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

if not, why not?”

From the Preface to “The Shoulder”
By Dr. Ernest A. Codman, 1934
“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 if not, why not?”

From the Preface to “The Shoulder”

By Dr. Ernest A. Codman, 1934
• 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
Patient-Reported Outcomes (PROs)

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

Measure the things that patients care about most:

- Symptoms
- Quality of life
- Disability
- Mobility
- Pain
<table>
<thead>
<tr>
<th>Table 1: Clinical outcomes versus patient-reported outcomes</th>
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</thead>
<tbody>
<tr>
<td><strong>Clinical outcomes</strong></td>
</tr>
<tr>
<td>Definition: Occurrence of specific clinical events</td>
</tr>
<tr>
<td>Example: 30-d procedural mortality</td>
</tr>
<tr>
<td>Advantages: Outcomes easily quantified</td>
</tr>
<tr>
<td>Available in clinical and administrative data</td>
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<tr>
<td>Comparable across providers</td>
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<tr>
<td>Disadvantages: Do not capture all aspects of recovery</td>
</tr>
<tr>
<td>In frequent for common, safe procedures</td>
</tr>
<tr>
<td>Risk differences difficult to interpret</td>
</tr>
<tr>
<td>Clinical outcomes</td>
</tr>
<tr>
<td>-------------------</td>
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<tr>
<td><strong>Definition</strong></td>
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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>
<thead>
<tr>
<th>Advantage</th>
<th>Generic Instruments</th>
<th>Condition-Specific Instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advantages</td>
<td>Can compare treatments across groups</td>
<td>Clinically relevant</td>
</tr>
<tr>
<td></td>
<td>Can compare with healthy individuals</td>
<td>Responsive to change over time</td>
</tr>
<tr>
<td></td>
<td>Can detect unexpected effects</td>
<td>Sensitive to outcomes of interest</td>
</tr>
<tr>
<td>Disadvantages</td>
<td>Lack relevant detail</td>
<td>Difficult to compare with general population</td>
</tr>
<tr>
<td></td>
<td>Limited responsiveness to change</td>
<td>Cannot compare across diseases</td>
</tr>
<tr>
<td></td>
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<td>May not detect unforeseen effects or symptoms</td>
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</tbody>
</table>
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 $\rightarrow$ chest wall deformity $\rightarrow$ pulmonary restriction
Treatment of EOS

Control spine & chest wall deformity while max. growth

Clinical (eg, complications) & radiographic outcomes
• 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
Treatment of EOS

Control spine & chest wall deformity while max. growth

Clinical (eg, complications) & radiographic outcomes

Improve HRQoL of patients, reduce caregiver burden

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*†

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 2011

JPO 2018
Treatment of EOS

Control spine & chest wall deformity while max. growth

Clinical (eg, complications) & radiographic outcomes

Improve HRQoL of patients, reduce caregiver burden

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
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
# 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∗

<table>
<thead>
<tr>
<th>TABLE 2. Questionnaire Results, Adjusted for Follow-up</th>
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<tr>
<td>Questionnaire Results (Mean)</td>
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<tr>
<td>Domain</td>
</tr>
<tr>
<td>--------------------------------</td>
</tr>
<tr>
<td>General health</td>
</tr>
<tr>
<td>Pain/discomfort</td>
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<tr>
<td>Physical function</td>
</tr>
<tr>
<td>Pulmonary function</td>
</tr>
<tr>
<td>Transfer</td>
</tr>
<tr>
<td>Daily living</td>
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<tr>
<td>Fatigue/energy level</td>
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<td>Emotion</td>
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<tr>
<td>Parental burden</td>
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<tr>
<td>Financial burden</td>
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<tr>
<td>Overall satisfaction</td>
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<tr>
<td>Average</td>
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</table>

Spine 2017
• Adolescent idiopathic scoliosis

• Completed by patient

• Option for EOS patients ≥10 years?
A cluster of high psychological and somatic symptoms in children with idiopathic scoliosis predicts persistent pain and analgesic use 1 year after spine fusion

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
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-Lewis¹ | Michelle S. Caird² | Alan R. Tait¹ | Frances A. Farley² |
Ying Li² | Shobha Malviya¹ | Afton Hassett¹ | Monica Weber¹ | Emily Currier¹ |
Trevor de Sibour¹ | Daniel J. Clauw¹

• 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.