Criterion Validity, Test-Retest Reliability and Internal Consistency Reliability of the EOSQ-24

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Patient Reported Outcomes in EOS

Difficult to measure

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



Development and Validation of EOSQ-24

Literature Review

Existing Instruments

Expert Opinion

Semi-structured Interview Topic Items



Parent interviews



Master List of 75 Items

Content Validity

• Relativity and Clarity

Construct Validity

Item Statistics

EOSQ-24

EOSQ-24

Caregiver form with 24 items, 3 domains, 11 sub-domains Raw scores transformed to 0-100 scale scores

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

Purpose of Current Study

- **Phase 1: Development of the EOSQ (JPO 2011)**
- **Phase 2:** Initial Validation and Responsiveness
- Phase 3: Collection of Age-Based Normative Data
- Phase 4: Prospective Validation, Reliability:
 - Criterion Validity
 - Test-Retest Reliability
 - Internal Consistency Reliability

Methods

Criterion Validity



- 16 EOS patients identified from 2 multi-center databases who completed the following within 12 days:
 - **EOSQ-24**
 - Pulmonary Function Testing:
 - % Predicted Value of Forced Vital Capacity
 - % Predicted Value of Forced Expiratory Volume in 1 Second
- Pearson's correlation coefficient (r) calculated

Methods

Test-Retest Reliability

- 15 caregivers of EOS pts prospectively enrolled
 - Idiopathic (N=6)
 - Neuromuscular (N=3)
 - Syndromic (N=2)
 - Congenital (N=4)
- EOSQ-24 twice within 1 month (7-29 days)
- Intraclass correlation coefficients (ICCs)

Wilson et al. 2001

- ≤0.40 poor to fair agreement
- 0.41-0.60 moderate agreement
- 0.61-0.80 good agreement
- 0.81-1.00 excellent agreement

Methods

Internal Consistency Reliability

- To examine the extent to which sub-domains within Children's HRQoL, Family Burden and Satisfaction are related to each other
- Utilized results of 31 EOSQ-24 questionnaires included in criterion validity and test-retest reliability
- Cronbach's alpha coefficients calculated
 - >0.70 acceptable (Hays & Revicki 2005)

Criterion Validity: PFT and EOSQ-24

Days Between Tests: 3.6 ± 4.7 days

N = 16	% FEV1 Predicted	% FVC Predicted
EOSQ Domain	r value	r value
General Health	0.61*	0.70**
Pain/Discomfort	0.35	0.23
Pulmonary Function	0.63*	0.56*
Transfer	-0.24	-0.30
Physical Function	0.51	0.57*
Daily Living	0.44	0.33
Fatigue/Energy Level	0.61*	0.56*
Emotion	0.24	0.25
Parental Burden	0.47	0.37
Financial Burden	0.16	0.27
Child Satisfaction	0.29	0.08
Parental Satisfaction	0.22	-0.05
	* = p < .05, ** = p < 0.01	

Test-Retest Reliability: Good to Excellent ICCs

EOSQ Domain	ICCS
General Health	.84**
Pain/Discomfort	.85**
Pulmonary Function	.90**
Transfer	.84**
Physical Function	.97**
Daily Living	.98**
Fatigue/Energy Level	.92**
Emotion	.68*
Parental Burden	.80*
Financial Burden	.94**
Child Satisfaction	.93**
Parental Satisfaction	.89**
N = 15	$* = p < .05, ** = p \le 0.01$

Internal Consistency Reliability

EOSQ Domain N = 25	Internal Consistency (Cronbach's α)
Patient's HRQoL (8 sub-domains)	.92
Satisfaction (Child and Caregiver)	.87
Family Burden (Parental and Financial)	.64

> 0.70 Considered Acceptable

Discussion

• The EOSQ-24 possesses criterion validity

• The EOSQ-24 provides a reproducible measure of QoL

• Patient's HRQoL and Satisfaction domains include adequate sub-domains to measure the same respective characteristics

Discussion

Parental Burden and Financial Burden need to be separate domains

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

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

Discussions

This study adds to the growing body of evidence supporting validity of the EOSQ-24

- Development, Construct and Content Validities: JPO 2011, ICEOS 2011
- Responsiveness: ICEOS 2012, SRS 2012, ISOQoL 2013
- Aged matched Norms: ICEOS 2012, SRS 2012, ISOQoL 2013
- Translation and Validation Completed: Spanish (Dr. Farrington) and Turkish (Dr. Yazici)

Conclusions

The EOSQ-24 can serve as a <u>patient reported</u> <u>outcome measure</u> in EOS studies

- 4 Domains
 - Patient's HRQoL
 - Parental Burden
 - Financial Burden
 - Satisfaction
- Valid, Reproducible, Responsive



Thank You









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