Transition of Caregiver Perceptions after Pediatric Neuromuscular Scoliosis Surgery

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Abstract:

Introduction: Spinal fusion for children with neuromuscular scoliosis has been known to improve sitting balance and quality of life as well as for high caregiver satisfaction. However, most studies performed were single surveys, and it remains unclear whether high satisfaction levels are maintained. Thus, in this article, we report the short- and medium-term improvements in caregiver standing assessment after neuromuscular scoliosis surgery in children with Gross Motor Function Classification System (GMFCS) level IV or V.

Methods: In total, 18 patients with GMFCS levels IV and V were included in this study. The underlying diseases were typical cerebral palsy in 12 cases, chromosomal abnormalities in 5 cases, and congenital myopathy in 1 case. The median age at the time of surgery was 14.5 years. The medians for the first and second follow-up surveys were after 1.4 and 5.9 years, respectively. All the patients had undergone posterior spinal fusion, whereas 12 had undergone pelvic fixation. These patients were assessed using a caregiver questionnaire, in addition to patient demographic data and radiographic assessments.

Results: The median BMI was 15.4 kg/m² preoperatively, 16.6 kg/m² at the first survey, and 17.1 kg/m² at the second survey. The main Cobb angles were 97.5°, 36.5°, and 37.0° and the spino-pelvic obliquity angles were 22.5°, 6.0°, and 6.5° preoperatively, at the first survey and at the second survey, respectively. In the questionnaire, most domains were rated similarly in the first and second surveys, but the ratings for the "children's QOL" and "digestion and defecation" domains were noted to increase, while that for the "transfer" and "satisfaction with treatment" domains have decreased.

Conclusions: Neuromuscular scoliosis surgery in children has been associated with extremely high treatment satisfaction in the early postoperative period. However, some caregivers showed a decline in the "transfer" and "treatment satisfaction" domains over time.

Keywords:

Neuromuscular scoliosis, cerebral palsy, congenital myopathy, scoliosis surgery, health-related quality of life, treatment satisfaction, questionnaire

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Introduction

We have previously investigated the outcomes of pediatric neuromuscular scoliosis surgery and reported a high level of caregiver satisfaction¹⁾. Although there are many similar reports globally²⁻⁴⁾ and the efficacy of surgical treatment has been established, most studies have evaluated the results in a single postoperative survey, and few have assessed the changes in the results over a time period. It will be interesting for surgeons to assess if high level of treatment satisfaction is maintained over a period after surgery. Thus, in this study, we aimed to determine the short- and medium-term improvements in caregiver standing assessment after scoliosis surgery in children with neuromuscular scoliosis with Gross Motor Function Classification System (GMFCS) level IV or V. GMFCS is a standardized system that classifies gross motor function in children with cerebral palsy into five levels, with level I being the mildest and IV and V being the non-ambulatory levels. We have also examined the impact of surgery-related complications on short- and mid-

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term postoperative caregiver ratings.

Materials and Methods

This study was conducted with the approval of the Ethics Committee of our hospital (approval number; 2102-5).

We previously evaluated the outcomes of spinal fusion surgery in children with neuromuscular scoliosis and caregiver satisfaction¹⁾. This study is a clinical evaluation of the participant of the previous research subject over time.

We included children with neuromuscular scoliosis who underwent spinal fusion surgery at our institution between April 2012 and November 2015. Additional inclusion criteria were as follows: (1) non-ambulatory children (GMFCS level IV or V), (2) children less than 20 years of age at the time of surgery, and (3) children who were followed up for at least 4 years after surgery.

The surgery was performed by a single surgeon.

We performed regular clinical and imaging evaluations. The median number of years for the first postoperative follow-up survey was 1.4 years (0.6-3.6), while that for the second survey was 5.9 years (4.8-8.2). Postoperative complications and length of hospital stay were also assessed.

Questionnaire assessment for caregivers

We performed a health-related assessment of the affected child and assessed their caregivers' satisfaction with surgical treatment using a specially designed questionnaire for caregivers of children with neuromuscular spinal deformities. The questionnaire was a modified evaluation method (ordinal variable)¹⁰ of Bridwell's questionnaire⁵⁰, with a 0-10 visual analog scale (VAS) and several additional questions. Typical questionnaire domains include sitting balance, digestion and defecation, sleep, transfer, perineal care, dressing, QOL of the child, respiratory, sociality, and satisfaction with treatment, which are similar to other questionnaires used in evaluating the treatment of children with neuromuscular diseases. A unique feature of this questionnaire is the use of VAS.

Perioperative complications

Complications such as general medical, dysphagia, gastrointestinal, respiratory, neurological, hip pain, and surgical site infection that have developed within 4 weeks postoperatively were investigated.

Additional outcome measures

General demographic data, including their underlying condition as detailed in the patient charts and the current hip status (i.e., normal, subluxated, dislocated, or postoperative), were collected for all patients. Radiographic data included the anteroposterior main Cobb angle, spino-pelvic obliquity (SPO), thoracic kyphosis angle from T5 to T12, and lumbar lordosis from T12 to S1.

Comparisons of the preoperative data, the first survey data, and the second survey data were performed using Friedman test. The comparison between the occurrence of perioperative complications and patient demographic data was analyzed using Mann-Whitney U test. The correlation between complications and each domain score of the second survey was analyzed using Spearman's rank correlation coefficient.

Statistical significance was set at P<0.05. All statistical analyses were performed using EZR (Saitama Medical Center, Jichi Medical University, Saitama, Japan)⁶, which is a graphical user interface for R (The R Foundation for Statistical Computing, Vienna, Austria). More precisely, it is a modified version of R commander designed to include statistical functions frequently used in biostatistics.

Results

In total, 19 patients were included in this study, of whom 1 died (sudden death at night). None of the patients were lost to follow-up; therefore, complete follow-up data was obtained for 18 patients (girls, 11; males, 7) in this study. The median age at the time of surgery was 14.5 years (11.6-19.4); 2 patients were classified as GMFCS level IV and 16 as GMFCS level V. The underlying disease was cerebral palsy in 17 patients (12 with typical cerebral palsy and 5 with chromosomal abnormalities) and muscle disease (congenital myopathy) in 1 patient. Moreover, 15 patients had moderate to severe global developmental delay, and 13 patients were nonverbal. Two patients had undergone gastrostomy, and 14 patients had epilepsy.

The median Cobb angle at surgery was $97.5^{\circ}(70^{\circ}-125^{\circ})$, and the median SPO was 22.5° (0°-51°).

All the patients had undergone single-stage posterior fusion, of whom 12 had undergone pelvic fixation. The upper instrumented vertebra was T2 in five patients, T3 in ten patients, and T4 in three patients.

After surgery, the patients' BMI were noted to have improved steadily (p<0.001).

There was significant improvement in coronal deformity at the first survey after the surgery from a median of 97.5° to 36.5° , which was maintained at the second survey (p< 0.001). SPO decreased to a median of 6.0° at the first survey and remained stable in the second survey, following surgery (p=0.005). However, in this cohort, there was no significant difference in T5-T12 kyphosis and L1S1 lordosis from the preoperative to the second survey (Table 1).

Analysis of caregivers' questionnaire scores showed a significant beneficial effect of surgery on sitting balance (p< 0.001), digestion and defecation (p<0.001), and QOL (p= 0.003). Transfer domain scores showed improvement from the preoperative to the first survey but decreased at the second survey (p=0.025). Scores for the sleep (p=0.184), perineal care (p=0.931), dressing (p=0.069), respiratory (p=

	Preope.	First survey	Second survey	P value
Age at surgery (year)	14.5 (11.6–19.4)			
Postoperative follow-up (year)		1.4 (0.6–3.6)	5.9 (4.8-8.2)	
Sex (F/M)	11/7			
BMI (kg/m ²)	15.4 (10.8–21.8)	16.6 (11.8–22)	17.1 (11.8–27.0)	< 0.001*
GMFCS level (IV/V)	2/16			
Comorbidities (cases)				
Developmental delay	15			
Nonverbal	13			
Epilepsy	14			
Gastrostomy	2			
Hip status (cases)				
Normal	12	12	12	
Subluxated	1	2	2	
Dislocated	3	2	2	
Postop. Hip	2	2	2	
Coronal Cobb angle (deg)	97.5 (70-125)	36.5 (22-66)	37.0 (26-63)	< 0.001*
T5-12 kyphosis (deg)	15 (-20-78)	25.5 (9-52)	26.0 (11-60)	0.593
L1-S1 lordosis (deg)	36.5 (-22-89)	38.0 (23-69)	30.5 (12-59)	0.696
Spino-pelvic obliquity (deg)	22.5 (0-51)	6.0 (0-12)	6.5 (1–13)	0.005*

Table 1.	Demographic D	ata and Radiographic	Measurements.

* P-values from Friedman test for variables.

Data are presented as the median and minimum-maximum.

	Preope.	First survey	Second survey	P-value
Sitting balance	1.8 (0–10)	9.4 (5.6–10)	9.3 (3.6–10)	< 0.001*
Digestion and defecation	2.0 (1-5)	5.0 (3.6-10)	8.0 (1.5-9.8)	< 0.001*
Sleep	7.5 (0.5–10)	8.4 (3.4–10.0)	7.6 (2–10)	0.184
Transfer	5.0 (1-10)	5.8 (4.2–10)	2.7 (0-9.5)	0.025*
Perineal care	5.0 (0-10)	5.0 (0-10)	6.6 (0-10)	0.931
Dressing	3.3 (0-10)	5.0 (0-10)	5.0 (0.8–9.1)	0.069
QOL	5.0 (1.4-10)	5.5 (2.1-10)	8.8 (1.7–10)	0.003*
Respiratory	8.3 (0-10)	8.7 (0.4–10)	9.1 (3.6–10)	0.367
Social	10.0 (4.6–10)	10.0 (4.6–10.0)	9.3 (1.7–10)	0.336
Satisfaction with surgical treatment		10.0 (5.8-10.0)	8.9 (5-10)	0.045*

Table	2.	Questionnaire Results for Caregivers.	
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* P-values from Friedman test.

Data are presented as the median and minimum-maximum.

0.367), and social (p=0.336) domains were not significantly different after surgery. Caregivers' satisfaction with surgical treatment decreased in the second survey compared to that in the first survey (p=0.045) (Table 2).

No consistent changes were observed for the sleep, perineal care, dressing, respiratory, and social domains (Table 3).

No significant correlation was also noted between residual spine deformity, quality of life score, and caregiver treatment satisfaction score at the time of the second survey (p=0.123-0.850).

There were 18 perioperative complications that occurred in 10 patients. One complication occurred in six patients, two in one patient, three in two patients, and four in one patient. Four patients had dysphagia, three had paralytic ileus, and one had temporary hip pain, aspiration pneumonia, urinary tract infection, superior mesenteric artery syndrome, and hepatic dysfunction to acetaminophen. In this cohort, there could be a possible effect of lumbar hyperlordosis and low body weight on the occurrence of complications (Table 4).

There was no correlation between the occurrence or number of complications and questionnaire scores in this cohort (Table 5).

There were no cases of SSI or reoperation in this cohort. All the patients recovered with symptomatic treatment for complications, and the median duration of hospitalization was 4.6 weeks (3.4-8.7). There was no significant correlation between complications and length of hospital stay (p= 0.106).

Table 3.	Two-point	Comparison	in Caregivers'	Questionnaire.

	Preop. to first survey	First survey to second survey	Preop. to second survey
Sitting balance	0.001*	0.248	0.001*
Digestion and defecation	< 0.001*	0.222	< 0.001*
Sleep	0.16	0.63	1
Transfer	0.128	0.005*	0.888
Perineal care	1	1	1
Dressing	0.38	1	0.3
QOL	0.226	0.278	0.003*
Respiratory	0.16	1	0.32
Social	1	1	1
Satisfaction with surgical treatment		0.045*	

* Pairwise comparisons using Wilcoxon signed rank test with Bonferroni correction-adjusted significance at p<0.0167.

Presence of con	nplication	No	Yes	P-value
n		8	10	
Hip_dislocation (%)	Dislocation	0 (0.0)	3 (30.0)	0.299
	Norm	6 (75.0)	6 (60.0)	
	Postope	1 (12.5)	1 (10.0)	
	Sublux	1 (12.5)	0 (0.0)	
PelvicFix (%)	No	3 (37.5)	3 (30.0)	1
	Yes	5 (62.5)	7 (70.0)	
Sex (%)	Boy	4 (50.0)	3 (30.0)	0.63
	Girl	4 (50.0)	7 (70.0)	
Age		14.10 [13.70, 15.28]	14.80 [13.93, 15.55]	0.534
BMI		16.90 [15.80, 18.15]	14.30 [14.03, 15.60]	0.197
EBL		3154.50 [2137.50, 4536.00]	4218.50 [2424.25, 6490.00]	0.534
Fusion levels		15.00 [12.75, 16.00]	16.00 [14.25, 16.00]	0.462
HT		144.35 [136.47, 147.62]	138.65 [128.75, 144.75]	0.131
OpeTime		606.00 [552.50, 634.75]	623.50 [541.50, 639.00]	1
PreCobb		90.50 [82.75, 97.50]	109.00 [90.00, 119.25]	0.155
PreL1S1		14.00 [0.50, 25.50]	66.50 [50.75, 78.25]	0.002*
PreSPO		25.00 [10.25, 41.50]	20.00 [6.75, 31.75]	0.594
PreT5T12		14.00 [-6.00, 16.75]	27.50 [3.50, 55.75]	0.131
WT		34.95 [29.77, 39.72]	25.15 [23.27, 30.15]	0.033*

* P-values from Mann-Whitney U test

Table 5. Correlation of Complications with Caregivers' Questionnaire Score (First Survey).

		Sitting	Digestion and defecation	Sleep	Transfer	Perineal care	Dressing	QOL	Respi- ratory	Social	Satisfaction with surgical treatment
Presence of complications	rho	-0.119	0.000	-0.195	-0.076	-0.151	-0.248	-0.022	-0.044	0.196	0.000
	p-value	0.638	0.500	0.438	0.766	0.550	0.321	0.932	0.864	0.436	1.000
No. of complications	rho	0.028	0.002	-0.145	-0.044	-0.032	-0.227	0.009	-0.053	0.218	0.067
	p-value	0.913	0.993	0.567	0.862	0.900	0.365	0.970	0.833	0.384	0.793

QOL, quality of life

Discussion

Spinal deformities associated with pediatric neuromuscular diseases are severe and progressive. Since the progression of spinal deformity cannot be controlled by brace treatment, spinal fusion has been considered to be the standard treatment⁷⁻⁹. Although corrective spinal fusion for pediatric neuromuscular scoliosis has a high risk of complications such as postoperative pneumonia^{2,10-17}, massive intraoperative bleeding^{10,13,18-23}, and wound infection^{2,3,13-18,21-28}, many benefits have been reported including stable sitting position²⁹⁻³¹, improved HRQoL of the child^{4,14,15,18,30,32-34}, high caregiver satisfaction^{2,4,23}, and weight gain³⁵.

Efforts are being made to assess the impact of surgery on HRQoL with a more patient-centered approach. This is because there is a growing recognition of the importance of patient-centered outcome measurements in terms of assessing the benefits of surgery. In recent years, several cerebral palsy-specific HRQoL assessment tools have been developed, but there is still no agreement in the literature on the most appropriate tool³⁶⁾. Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD)³⁷⁾ is a tool that has been validated and has gained recognition in the assessment of children with cerebral palsy. Sewell et al. retrospectively compared 18 patients with cerebral palsy who were treated surgically with 15 patients with cerebral palsy who were treated conservatively. They reported that personal care, positioning, and comfort scores increased significantly in patients who were treated surgically, while there was a slight decrease in the scores of those treated conservatively.

However, the use of CPCHILD is challenging, owing to its large number of questions and the long duration (approximately 30 min) required for the caregivers to answer them. In addition, some questions that are appropriate for children with GMFCS I-III (high motor function) may appear uncomfortable for the caregivers of children with GMFCS IV-V, which can affect their self-esteem. From the authors' experience, most caregivers stop answering midway in the questionnaire or deliberately skip some questions. Therefore, we have been using a simple questionnaire¹⁾ with the VAS, which is a modification of Bridwell et al.'s questionnaire⁵⁾ that is specialized for children with GMFCS IV and V, which was also used by Watanabe et al.⁴⁾ The caregivers answer the question in about 5 minutes, and none of the questions are skipped.

Most studies perform only a single postoperative survey, but there are a few reports of multiple follow-up surveys^{30,32}. Di Fazio et al. reported on 26 patients with CP (3 with GMFCS IV and 23 with V) who showed improvement in the total CPCHILD score in the first postoperative year but returned to baseline in the second year³². In contrast, Miyanji et al. reported similar improvements in the personal care, positioning, and comfort domains in the first year, and no worsening of scores was observed in the second and fifth postoperative years. However, it was noted from their study that the total score of 29% of the patients decreased by the fifth postoperative year³⁰.

Although simple comparisons cannot be performed between the results in previous studies and that in our study due to the difference in questionnaires, the improvements observed in the first survey of our study were maintained in the second survey in many domains including the HRQoL of the children. In this study, the presence of complications and residual deformities did not correlate with reduction in caregiver satisfaction or the quality of life of the children. This is consistent with the report by Miyanji et al.³⁰ which indicates that the presence of residual deformity or complications does not correlate with final caregiver satisfaction or the patient's HR-QOL score. On the other hand, Watanabe et al.⁴ used a two-group comparison of "Satisfied" and "Less Satisfied," wherein a difference was noted between these indicators which may be a difference in evaluation due to differences in statistical analysis.

In contrast, in this cohort, some caregivers experienced difficulty in transferring their children, which decreased their satisfaction with the treatment over time. Assessing the weight gain of children who have undergone spinal fusion over time and aging of caregivers may be the focus for future research.

This study has limitations: the Japanese translation of Bridwell's questionnaire has not been officially validated, and there are no data on nonoperative cases. Spinal fusion is the standard of care for children with NMS, and patients cannot be randomly assigned to nonoperative group.

In conclusion, this current study showed that spinal fusion for NMS children with GMFCS level IV or V function significantly improved and maintained the HRQoL of the affected children. And the effect was maintained in the medium-term. However, some caregivers showed a decline in the "transfer" and "treatment satisfaction" domains over time.

Conflicts of Interest: The authors declare that there are no relevant conflicts of interest.

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Author Contributions: Naoyuki Nakamura, Jiro Machida, and Yutaka Inaba designed the study; Naoyuki Nakamura, Masatoshi Oba, Takako Momose, and Yuichiro Kawabe performed the experiments and analyzed the data; Jiro Machida and Yutaka Inaba supervised the study; and Naoyuki Nakamura wrote the manuscript.

Ethical Approval: This study was approved by the Ethics Committee of Kanagawa Children's Medical Center (approval code: 2102-5).

Informed Consent: Informed consent for publication was obtained from all participants in this study.

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