Quality of Life: EOSQ, Other Indicators

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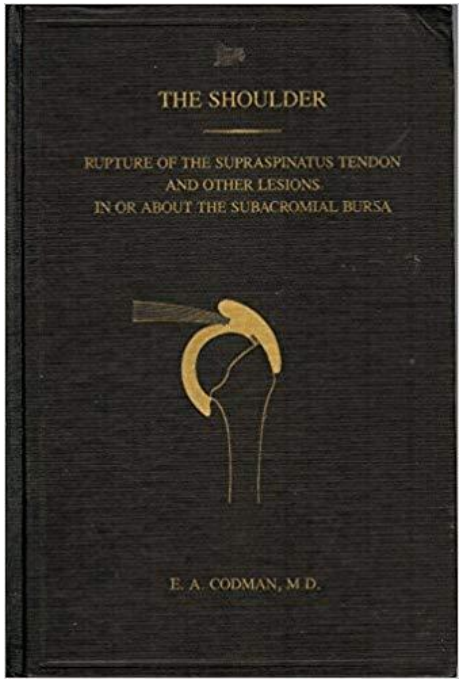
Disclosures

- Li: see program

- 48.3 million Americans undergo surgery each year in the U.S.
- 7.1 million surgeries on the musculoskeletal system
- Expenditures exceed $500 billion USD → $912 billion USD in 2025

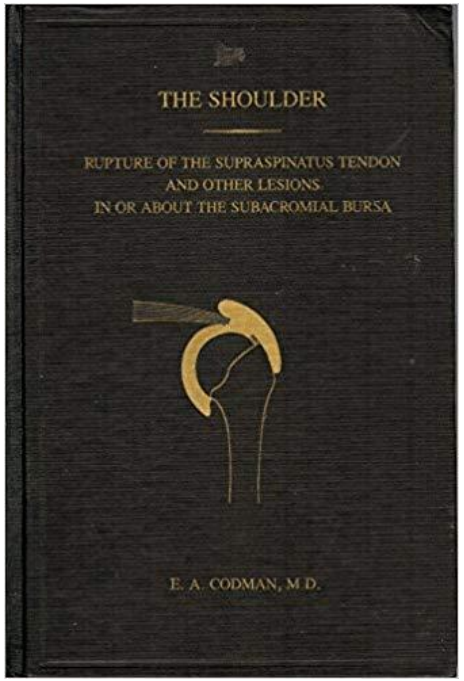


"Already in 1900 I had become interested in what I have called the End Result Idea, which was merely **the common-sense notion that every hospital should follow every patient it treats, long enough to determine whether or not the treatment has been successful, and then to inquire**

<u>if not, why not?"</u>

From the Preface to "The Shoulder"
By Dr. Ernest A. Codman, 1934

How is success defined?



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- Measures of treatment effectiveness and quality for surgical conditions primarily centered on clinical outcomes
  - Complication rates
  - Mortality
  - Readmission

- Easy to collect, quantify, categorize

- Tracking clinical outcomes improves care

- Postoperative clinical outcomes can reflect many aspects of perioperative safety and technical performance

- Do not capture the patient (or caregiver) perspective

Patient-Reported Outcomes (PROs)

- Describe aspects of health status reported directly from patients, without interpretation by a healthcare provider

Symptoms
Quality of life
Disability
Mobility
Pain

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Measure the things that patients care about most

Symptoms
Quality of life
Disability
Mobility
Pain

Table 1
Clinical outcomes versus patient-reported outcomes

	Clinical outcomes	PROs
Definition	Occurrence of specific clinical events	Self-reported health status or experience
Example	30-d procedural mortality	Health-related quality of life
Advantages	Outcomes easily quantified	Outcomes obtained directly from patients
	Available in clinical and administrative data	Germane to patient experiences
	Comparable across providers	Reflect long-term effects
Disadvantages	Do not capture all aspects of recovery	Labor intensive data collection
	Infrequent for common, safe procedures	Validity and reliability vary by instrument
	Risk differences difficult to interpret	Difficult to obtain if communication barriers

Waljee, Dimick. Adv Surg 2017

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Waljee, Dimick. Adv Surg 2017

Patient-Reported Outcomes (PROs)

Generic
eg, PROMIS

Capture well-being along dimensions that are **common across conditions**
(physical/social function, pain, depression, anxiety)

Condition-specific
eg, SRS-22, EOSQ-24

Capture aspects of health status related to a **specific disease or disability**

Table 2
Generic versus condition specific instruments

	Generic Instruments	Condition-Specific Instruments
Advantages	Can compare treatments across groups	Clinically relevant
	Can compare with healthy individuals	Responsive to change over time
	Can detect unexpected effects	Sensitive to outcomes of interest
Disadvantages	Lack relevant detail	Difficult to compare with general population
	Limited responsiveness to change	Cannot compare across diseases
		May not detect unforeseen effects or symptoms

Waljee, Dimick. Adv Surg 2017

Patient-Reported Outcomes (PROs)

- Not the same as patient-reported experiences

- Satisfaction around a clinical encounter
  - Lavela SL (Patient Exp J 2014): “the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care”

- Consumer Assessment of Healthcare Providers and Systems (CAHPS)
  - Provider communication, cleanliness, accessibility of services

- PROs essential to define treatment effectiveness
- Early onset scoliosis (EOS) potentially fatal if untreated
- Spine deformity → chest wall deformity → pulmonary restriction

Treatment of EOS

Control spine & chest wall deformity while max. growth

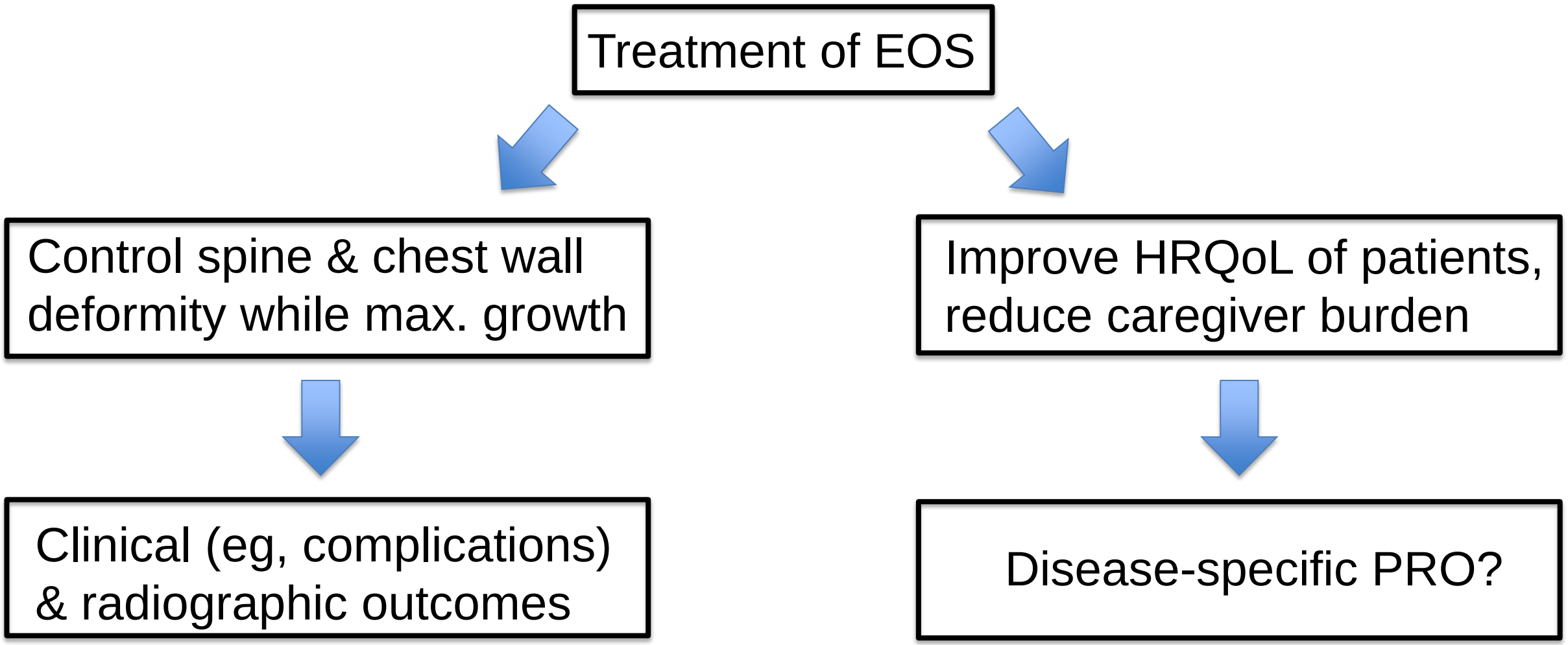
Clinical (eg, complications) & radiographic outcomes

Health-Related Quality of Life in Children With Thoracic Insufficiency Syndrome

Michael G. Vitale, MD, MPH,†‡ Hiroko Matsumoto, MA,*†‡ David P. Roye Jr, MD,*†*
Jaime A. Gomez, MD,† Randal R. Betz, MD,§ John B. Emans, MD,|| David L. Skaggs, MD,¶*
*John T. Smith, MD,# Kit M. Song, MD,** and Robert M. Campbell Jr, MD††*

- Child Health Questionnaire (CHQ)
- HRQoL in children with EOS significantly impaired with regard to physical function and caregiver burden
- CHQ had limited responsiveness to treatment, unable to examine issues related to pulmonary function → need for disease-specific PRO

JPO 2008


Treatment of EOS
Control spine & chest wall deformity while max. growth
Improve HRQoL of patients, reduce caregiver burden
Clinical (eg, complications) & radiographic outcomes
Disease-specific PRO?

Measuring Quality of Life in Children With Early Onset Scoliosis: Development and Initial Validation of the Early Onset Scoliosis Questionnaire

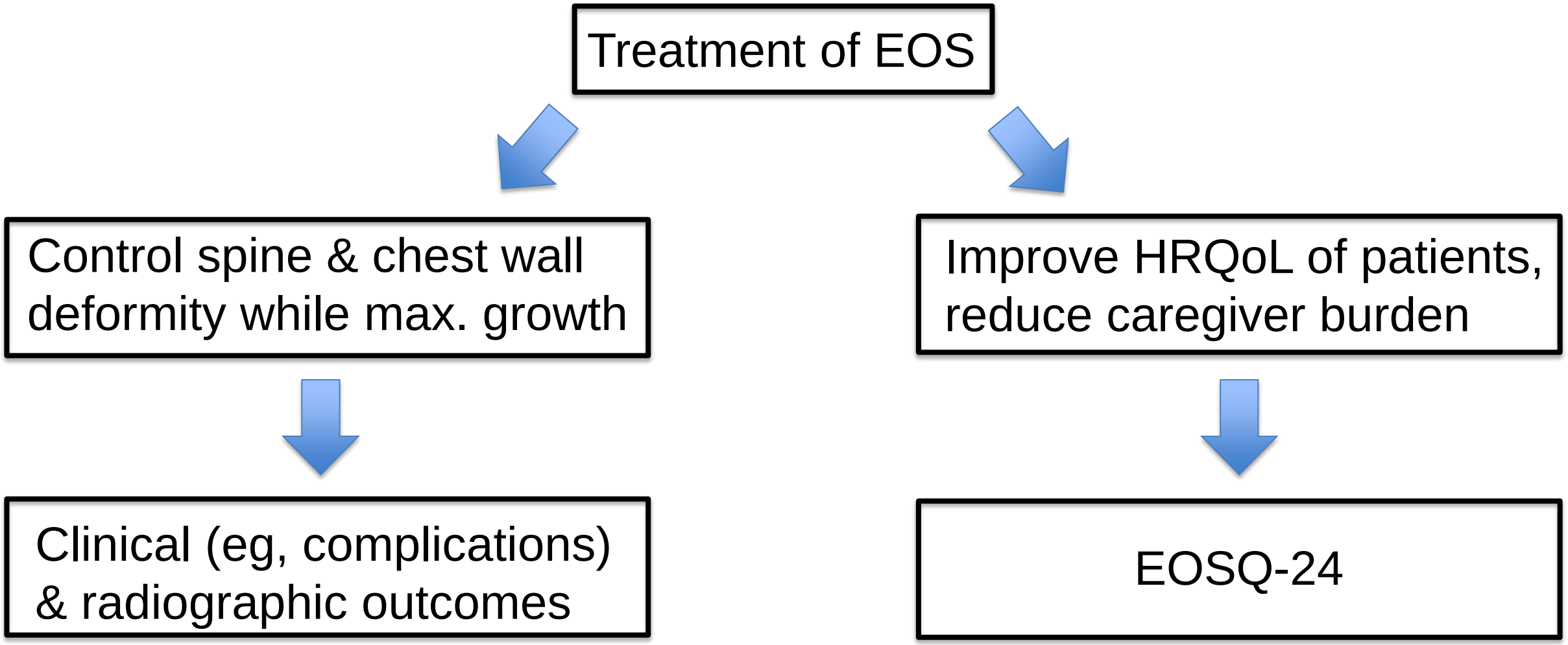
Jacqueline Corona, MD,† Hiroko Matsumoto, MA,*†*
David P. Roye, Jr, MD,† and Michael G. Vitale, MD, MPH*†*

JPO 2011

The Final 24-Item Early Onset Scoliosis Questionnaires (EOSQ-24): Validity, Reliability and Responsiveness

Hiroko Matsumoto, MA,† Brendan Williams, MD,‡ Howard Y. Park, MD,§*
Julie Y. Yoshimachi, BA, Benjamin D. Roye, MD, MPH,* David P. Roye, Jr, MD,**
*Behrooz A. Akbarnia, MD,‖ John Emans, MD,¶ David Skaggs, MD,§# John T. Smith, MD,***
*and Michael G. Vitale, MD, MPH**

JPO 2018


Treatment of EOS
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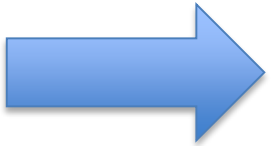
Clinical (eg, complications) & radiographic outcomes
EOSQ-24

EOSQ-24

Completed by caregiver



- General Health
- Pain
- Pulmonary Function
- Transfer
- Physical Function
- Daily Living
- Fatigue
- Emotion
- Parental Impact
- Financial Impact
- Child Satisfaction
- Parent Satisfaction

Health-Related Quality of Life in Early-Onset Scoliosis Patients Treated Surgically

EOSQ Scores in Traditional Growing Rod Versus Magnetically Controlled Growing Rods

Michael E. Doany, BS,* Z. Deniz Olgun, MD,† Gizem Irem Kinikli, PT,‡ Senol Bekmez, MD,§
Aykut Kocyigit, MD,¶ Gokhan Demirkiran, MD,¶ A. Ergun Karaagaoglu, PhD,|| and Muharrem Yazici, MD¶

- 25 TGR, 19 MCGR
- Similar age at index surgery, deformity correction, complication rates
- TGR patients older at time of EOSQ-24, had longer follow-up

Spine 2017

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TABLE 2. Questionnaire Results, Adjusted for Follow-up

	Questionnaire Results (Mean)			Adjusted for Follow-up (Means; 95% Confidence Interval)		
Domain	**MCGR**	**TGR**	***P***	**MCGR**	**TGR**	***P***
General health	59.9	58	.703	66.6 (56.5–76.7)	52.9 (44.7–61.1)	.084
Pain/discomfort	71.1	77	.642	86.0 (72.4–99.7)	65.6 (54.4–76.8)	.059
Physical function	72.4	57	.075	78.0 (60.0–96.0)	52.7 (38.0–67.4)	.075
Pulmonary function	86.2	87	.896	95.3 (82.6–107.9)	80.0 (69.7–90.5)	.127
Transfer	65.8	51	.16	54.3 (32.7–76.0)	59.7 (42.0–77.4)	.749
Daily living	50	61.5	.287	55.0 (32.1–77.9)	57.7 (39.0–76.5)	.877
Fatigue/energy level	71.1	77	.421	76.1 (60.4–91.7)	73.2 (60.4–86.0)	.812
Emotion	61.2	52	.219	57.6 (41.8–73.4)	54.7 (41.8–67.6)	.811
Parental burden	53.4	46	.308	51.3 (35.8–66.8)	47.6 (34.9–60.3)	.758
Financial burden	61.8	38	**.002**	61.4 (45.6–77.2)	38.3 (25.4–51.2)	.064
Overall satisfaction	82.9	67.5	**.01**	83.2 (70.7–95.8)	67.2 (57.0–77.6)	.106
Average	66.9	61.1	.194	69.6 (60.2–78.9)	59.1 (51.4–66.8)	.155

Spine 2017

The Reliability and Concurrent Validity of the Scoliosis Research Society-22 Patient Questionnaire for Idiopathic Scoliosis

Marc Asher, MD,* Sue Min Lai, PhD,† Doug Burton, MD,* and Barbara Manna, RN*

- Adolescent idiopathic scoliosis
- Completed by patient
- Option for EOS patients ≥10 years?

Function
Pain
Self-Image
Mental Health
Satisfaction

Spine 2003

A cluster of high psychological and somatic symptoms in children with idiopathic scoliosis predicts persistent pain and analgesic use 1 year after spine fusion

Terri Voepel-Lewis[1] | Michelle S. Caird[2] | Alan R. Tait[1] | Frances A. Farley[2] | Ying Li[2] | Shobha Malviya[1] | Afton Hassett[1] | Monica Weber[1] | Emily Currier[1] | Trevor de Sibour[1] | Daniel J. Clauw[1]

- 95 AIS patients undergoing posterior spinal fusion

- PROs administered preop and 1 year postop
  - PROMIS fatigue, depression, anxiety, pain catastrophizing, pain interference
  - painDETECT (neuropathic pain)
  - Pain intensity, location, duration

Paediatr Anaesth 2018

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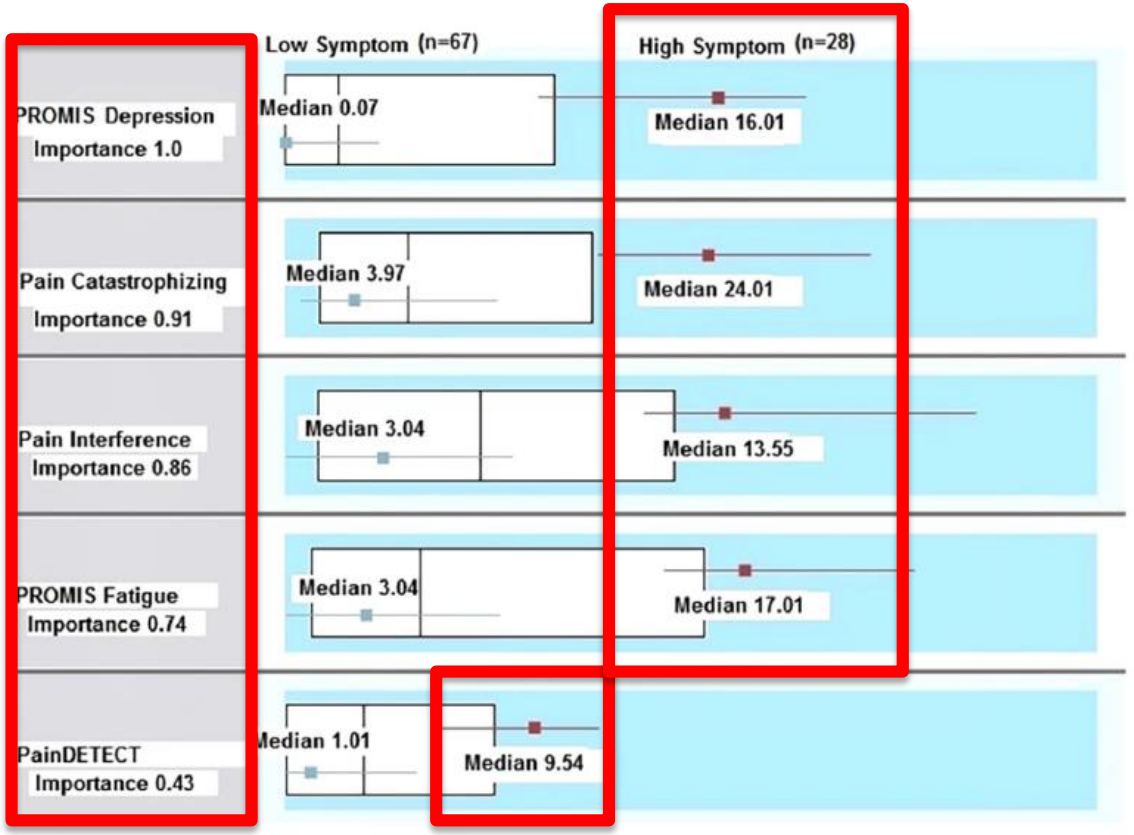
- 1/3 patients in “High Symptom Cluster”
- Higher pain intensity, pain interference, neuropathic pain
- More likely to be taking analgesics at 1 year postop



Paediatr Anaesth 2018

Patient-Reported Outcomes (PROs)

- Describe aspects of health reported directly from patients (or caregivers)
- Encompass important elements of disability and function
- Distinct from clinical outcomes and patient experience
- Offer a unique perspective of clinical effectiveness of treatment options


ANY PAIN?
MY ARM REALLY HURTS.
HOW WOULD YOU RATE THE PAIN, FROM ONE TO TEN, WHERE TEN IS THE WORST PAIN YOU CAN IMAGINE?
THE WORST PAIN I CAN IMAGINE?
ONE.
... WHAT THE HELL IS WRONG WITH HIS IMAGINATION?
IT'S NOT A NORMAL PLACE.