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Reliability and Construct Validity of the Adapted Norwegian Version of the Early-Onset Scoliosis 24-item Questionnaire

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Abstract

Background: The Early-Onset Scoliosis 24-item Questionnaire (EOSQ-24) reflects issues important for patients with early-onset scoliosis (EOS) and their parents. The aim of this study was to translate the original EOSQ-24 into Norwegian and to evaluate the resulting questionnaire's reliability and construct validity.

Methods: The EOSQ-24 was translated using a forward-backward translation method, followed by an expert review. One hundred parents of a heterogenic group of patients with EOS answered the EOSQ-24 and scored Numeric Rating Scales (NRSs) to evaluate the children's general health, pain, and physical function. Two weeks later, 55 parents (55%) answered the retest questionnaire. Data quality, internal consistency, and test-retest reliability were assessed, including the minimal detectable change. Construct validity was evaluated by predefined hypotheses and correlations with NRS scores.

Results: There were considerable ceiling (19.0% to 63.0%) and floor effects (zero to 26.0%). The internal consistency was excellent (Cronbach $\alpha = 0.95$). The minimal detectable change for the EOSQ-24 total score was 15.2 and ranged from 21.6 to 33.0 for the subdomains scores. The EOSQ-24 showed discriminate capabilities among patients with different etiology, treatment status, and severity of deformity. High correlations were found between the EOSQ-24 total score and the NRS scores for general health ($r = -0.66$), pain ($r = -0.63$), and physical function ($r = -0.78$).

Conclusion: The Norwegian version of the EOSQ-24 has acceptable reliability and validity for measuring quality of life and caregiver burden among EOS children. The EOSQ-24 total score is acceptable for evaluation of these patients over time.

Level of Evidence: Level III, diagnostic study

Early-onset scoliosis (EOS) is defined as a spinal and/or thoracic deformity in children aged <10 years.¹

EOS is a heterogenic condition, often classified by etiology and severity of the deformity.² Congenital scoliosis is

caused by an early embryologic development failure of the vertebral column,³ whereas neuromuscular scoliosis is primarily due to neuromuscular abnormality.⁴ Syndromic scoliosis develops in association with a known syndrome.¹ Children with neuromuscular and syndromic scoliosis commonly have several medical comorbidities,¹ in contrast to children with idiopathic scoliosis.⁵ Comorbidity may influence outcome in all types of scoliosis.⁶ The deformity may inhibit heart and pulmonary development and function, which represents two of the most severe consequences of deformity.⁷⁻⁹ Available outcomes for evaluation of these patients range from the simple Barthel Index to the more complex Early-Onset Scoliosis 24-item Questionnaire (EOSQ-24).^{10,11}

The exact incidence of EOS is unknown. On the basis of national reference rates in Norway, approximately 70 patients with EOS are diagnosed among the country's 60,000 annual births. The deformity may require extensive treatment to avoid serious consequences, including shortened life expectancy.¹² Nonsurgical treatment is used to improve quality of life (QOL) and may influence the natural development of the deformity. For a small fraction, multiple complex surgeries from early childhood until maturity are considered crucial. The primary goals are to control the deformity, maximize spinal growth, and allow for thoracic cage and lung development.¹ Because both the disease and its long-lasting treatments may have an adverse effect on the children and their relatives, the overall goal is to improve their QOL.

The measurement of QOL in patients with EOS is challenging because of their young age, comorbidities, and

the heterogeneity of the population. Therefore, the EOSQ was developed to reflect issues important for these patients and their relatives.¹¹ The final 24-item version questionnaire is reported to be reliable, valid, and responsive.¹³ It has been translated and cross-culturally adapted into several languages, including Turkish, Spanish, and Chinese.¹⁴⁻¹⁶

The objective of the present study was to translate the EOSQ-24 into Norwegian and to test the reliability and construct validity of this Norwegian version.

Methods

Patients and Study Design

Patients were recruited from Oslo University Hospital from March 2016 to September 2016. Patients and parents who did not understand Norwegian were excluded. Written consent forms were obtained from the parents.

Parents completed the EOSQ-24 questionnaire twice within a 2-week period. The Regional Committee for Medical and Health Research Ethics of Eastern Norway approved this study.

The Translation Process

The English version of the EOSQ-24 was translated into Norwegian by a qualified, independent, and bilingual translator whose native language was Norwegian. Health professionals reviewed the Norwegian version before it was retranslated back to English by another translator whose native language was English. These two translators collaborated with a multidisciplinary group to further compare the

reports and reach a consensus on the final version.¹⁷

Questionnaires

The EOSQ-24 is a parent-based questionnaire that evaluates the QOL, burden, and satisfaction within the previous 4 weeks. It includes 24 items that cover 11 subdomains: general health, pain, pulmonary function, transfer, physical function, daily living, fatigue, emotion, parental burden, financial burden, and satisfaction. Each item has five possible response categories, ranging from one (poor) to five (excellent). Subdomain scores are calculated as follows: $(\text{The algebraic means of the item scores within each subdomain} - 1) / 4 \times 100$. The average of these 11 subdomain scores is called the total score. The subdomain scores and the total score range from zero (poor) to 100 (excellent).

For validity purposes, numeric rating scales (NRSs) (zero to 10) were used to rate the child's general health, pain, and physical function within the previous 4 weeks.¹⁸

Statistical Analysis

Mean values, SDs, medians, interquartile ranges, and frequencies were calculated for items and subdomains. Ceiling and floor effects of items were analyzed by calculating the frequency of the minimum and maximum scores.

Internal consistency estimates the degree of interrelatedness among the items, assuming that all items in the scale are part of one underlying construct.¹⁹ Cronbach coefficient $\alpha > 0.70$ was considered an acceptable correlation between items.²⁰ Cronbach α for each subdomain assessed the correlation between items within each subdomain separately.

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The discrimination characteristic of each item was examined by a corrected item–total correlation analysis, which estimates how each item is related to other items in the scale. Values >0.3 were considered an acceptable distinction ability.²¹

Single imputation by the mean outcomes of the item responses was used to achieve complete data for the test-retest analysis. Within-subject and total variation in test-retest scores were examined by calculating the intraclass correlation coefficient of agreement ($ICC_{\text{agreement}}$).^{22,23} An estimate of $ICC < 0.7$ was considered to reflect large within-subject variability.²⁰

A Bland-Altman plot was constructed to visualize agreement between the test and retest scores and the limits of agreement.²⁴ Test and retest scores were checked for significant differences using either the paired Student *t*-test (parametric) or the Wilcoxon signed-rank test (nonparametric) to allow for agreement statistics.²⁵

The standard error of the mean ($SEM_{\text{agreement}}$) was estimated by the square root of the total error variance from variance components estimation.²⁶ Minimal detectable change within individuals ($MDC_{\text{individual}}$) was calculated by $SEM_{\text{agreement}} \times 1.96 \times \sqrt{2}$. The MDC_{group} was calculated by dividing $MDC_{\text{individual}}$ by the square root of the sample size.^{20,22,23}

Convergent and discriminant construct validity evaluates the ability to detect correspondences and differences between subgroups of patients and clinical characteristics. On the basis of a structured literature review and the international classification system of EOS,² we formulated eight hypotheses (Table 1). Ideally, 75% of our hypotheses should be confirmed.²⁰ Nonparametric Kruskal-Wallis (three or more groups) or Mann-Whitney *U* test (two groups) was used to compare groups.²⁵ The Spearman rank correlation coefficient assessed the correlation between the NRS scores and the

Table 1**A Priori Hypotheses for the Convergent and Discriminant Construct Validity of the EOSQ-24**

A Priori Hypotheses ^a	Confirmed (+)
1. The total score will decrease with increasing deformity from major curve angle group 1 ($<20^\circ$) to major curve angle group 4 ($>90^\circ$).	+
2. Patients with the most complex etiologies (ie, neuromuscular or syndromic) will report a significantly lower total score than those with other EOS etiologies (ie, idiopathic or congenital).	+
3. Patients treated with long-lasting surgery will report a significantly lower total score than those with conservative treatments.	+
4. No significant differences in the total score will be observed between sexes.	+
5. A correlation < -0.6 will be found between the subdomain score for general health and NRS general health score.	+
6. A correlation < -0.6 will be found between the subdomain score for pain and NRS pain score.	+
7. A correlation < -0.6 will be found between the subdomain score for physical function and NRS function score.	+
8. A correlation < -0.6 will be found between the EOSQ-24 total score and each of the three NRS scores.	+
Hypotheses confirmed (%)	8/8 (100)

EOS = early-onset scoliosis, EOSQ-24 = Early-Onset Scoliosis 24-item Questionnaire, NRS = Numeric Rating Scale

^a Values of $P < 0.05$ were considered to be statistically significant.

Table 2**Demographic Characteristics of the Participants (n = 100)**

Factor	Value
Treatment status, n (%)	
Surgery graduated	11 (11.0)
Bracing	19 (19.0)
Observation	40 (40.0)
Growing instrumentarium	30 (30.0)
Female, n (%)	70 (70.0)
Age (yr), mean (range)	8.9 (1.8-17.5)
Etiology, n (%)	
Congenital	27 (27.0)
Neuromuscular	33 (33.0)
Syndromic	20 (20.0)
Idiopathic	20 (20.0)
Major curve angle, n (%)	
1 ($<20^\circ$)	18 (18.0)
2 (20° - 50°)	49 (49.0)
3 (51° - 90°)	27 (27.0)
4 ($>90^\circ$)	5 (5.0)

EOSQ-24.²⁷ Values of $r > -0.3$, -0.3 to -0.6 , and < -0.6 were considered low, moderate, and high cor-

relations, respectively.²⁸ Values of $P < 0.05$ were considered statistically significant.

Statistical analyses were performed using IBM Statistical Package for the Social Sciences software

Table 3
Data Quality and Internal Consistency Analysis of the EOSQ-24 (n = 100)

Subdomains (items)	N	Mean (SD)	Median (IQR)	Floor (%)	Ceiling (%)	Corrected Item-Total Correlation	Cronbach α for Each Subdomain	Cronbach α if Item Deleted
Total score	96	67.8 (21.2)	72.3 (27.6)	—	—	—	—	—
General health	100	66.6 (23.4)	75.0 (37.5)	—	—	—	0.78	0.95 ^a
Q1	100	3.6 (1.2)	4.0 (2.0)	6	27	0.63	—	0.95
Q2	100	3.7 (0.9)	4.0 (1.0)	1	19	0.51	—	0.95
Pain	99	68.6 (21.2)	75.0 (37.5)	—	—	—	0.88	0.95 ^a
Q3	100	3.9 (1.0)	4.0 (1.0)	1	20	0.64	—	0.95
Q4	99	3.9 (0.8)	4.0 (2.0)	0	25	0.62	—	0.95
Pulmonary function	100	72.4 (26.0)	75.0 (34.4)	—	—	—	0.65	0.95 ^a
Q5	100	4.3 (1.2)	5.0 (1.0)	6	63	0.63	—	0.95
Q6	100	3.5 (1.2)	4.0 (2.0)	8	28	0.38	—	0.96
Mobility	99	71.7 (21.0)	75.0 (50.0)	—	—	—	—	—
Q7	99	3.7 (1.4)	4.0 (2.0)	11	45	0.67	—	0.95
Physical function	99	67.2 (33.7)	75.0 (66.7)	—	—	—	0.87	0.95 ^a
Q8	100	3.7 (1.4)	4.0 (2.0)	12	45	0.71	—	0.95
Q9	99	3.8 (1.5)	5.0 (2.0)	17	50	0.68	—	0.95
Q10	99	3.6 (1.5)	4.0 (3.0)	18	40	0.70	—	0.95
Daily living	99	53.8 (34.7)	50.0 (62.5)	—	—	—	0.70	0.95 ^a
Q11	99	3.2 (1.5)	3.0 (3.0)	22	30	0.64	—	0.95
Q12	99	3.1 (1.6)	3.0 (4.0)	26	30	0.70	—	0.95
Fatigue	100	65.0 (26.5)	75.0 (46.9)	—	—	—	0.79	0.95 ^a
Q13	100	3.7 (1.0)	4.0 (2.0)	1	30	0.67	—	0.95
Q14	100	3.4 (1.3)	4.0 (2.5)	12	24	0.81	—	0.95
Emotion	97	70.0 (29.1)	75.0 (50.0)	—	—	—	0.79	0.95 ^a
Q15	98	4.0 (1.1)	4.0 (2.0)	5	44	0.60	—	0.95
Q16	97	3.6 (1.4)	4.0 (2.0)	15	37	0.76	—	0.95
Parental burden	99	68.5 (23.9)	70.0 (39.0)	—	—	—	0.86	0.94 ^a
Q17	100	3.7 (1.0)	4.0 (2.0)	1	34	0.62	—	0.95
Q18	100	3.8 (1.3)	4.0 (2.0)	4	43	0.73	—	0.95
Q19	100	3.3 (1.4)	3.0 (3.0)	15	27	0.83	—	0.95
Q20	100	3.6 (1.2)	3.0 (2.0)	5	32	0.75	—	0.95
Q21	99	4.1 (1.1)	4.0 (1.0)	3	48	0.62	—	0.95
Financial burden	100	76.2 (31.7)	100.0 (25.0)	—	—	—	—	—
Q22	100	4.0 (1.3)	5.0 (1.0)	9	51	0.68	—	0.95
Satisfaction	98	63.9 (28.4)	62.5 (37.5)	—	—	—	0.88	0.95 ^a
Q23	98	3.5 (1.2)	3.0 (2.0)	6	26	0.77	—	0.95
Q24	99	3.6 (1.2)	4.0 (2.0)	7	32	0.80	—	0.95
	—	—	—	—	—	α	—	0.95 ^b

EOSQ-24 = Early-Onset Scoliosis 24-item Questionnaire, IQR = interquartile range, Q = question

^a Alpha coefficient if subdomain deleted

^b Alpha coefficient for the total EOSQ scales

Bold type indicates the distinction between numbers answered and mean score of subdomain scores and item scores.

Table 4

Intraclass Correlation Coefficient of Agreement, Mean Differences, Standard Error of the Mean Agreement, and Minimal Detectable Change Between the Test and Retest (n = 55)

Factor	ICC ^a (95% CI)	Mean Difference (SD)	SEM ^b	MDC _{ind} ^c	MDC _{group} ^d
Total score	0.93 (0.89-0.96)	-1.17 (7.82)	5.48	15.19	2.05
Subdomains					
General health	0.84 (0.73-0.90)	-0.91 (14.0)	9.84	27.28	3.68
Pain	0.88 (0.81-0.93)	-0.23 (11.15)	7.79	21.59	2.91
Pulmonary function	0.86 (0.77-0.91)	-0.45 (13.81)	9.77	27.08	3.65
Mobility	0.76 (0.62-0.85)	-1.82 (15.85)	11.01	30.52	4.12
Physical function	0.90 (0.83-0.94)	-3.09 (15.04)	10.89	30.19	4.07
Daily living	0.93 (0.88-0.96)	-1.59 (12.97)	9.24	25.61	3.45
Fatigue	0.82 (0.71-0.89)	-0.23 (16.40)	11.60	32.15	4.34
Emotion	0.84 (0.73-0.90)	0.91 (16.81)	11.90	32.98	4.45
Parental burden	0.88 (0.81-0.93)	-0.91 (11.39)	8.02	22.23	3.00
Financial burden	0.82 (0.71-0.89)	-3.64 (18.89)	11.53	31.96	4.31
Satisfaction	0.86 (0.77-0.92)	0.45 (13.39)	9.47	26.25	3.53

CI = confidence interval, ICC = intraclass correlation coefficient, ind = individual, MDC = minimal detectable change, SEM = standard error of the mean

^a ICC_{agreement}: two-way random effects model (absolute agreement).

^b SEM_{agreement}: $\sqrt{\text{within people residual mean square}}$.

^c MDC_{ind} = SEM \times 1.96 \times $\sqrt{2}$.

^d MDC_{group} = MDC_{ind}/ \sqrt{n} .

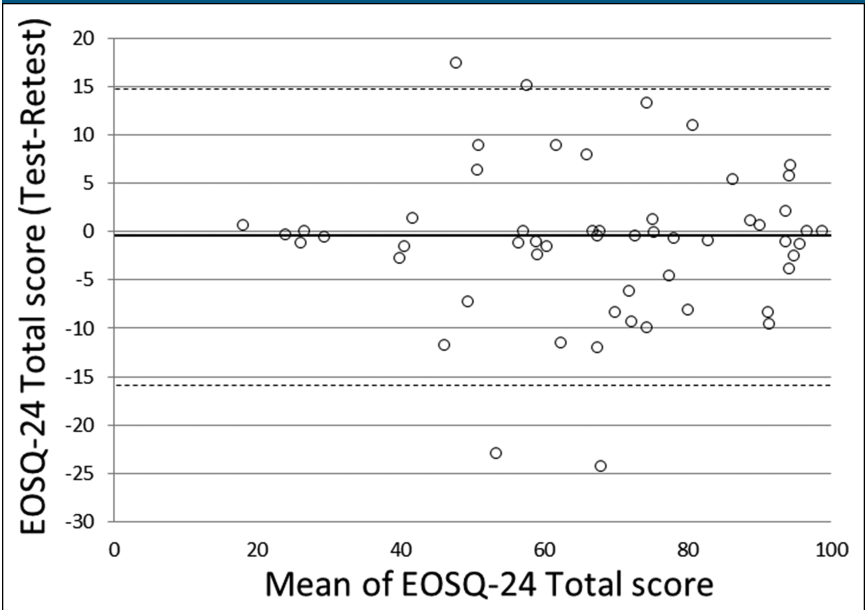
(Statistical Package for the Social Sciences 23.0).

Results

The parents of 112 patients with EOS were invited to participate. Nine parents declined, and three were excluded because of insufficient language skills. One hundred parents completed the first questionnaire, and 55 of them also answered the second retest questionnaire (55%). No differences in demographic characteristics were observed between the children of parents who did not complete the retest and the children of parents who completed both ($P < 0.05$). The patients' characteristics are shown in Table 2.

The proportion of missing answers was small (zero to 3%). All items included the whole range of possible answers (one to five). The answers were left skewed in favor of a healthier status for 19 items, with three questions (Q) (ie, Q5, Q9, and

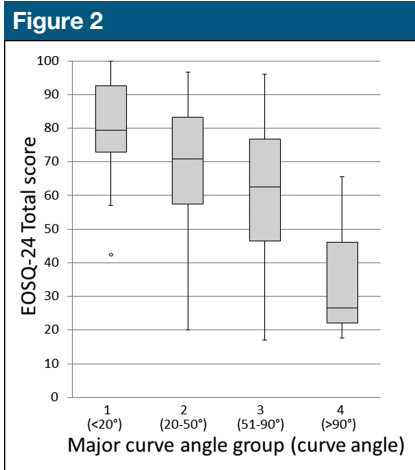
Figure 1



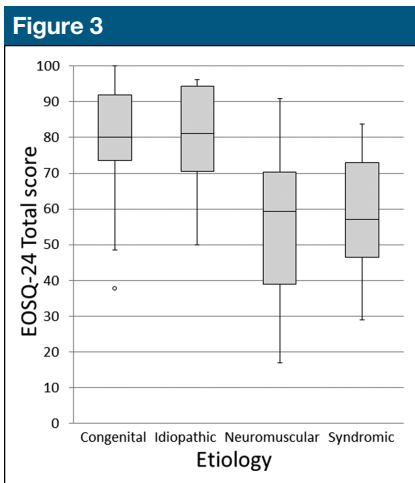
Bland-Altman plot illustrating the mean of the Early-Onset Scoliosis 24-item Questionnaire (EOSQ-24) total score versus differences between the test and retest EOSQ-24 total scores.

Q22) showing a median score of 5. Five items (ie, Q11, Q12, Q19, Q20, and Q23) had a median score of 3.

The ceiling effect ranged from 19% to 63%. Six items also had a floor effect $\geq 15\%$ (Table 3).

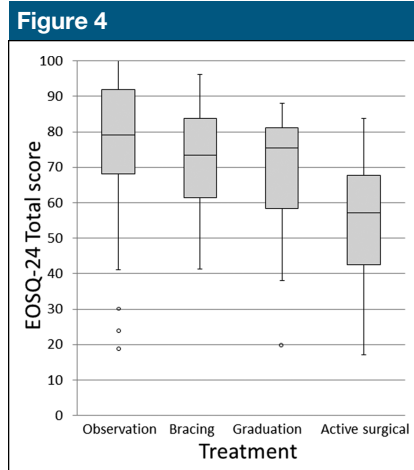


Box plot illustrating the Early-Onset Scoliosis 24-item Questionnaire (EOSQ-24) total score categorized by the major curve angle group.



Box plot illustrating the Early-Onset Scoliosis 24-item Questionnaire (EOSQ-24) total score categorized by etiology.

Cronbach α for the 24-item scale was 0.95, indicating excellent internal consistency (Table 3). Cronbach α for items within each subdomain was >0.70 in all subdomains except pulmonary function ($\alpha = 0.65$). Cronbach α for the total score was slightly higher when item 6 was deleted ($\alpha = 0.96$). The corrected item-total correlation was acceptable but varied largely (0.38 to 0.83), with item 6 showing the



Box plot illustrating the Early-Onset Scoliosis 24-item Questionnaire (EOSQ-24) total score categorized by treatments: observation (patients under active observation), bracing (patients under bracing), graduation (patients with final fusion), and active surgical (patients under non-fusion treatment).

weakest relation to the other items ($\alpha = 0.38$).

The difference between the test and retest scores ranged from -3.64 to -0.45 ($P \geq 0.14$) (Table 4). The intraindividual differences between the test and retest EOSQ-24 total scores are illustrated by a Bland-Altman plot (Figure 1).

The strength of the relationship between the test and retest scores was good, with $ICC_{\text{agreement}} \geq 0.76$. The SEM for the EOSQ-24 total score was 5.5 and ranged from 8.0 to 11.9 for the subdomain scores. The total score showed an MDC of 15.2 at the individual level and 2.1 at the group level. For subdomain scores, MDC ranged from 21.6 to 33.0 at the individual level and from 2.9 to 4.5 at the group level (Table 4).

All our a priori hypotheses were confirmed (Table 1). The EOSQ-24 total score was significantly lower as deformity increased ($P = 0.006$) (Figure 2). Neuromuscular and syndromic scoliosis represented 66.6% of patients in major curve angle

group 3 (51° to 90°) and all patients in group 4 ($>90^\circ$). The total score decreased with increasing etiology complexity, whereby patients with neuromuscular or syndromic scoliosis had a significantly lower score than those with idiopathic or congenital scoliosis ($P < 0.001$) (Figure 3). Children who were in an active surgical treatment period had a significantly lower total score than children who were conservatively treated ($P < 0.001$) (Figure 4). Most of these children had neuromuscular or syndromic scoliosis (77%). No sex differences were observed.

High correlations were found between the EOSQ-24 total score and NRS general health ($r = -0.66$), NRS pain ($r = -0.63$), and NRS physical function ($r = -0.78$) ($P < 0.001$). The subdomain scores of general health, pain, and physical function were strongly correlated with their corresponding NRS scores ($r = -0.78$, $r = -0.78$, $r = -0.70$; $P < 0.001$).

Conclusion

The Norwegian version of the EOSQ-24 showed an acceptable measurement ability to detect clinically relevant changes in patient QOL and caregiver burden over time.

Corresponding to previous research, the Norwegian version demonstrated excellent internal consistency.¹³⁻¹⁶ The interrelatedness among items was even higher when item 6, examining shortness of breath during physical activity, was deleted. The same item had also low distinction ability ($\alpha = 0.38$). In Norwegian, “shortness of breath” can mean a positive, desired aim to achieve during exercise or a negative experience of breathing discomfort during normal activity. Accordingly, this result may reflect the differing interpretations. The expert panel could not find any Norwegian translation that avoided this result,

and we therefore suggest that the weakness of item 6 may be explained by a language-specific challenge. It also demonstrates the importance of thorough work in the translation process to avoid these issues. A pilot study among qualified parents would be helpful to test whether the message is clearly understood.

Floor and ceiling effects <15% were considered to be acceptable.²⁰ The responses showed high levels of floor and especially ceiling effects, which might reduce the capability to detect extreme scores, with potentially less usefulness in follow-up examinations. These trends seem to be a general issue with the EOSQ-24, as also other studies have experience similar results reporting floor effects ranging from zero to 30% and ceiling effects from 19% to 74%.¹⁴⁻¹⁶ The high percent of patients with moderate deformity ($\leq 50^\circ$) and under observation only might explain some of these trends. Similarly, our population consisted of 53% of patients with neuromuscular or syndromic scoliosis. These patients have previous shown significantly lower scores in subdomains who currently exhibited floor effects.¹³ The potential challenge in follow-up examinations was further illuminated by the reliability analysis. Reliability is a useful parameter for discriminative purposes, whereas agreement is useful for follow-up examinations.^{23,24} The ICC_{agreement} analysis showed good-to-excellent test-retest reliability between subjects, in agreement with a previous study.¹³ The MDC total (15.2) and subdomain (21.6 to 33.0) scores were slightly higher than the results from corresponding patient-reported outcome measurements for adolescent idiopathic scoliosis and chronic low back pain.^{29,30} This result indicates that the measurement error is considerable, particularly for the subdomain scores.

The EOSQ-24 total score decreased with increasing deformity and etiol-

ogy complexity, as previously reported.^{13,15,16} It discriminated between patients in an active surgical treatment period and those in a conservative treatment period. The use of growing rod instrumentation requires repetitive surgeries, with risk of complications.³¹ Earlier studies have suggested that repetitive surgeries have a significant effect on psychosocial function.^{32,33} On the contrary, Vitale et al³⁴ reported psychosocial scores in the normal range but lower QOL and higher caregiver burden among EOS children with thoracic outlet syndrome undergoing repetitive surgeries. From preoperative to after surgery, the scores did not change. Recent study examined the effect on QOL by comparing traditional, repetitive surgeries to new surgical devices with magnetically controlled growing rods.³⁵ When controlling for follow-up, the authors found no significant differences and felt that many EOSQ-24 outcomes were primarily affected by the underlying condition. Thus, our observation of lower scores in patients undergoing an active surgical treatment period may reflect a more serious underlying condition more than the effect of surgery itself. Therefore, the results should be carefully interpreted, especially in light of the underlying etiology.

The present study's sample of 100 EOS participants represented a varied range of ages, deformities, etiologies, and treatment modalities. We included ≥ 50 patients recommended for test-retest evaluation,²⁰ but the results might be biased because of the low response rate from the total sample. This finding also suggests that it is critical to establish good routines to increase the response rate in daily clinical practice and in future studies.

The NRSs have not been previously validated in this patient group, and our results thus add to the knowledge of QOL in patients with EOS. Norway

has a public healthcare system, whereby financial burden is less applicable than in other countries without a public healthcare system. Therefore, item 22 reflects other financial burdens than the same item would in countries with a private or insurance-based healthcare system. One independent bilingual translator performed the translation process at each step, in contrast to the recommendation for two translators. With this exception, the process was performed as recommended; thus, we consider the translation process and the cultural adaptation valid.

The adapted Norwegian version of the EOSQ-24 has acceptable reliability and validity for measuring QOL and caregiver burden among EOS children. It exhibits excellent discriminative characteristics and usefulness in distinguishing between patients with different etiology, severity of deformity, and treatment status. High correlations were found between the EOSQ-24 total score and corresponding NRS ratings of general health, pain, and physical function, and the predefined hypotheses were confirmed, indicating good construct validity. Our results suggest that the EOSQ-24 total score is useful for evaluating patients over time, whereas the clinical application of subdomain scores in follow-up evaluations is questionable.

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