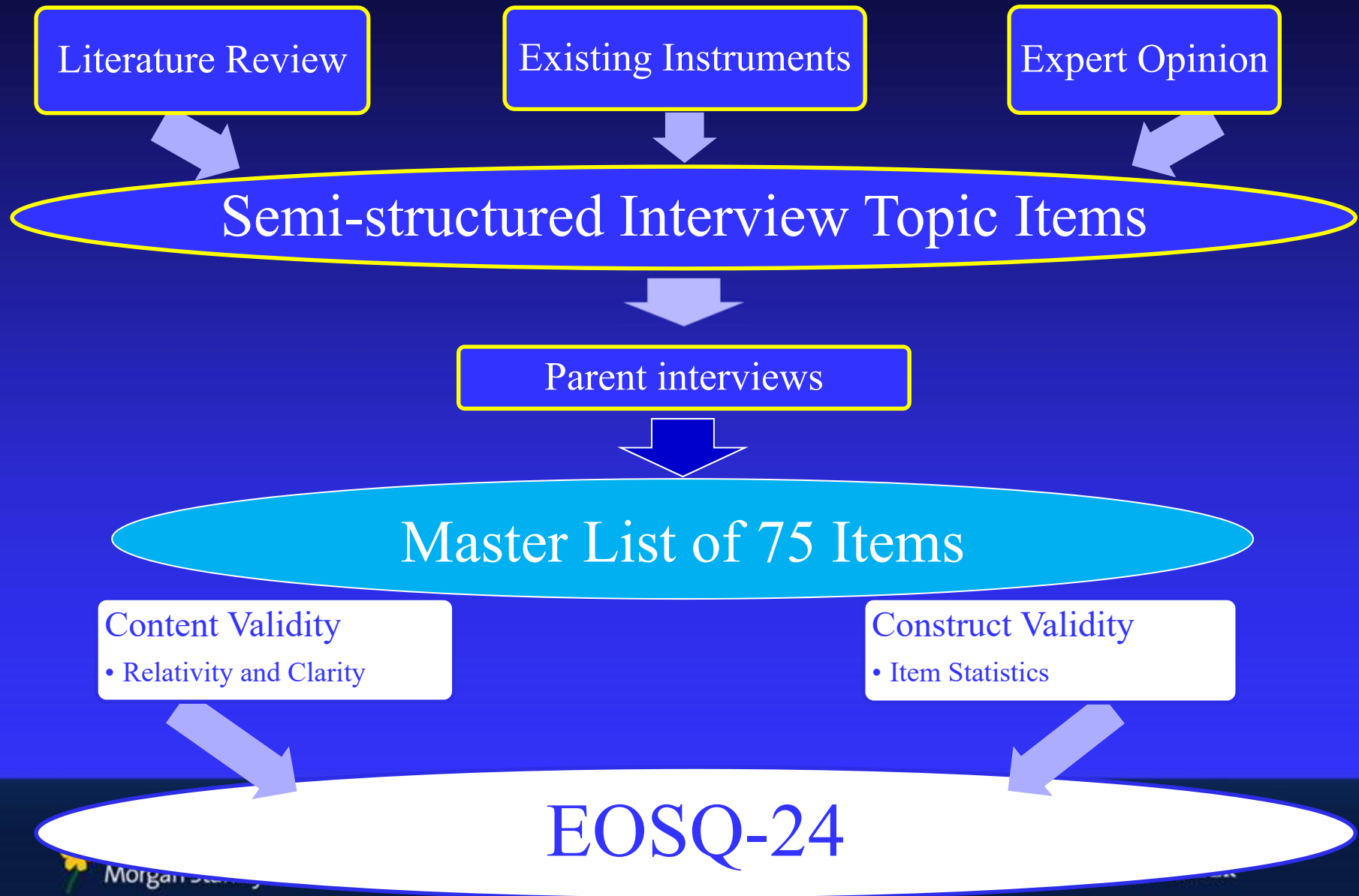
# Patient-based Outcomes in EOS

## Difficult to measure

- Heterogenous population
- Significant comorbidities
- Age is variable
- Natural history can be subclinical in childhood



# Development and Validation of EOSQ-24



# Early Onset Scoliosis Questionnaire-24

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- Caregiver form with 24 items, 3 domains, 11 sub-domains

Domain	Sub-Domain
Patient Quality of Life	General Health
	Pain/Discomfort
	Pulmonary Function
	Physical Function/Transfer
	Daily Living
	Fatigue/Energy Level
	Emotion
Burden of Care	Parental Burden
	Financial Burden
Satisfaction	Patient Satisfaction
	Parent Satisfaction

# **Purpose of Current Study**

**Phase 1: Development and Initial Validation**

**Phase 2: Prospective Multicenter Validation**

➤ **Responsiveness**

**Phase 3: Collection of Age-Based Normative Data**

**Phase 4: Foreign language Translation and Validation**

# Methods and Materials

## 1) Responsiveness

EOSQ-24 at 3 Time Points:

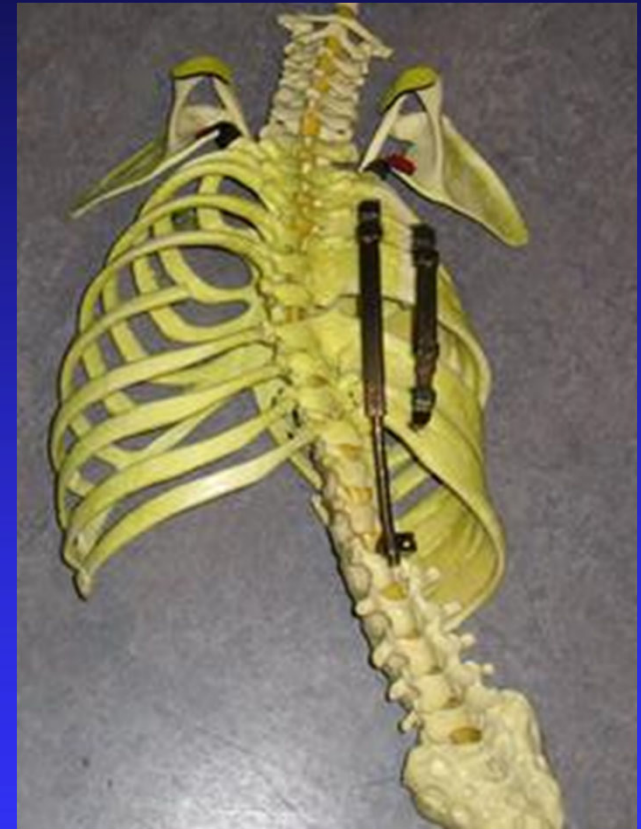
- 1) Prior to initial instrumentation
- 2) Prior to first lengthening (or 4-6 mo post-Shilla)
- 3) Prior to second lengthening

### Inclusion

- EOS
- No prior surgical treatment
- Cobb angle greater than 20 degrees
- Planned to undergo surgical treatment

## 2) Norms

Non-scoliosis pediatric patients given EOSQ-24 once



# Participating Sites

Site	PI	Pre-OP	1 <sup>st</sup>	2 <sup>nd</sup>
CHONY	Michael G. Vitale	25	24	22
Primary Children's - Utah	John T. Smith	10	9	5
Boston Children's	John Emans	9	9	6
UCSD	Behrooz Akbarnia	12	11	10
CHLA	David Skaggs	5	3	1
	TOTALS:	61	56	44



# Responsiveness Study Demographics

- 61 Patients
- Mean age:  $6.4 \pm 2.9$
- 32 VEPTR, 25 Growing Rod, 4 Shilla

Gender	Female	33	54.1%
	Male	28	45.9%

Etiology	Idiopathic	9	14.8%
	Neuro-muscular	23	41.0%
	Syndromic	12	19.7%
	Congenital	17	27.9%

	Cobb
Pre-Index	66.89 <sup>o</sup>
Pre-1st L	49.05 <sup>o</sup>
Pre-2nd L	50.31 <sup>o</sup>

# Normative Patients with Varying Diagnoses

- 150 non-scoliosis pt
- Mean age 6.3; Range (0-18)

Diagnosis	Frequency	Percent
Pes Planus	7	4.7
Tibial Torsion	13	8.7
DDH	23	15.3
Abnormal Gait	18	12.0
Femoral Anteversion	12	8.0
Fracture	57	38.0
Joint Pain	8	5.3
Other	7	4.7
Negative Eval	5	3.3
Total	150	100.0

# Normative Score Range: 90-96

Age	Average Score		
	Count	Mean	SD
0-1 yo	9	90.25	8.94
1-2 yo	13	89.68	7.86
2-3 yo	10	91.48	5.88
3-4 yo	14	96.29	3.81
4-5 yo	12	94.64	4.16
5-6 yo	12	94.54	7.45
6-7 yo	11	91.83	8.35
7-8 yo	12	95.22	5.41
8-9 yo	11	96.42	4.00
9-10 yo	9	95.47	4.75
10-11 yo	7	91.92	4.72
11-12 yo	6	92.67	3.10
12+	22	92.02	10.67

Min: 89.68

Max: 96.42

Basis of comparison  
for EOS patient  
EOSQ-24 scores

# All Pts, Significant Improvement in Parental Burden

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Cohort	Domain	Pre-op	Post-op	P	Age Norm
All Patients	Parental Burden	60	66	0.041	91

# Neuromuscular pts, improvements in Fatigue, Emotion, and Parental Burden

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Cohort	Domain	Pre-op	Post-op	P	Age Norm
Neuro-muscular	Fatigue	56	66	0.083	93
	Emotion	71	78	0.046	94
	Parental Burden	49	59	0.020	92

# SMA pts, improvements in Pulmonary Function, Transfer, Fatigue, and Emotion

Cohort	Domain	Pre-op	Post-op	P	Age Norm
SMA	Pulmonary Function	<b>58</b>	<b>98</b>	0.083	98
	Transfer	<b>39</b>	<b>61</b>	0.045	99
	Fatigue	<b>41</b>	<b>52</b>	0.078	93
	Emotion	<b>53</b>	<b>69</b>	0.080	94
	Parental Burden	<b>40</b>	<b>63</b>	0.008	93

# Idiopathic pts, worsened in Physical Function, Fatigue, and Emotion

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Cohort	Domain	Pre-op	Post-op	P	Age Norm
Idiopathic	Physical Function	<b>94</b>	<b>84</b>	0.048	97
	Fatigue	<b>88</b>	<b>69</b>	0.076	92
	Emotion	<b>81</b>	<b>60</b>	0.006	95

# Complications worsen Pain; Without complication, Pulmonary Function and Parental Burden Improve

Cohort	Domain	Preop	Postop 1 <sup>st</sup> /2 <sup>nd</sup>	P	Age Norm
With Intra-op Complication	Pain	72	59	0.092	95
No Post-op Complication	Pulmonary Function	83	88	0.075	97
	Parental Burden	61	66	0.056	91



# Discussion

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- The EOSQ-24 is sensitive to changes following surgical treatments.
  - Starting scores and their trajectories differed when the dataset was analyzed by etiology (eg. Neuromuscular and Idiopathic)
  - Accurate HRQoL information emerge as subjects are grouped by common characteristics
- Best to analyze scores by common characteristics

# Discussion

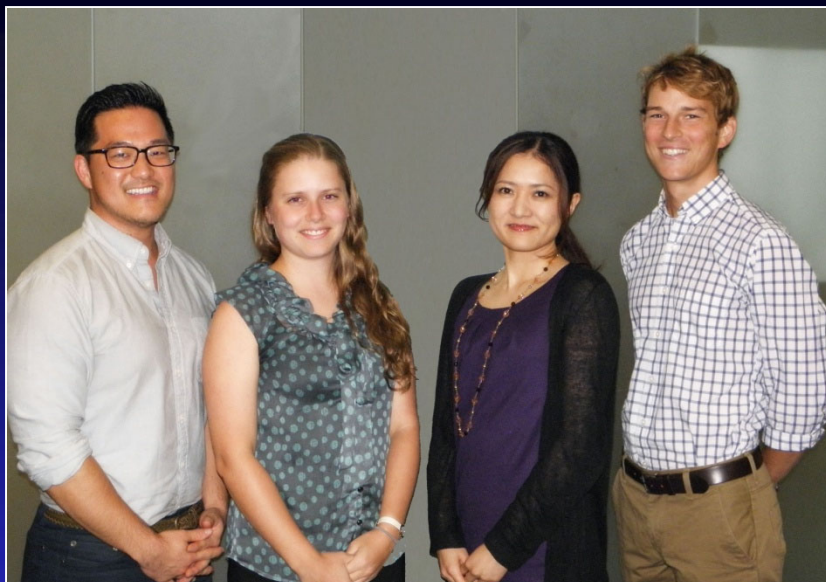
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- **EOS surgical patients' HRQoL and burden of care are worse compared to norms**
- **Small differences in EOSQ-24 scores across different instrumentation techniques due to small sample size**

# Ongoing Projects

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- **Reliability testing**
- **Translation: Spanish, Hispanic Spanish, Turkish, Japanese, French and German**
- **Differences in HRQoL, Burden of Care and Satisfaction**
  - Casting, Different instrumentation
  - Etiology, Ambulatory status
  - Different complications



**Thank You**  
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