EOSQ-24: Research Tool or Does it Change my Practice?

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Disclosures

- **Royalties:** Zimmer-Biomet
- **Consultant:** Stryker, Zimmer-Biomet
- **Research Support:** PSSG, SRS, POSNA; OREF
- **BOD:** POSNA, PSSG; SP3
Health-Related Quality of Life

• Interest in Health-Related Quality of Life has grown exponentially.
• Approximately 80,000 documents studied HRQoL in 2018
Patient-Based Outcomes in EOS

Difficult to measure

– Heterogeneous population

– Significant comorbidities

– Age is variable

– Natural history can be subclinical in childhood
Who are your patients?

AIS

Sports without Limitations
- Vigorous activities with limitations
- Moderate activities
- Moderate activities with limitations
  - Walk slowly
  - Trouble bending, stooping
- Need help to bathe
- Cannot maintain balance
- Move about with help
- Stand up with help
- Staying in bed/partly undressed
- Lying down most of time
- Confined to room, bed
Measuring Quality of Life in Children With Early Onset Scoliosis: Development and Initial Validation of the Early Onset Scoliosis Questionnaire

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Semi-structured Interview Topic Items

- Literature Review
- Existing Instruments
- Expert Opinion

Parent interviews

Master List of 75 Items

Content Validity
- Relativity and Clarity

Construct Validity
- Item Statistics

EOSQ-24
EOSQ-24 Domains
Questionnaire with 24 items, 11 domains

- **Health Related Quality of Life**
  - General Health
  - Pain/Discomfort
  - Transfer
  - Physical Function
  - Daily Living
  - Fatigue/Energy Level
  - Emotion

- **Parental Burden**
- **Financial Burden**

- **Satisfaction**
  - Child Satisfaction
  - Parental Satisfaction
EOSQ: 2012-Present

• In clinical and research use since 2012
• Multiple validation studies
• Translated to Turkish, Mandarin Chinese, Spanish, Norwegian, Arabic, Dutch, German
• 17,927 EOSQ-24s administered and entered in PSSG Registry
• 26 publications available on PubMed
EOSQ-24 as a Research Tool

EOSQ-24 is a Disease Specific HRQoL Measuring Tool
- Measuring HRQoL provides new prospective on new and old questions
- Studies using EOSQ-24 have been cited 73 times

Example Research Questions We’ve Been Able to Answer:
- Improvement in QoL with conversion from TGR to MCGR?
- Difference in QoL for Growing Rod “Graduates” with Severe vs. Moderate EOS?
- Does Decreased Surgical Stress Improve QoL?
- Difference in QoL for Single Fusion Vs. Growth Friendly Surgery in Older EOS Patient?
- Improvement in Pulmonary Function in Patients with SMA After VEPTR?
- Many additional abstracts, publications, and ongoing studies…
Patient JL – 7-year-old girl with SMA Type 2

Patient requires improvement in respiratory status.
- EOSQ-24 PF Score - 26
- EOSQ-24 HRQoL Score - 47
Patient JL – 7-year-old girl with SMA Type 2

Patient experiences improvement in respiratory status after TGR
- EOSQ-24 PF Score - 26
- EOSQ-24 HRQoL Score – 47

Post-operatively, dramatic improvement in respiratory status.
- EOSQ-24 PF Score – 53
- EOSQ-24 HRQoL Score - 81
In patients with SMA, Pulmonary Functioning Testing did not increase post rib based growing constructs.
However, EOSQ-24 Pulmonary Function Scores Increased Post-Operatively

EOSQ-24 data can provide quality of life assessments not captured by traditional testing.
Are HRQoL Measures Similar at 24 Months Between Magnetically-Controlled Growing Rod Patients and Traditional Growing Rod Patients?

No statistical difference with HRQoL for MCGR Vs. TGR at 2-year follow-up

- Is EOSQ-24 missing something?
- Is 2-year follow-up too short?
Idiopathic EOSQ Decline Significantly in 6 Domains While In-Cast
Questions We’ve Answered With EOSQ-24

Does Unplanned Returns to the Operating Room (UPROR) impact HRQoL?
• EOSQ scores decreased for congenital, neuromuscular, and syndromic EOS patients but not idiopathic etiology.

Does residual pelvic obliquity after definitive spinal fusion impact HRQoL?
• EOSQ scores were negatively correlated with pelvic obliquity only in ambulatory idiopathic, syndromic, and neuromuscular patients.

Does HRQoL change for patients after TGR implantation?
• EOSQ scores were unchanged 2-years post-operatively in patients who received TGR.

Does HRQoL change in patients undergoing serial Mehta casting?
• EOSQ scores decrease while in-cast for both idiopathic and non-idiopathic patients.
• Non-idiopathic patients have improvement in QoL after casting while idiopathic remains static.
EOSQ for Adolescents

Current EOSQ-24 measures parents’ perspectives on their children’s HRQoL

Goal: To develop a self-reported health-related quality of life (HRQoL) instrument appropriate for adolescents with EOS between 8-18 years of age
Phase I: EOSQ-A

- Phase I – Semi Structured Interview - 12 patients
- 59 item master list of questions developed
  - 14 domains (4 new domains)

  - General Health (2 questions)
  - Pain/Discomfort (2 questions)
  - Pulmonary Function (2 questions)
  - Transfer (2 questions)
  - Physical Function (7 questions)
  - Daily Living (5 questions)
  - Fatigue/Energy Level (2 questions)
  - Emotion (12 questions)
  - Satisfaction (3 questions)
  - Sleep (7 questions)
  - Appearance (6 questions)
  - Relationships (6 questions)
  - Family Dynamics (3 questions)
Excerpts of Surveys

Excerpt of Global Assessment Form (GAF) – Completed by Parent/Patient

<table>
<thead>
<tr>
<th>General Health: During the past 8 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In general, how would say your child’s health has changed before and after surgery?</td>
</tr>
<tr>
<td>Significantly worse</td>
</tr>
<tr>
<td>2. How has the frequency of your child being sick changed before and after surgery?</td>
</tr>
<tr>
<td>Significantly worse</td>
</tr>
</tbody>
</table>

Physician Prognosis Form

4) What is your overall assessment of the change in this patient after intervention? (Check One)
   □ Important deterioration
   □ Slight deterioration
   □ No change
   □ Slight improvement
   □ Important improvement

5) What is your assessment of this patient’s pain/discomfort after intervention?
   □ Important deterioration
   □ Slight deterioration
   □ No change
   □ Slight improvement
   □ Important improvement
EOSQ for Adolescents – Status and Future

Status:
Currently enrolling for Phase II—Reliability and Validity assessment
  • Currently 74 patients enrolled
Phase III – Responsiveness assessment
  • Administer before and after interventions
Phase IV – Normative data collection
Preliminary Analysis on Content Validity

Q15) How difficult has it been for you to move your head/neck to use a computer?

Q39) How often does your health condition create problems/issues between you and your girlfriend/boyfriend?

Mean Relevancy Score
3.47

Mean Relevancy Score
2.47
MCID of the EOSQ-24 funded by grant from SRS

- Define the minimal clinically important difference (MCID)
- Traditional assumption has been that a change of 10% in HRQoL scores is the MCID
- 62/80 patients enrolled

**Table 4. Calculated Minimum Clinically Important Difference (MCID) Based on Receiver-Operating Characteristic Curve Analysis of Domain Scores**

<table>
<thead>
<tr>
<th>Domain</th>
<th>ROC MCID</th>
<th>AUC</th>
<th>SEM</th>
<th>MDC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appearance</td>
<td>0.98</td>
<td>0.63 (0.60–0.68)</td>
<td>0.21</td>
<td>0.47</td>
</tr>
<tr>
<td>Activity</td>
<td>0.08*</td>
<td>0.65 (0.60–0.69)</td>
<td>0.17</td>
<td>0.41</td>
</tr>
<tr>
<td>Pain</td>
<td>0.20</td>
<td>0.72 (0.70–0.77)</td>
<td>0.15</td>
<td>0.33</td>
</tr>
</tbody>
</table>

Standard error of measurement (SEM) and 90% minimum detectable change (MDC) of preoperative scores.

*ROC-determined MCID for the activity domain is smaller in value than both the SEM and MDC.

**PROMIS**

<table>
<thead>
<tr>
<th>PRO</th>
<th>Domain</th>
<th>MID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult PROMIS</td>
<td>Pain</td>
<td>3.5-5.5</td>
</tr>
<tr>
<td>Pediatric PROMIS</td>
<td>Pain</td>
<td>2.0-3.0</td>
</tr>
</tbody>
</table>
Future Directions

• Applying EOSQ-24 Scores to patients and not populations
  • Changing surgical decision making based on outcomes
• Continue studying quality of life outcomes for surgical techniques
• Optimizing time to intervene based on quality of life and radiographic parameters
Don’t be the Blind Man

“Bad QOL”

“Bad Lungs”

“Crooked Spine”
Thank You!

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