

# Scoliosis Surgery in Children With Neuromuscular Disease

## Findings From the US National Inpatient Sample, 1997 to 2003

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**Background:** Scoliosis is a frequent complication of pediatric neuromuscular disease (NMD). Scoliosis surgery in children with NMD is thought to carry greater morbidity and mortality.

**Objectives:** To study demographics, comorbidities, outcomes, and hospitalization expenditures among children with NMD undergoing scoliosis surgery.

**Design:** Using the Kids Inpatient Database, a large all-payer US database of hospital discharges among children and adults younger than 20 years, we studied children undergoing scoliosis surgery between January 1, 1997, and December 31, 2003. Continuous variables were compared by *t* test, and categorical variables were compared by Pearson product moment correlation  $\chi^2$  test.

**Setting:** National database of pediatric hospital discharges.

**Patients:** Children with and without NMD.

**Main Outcome Measures:** Demographics, hospital length of stay, and in-hospital mortality associated with scoliosis surgery.

**Results:** Of 17 780 reported hospitalizations owing to scoliosis surgery, 437 children (2.5%) had NMD. Compared with children undergoing scoliosis surgery for other indications, children with NMD were more likely to be younger (12.4 vs 14.2 years), male (73.5% vs 38.3%), and insured by Medicaid (35.6% vs 20.3%). Comorbidities that were more common among children with NMD included pulmonary complications (lung disease not classified, pulmonary collapse, pulmonary insufficiency, chronic respiratory failure, and ventilator requirement) and cardiovascular complications (cardiomyopathy, hypotension, and tachycardia). Scoliosis surgery in children with NMD was associated with increased hospital length of stay (10.3 vs 7.7 days) and hospitalization expenditures (\$80 251 vs \$62 154), and higher in-hospital mortality (1.6% vs 0.2%).

**Conclusion:** Children with NMD have increased hospital length of stay and higher in-hospital mortality associated with scoliosis surgery, highlighting the need for further study of measures that could reduce complications and improve outcomes in this population.

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**S**EVERE WEAKNESS OF TRUNK muscles, often leading to scoliosis, is a frequent feature of neuromuscular diseases (NMDs) such as spinal muscular atrophy, congenital myopathies, Duchenne muscular dystrophy (DMD), and other muscular dystrophies.<sup>1-9</sup> Scoliosis in patients with NMD is often progressive and frequently requires surgical treatment.<sup>1,10</sup> Although no randomized controlled trials demonstrate the safety and efficacy of spinal surgery,<sup>11</sup> several retrospective studies have reported the characteristics and outcomes of spinal surgery in patients with NMD. In a retrospective series of 125 patients undergoing scoliosis surgery, NMD was an independent predictor of prolonged postoperative mechanical ventila-

tion.<sup>12</sup> Among 126 children (including 31 with NMD or cerebral palsy) who underwent scoliosis surgery at an Israeli medical center, a similar association was found between neuromuscular scoliosis and unfavorable outcomes.<sup>13</sup> Major complications, including delayed extubation, prolonged sensory or motor symptoms, and pulmonary compromise, were more common among 31 children with neurologic disease compared with children having idiopathic scoliosis.

Scoliosis surgery studies<sup>13-17</sup> in the orthopedic literature use the term *neuromuscular scoliosis* to describe patients with any neurologic disease, including cerebral palsy. In contrast, neurologists reserve the term *neuromuscular* to describe disorders associated with the peripheral nervous sys-

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**Table 1. Demographics of Children Hospitalized for Scoliosis Surgery With and Without NMD**

	NMD (n=437)	Non-NMD (n=17 343)	P Value <sup>a</sup>
Age, mean (SD), y	12.4 (3.1)	14.2 (3.7)	<.001
Male sex, No. (%)	321 (73.5)	6642 (38.3)	<.001
Race/ethnicity, No. (%)	(n=354)	(n=13 245)	
White	252 (71.2)	9049 (68.3)	<.001
African American	19 (5.4)	1729 (13.1)	
Hispanic	60 (16.9)	1502 (11.3)	
Asian	7 (2.0)	282 (2.1)	
Native American	2 (0.6)	55 (0.4)	
Other	14 (4.0)	628 (4.7)	
Neuromuscular diagnosis, No. (%)			
Muscular dystrophy	259 (59.3)	...	
Other muscular myopathies	50 (11.4)	...	
Motor neuron disease	127 (29.1)	...	
Acid maltase deficiency	1 (0.2)	...	

Abbreviation: NMD, neuromuscular disease.

<sup>a</sup> † Test for continuous variables and  $\chi^2$  test for categorical variables.

tem such as diseases of the motor neuron or muscle.<sup>18</sup> The distinction is important because patients with NMD typically have flaccid weakness (rather than the spasticity typically associated with cerebral palsy) and typically have no involvement of the central nervous system.<sup>18</sup> Therefore, the complications and prognosis reported in the orthopedic literature are unlikely to fully apply to patients with NMD.

The relative paucity of data limits the ability of physicians to properly advise parents of children with NMD regarding the timing, benefits, and risks of scoliosis surgery. A prospective controlled design would be the preferred method to study characteristics and outcomes of hospitalizations owing to scoliosis surgery among children with NMD; however, such an effort would be time consuming, expensive, and methodologically challenging. The availability of public access to national health care statistics in the United States raises the possibility of obtaining preliminary data about scoliosis surgery in children with NMD from large national data sets. A previous study<sup>17</sup> reported results for the year 2000 but incorporated children with any neurologic disease, including central nervous system disease. Using the Kids Inpatient Database (KID), a large all-payer US database of hospital discharges among children and adults younger than 20 years between January 1, 1997, and December 31, 2003, we studied the demographics, comorbidities, outcomes, and hospitalization expenditures among children with NMD undergoing scoliosis surgery in 1997, 2000, and 2003.

## METHODS

We performed a retrospective analysis of US hospitalizations in 1997, 2000, and 2003 (from January 1 to December 31 of each year) using data from the KID. This is a component of the Healthcare Cost and Utilization Project maintained by the Agency for Healthcare Research and Quality and is the only US-based hospital administrative data set designed to assess and collate newborn, child, and adolescent use of hospital services and hospital discharge information on pediatric treatments and other re-

source use. It includes pediatric discharges from a sample of more than 3500 US community hospitals (defined as short-term, non-federal, general, and specialty hospitals, excluding hospital units of other institutions) and contains data drawn from up to 36 state inpatient databases on children and adults younger than 20 years.

We included all 1997, 2000, and 2003 hospital discharge records for children who had scoliosis listed as a diagnosis code (*International Classification of Diseases, Ninth Revision [ICD-9] code 737*)<sup>19</sup> and spinal surgery listed as one of the procedure codes (codes 81.0, 81.3, and 81.6). Within this data set, we compared children with and without NMD. The NMD diagnoses used are the following: (1) muscular dystrophy (*ICD-9 codes 359, 359.1, and 359.2*), including DMD, Becker muscular dystrophy, Emery-Dreifuss muscular dystrophy, limb-girdle muscular dystrophy, facioscapulohumeral muscular dystrophy, myotonic muscular dystrophy, and congenital muscular dystrophy; (2) other muscular myopathies (codes 359.8, 359.89, and 359.9); (3) motor neuron disease, including spinal muscular atrophy and spinoperoneal muscular atrophy (codes 335.1, 335.11, 335.21, and 335.19); and (4) acid maltase deficiency (code 271). Hospital discharge records were compared for children with and without NMD.

We extracted demographic variables (age, sex, and race/ethnicity), payment source, and socioeconomic status. We studied hospital length of stay, in-hospital mortality, and hospital discharge disposition. To obtain information on concurrent diagnoses and procedures performed, we extracted *ICD-9* diagnosis codes other than those listed for NMD in the previous paragraph and procedures according to *ICD-9* procedure codes. These data were tabulated descriptively. All data were analyzed without population weighting ratio adjustments, as this is more conservative given the few children with NMD in the sample. Continuous variables were compared by *t* test, and categorical variables were compared by Pearson product moment correlation  $\chi^2$  test. Statistical analyses were performed using commercially available software (SPSS, version 13.0; SPSS Inc, Chicago, Illinois).

## RESULTS

### DEMOGRAPHIC DATA

Of 17 780 reported hospitalizations owing to scoliosis surgery in the KID for 1997, 2000, and 2003 combined, 437 children (2.5%) had NMD (**Table 1**). Compared with children undergoing scoliosis surgery for other indications, children with NMD were significantly more likely to be younger (12.4 vs 14.2 years) and male (73.5% vs 38.3%) ( $P < .001$  for both). The race/ethnicity of children with NMD also differed significantly from that of children without NMD, with more white (71.2% vs 68.3%) and Hispanic (16.9% vs 11.3%) children and fewer African American children (5.4% vs 13.1%) having NMD. Among the NMD cohort were 259 children with DMD or other muscular dystrophy, 127 children with spinal muscular atrophy or other motor neuron disease, 50 children with other muscular myopathies, and 1 child with acid maltase deficiency.

### CHARACTERISTICS AND OUTCOMES OF HOSPITALIZATIONS

Children with NMD had a significantly increased hospital length of stay compared with children without NMD (10.3 vs 7.7 days,  $P < .001$ ) (**Table 2**). However, the hospital length of stay before the first procedure was not sig-

**Table 2. Characteristics of Children Hospitalized for Scoliosis Surgery With and Without NMD**

Characteristic	NMD (n=437)	Non-NMD (n=17 343)	P Value <sup>a</sup>
Hospital length of stay, mean (SD), d	10.3 (13.9)	7.7 (9.0)	<.001
Primary payer, No. (%)	(n=435)	(n=17 302)	
Medicaid	155 (35.6)	3509 (20.3)	<.001
Private, including health maintenance organization	251 (57.7)	12 444 (71.9)	
Self-pay	4 (0.9)	362 (2.1)	
Other	25 (5.7)	987 (5.7)	
Hospitalization expenditures, mean (SD), \$	80 251 (70 320)	62 154 (60 091)	<.001
Hospital length of stay from admission to procedure, mean (SD), d	0.5 (2.5)	0.8 (3.2)	.63
In-hospital mortality, No. (%)	7 (1.6)	41 (0.2)	<.001

Abbreviation: NMD, neuromuscular disease.

<sup>a</sup> † Test for continuous variables and  $\chi^2$  test for categorical variables.

nificantly different (0.5 vs 0.8 days). The primary payer mix was significantly different, with children having NMD more frequently being insured by Medicaid (35.6% vs 20.3%). The mean hospitalization expenditures for children with NMD were significantly higher at \$80 251 compared with \$62 154 for children without NMD. In-hospital mortality was significantly increased for children with NMD at 1.6% compared with 0.2% for children without NMD ( $P < .001$ ).

### CONCURRENT DIAGNOSES

Pulmonary comorbidities were the most commonly listed concurrent diagnoses for children with NMD, followed by acute posthemorrhagic anemia, cardiac disease, and volume and electrolyte depletion (**Table 3**). Significantly more frequent among children with NMD were unclassified lung disease, pulmonary collapse, chronic respiratory failure, ventilator requirement, cardiomyopathy, hypotension, and unspecified tachycardia. Conversely, asthma and convulsions were significantly less frequent among children with NMD.

### COMMENT

In a US sample of pediatric hospital discharges, we observe that hospitalization for scoliosis surgery among children with NMD is associated with increased hospital length of stay and hospitalization expenditures, and higher in-hospital mortality. This is consistent with previous scoliosis surgery outcomes comparing children having more broadly defined neurologic disease with children having idiopathic scoliosis.<sup>17</sup> However, our results show that scoliosis surgery performed among children with NMD as a subgroup carries an even higher in-hospital mortality risk than that found in the study by Murphy et al.<sup>17</sup>

Pulmonary dysfunction is a common complication of NMDs such as spinal muscular atrophy and DMD; for this reason, close pulmonary monitoring and early involvement of pulmonary specialists should comprise the basic clinical management of these children. For the same reason, it is not surprising that pulmonary complications are common in patients with NMD at the time of scoliosis surgery, particularly among those with poor preoperative pulmonary function.<sup>20</sup> Although scoliosis re-

**Table 3. Concurrent Diagnoses of Children Hospitalized for Scoliosis Surgery With and Without NMD**

Concurrent Diagnosis	No. (%)		P Value <sup>a</sup>
	NMD (n=437)	Non-NMD (n=17 343)	
Lung disease, unclassified	80 (18.3)	219 (1.3)	<.001 <sup>b</sup>
Pulmonary collapse	60 (13.7)	1481 (8.5)	.002 <sup>b</sup>
Asthma	7 (1.6)	1151 (6.6)	<.001 <sup>c</sup>
Pleural effusion	6 (1.4)	588 (3.4)	.13
Acute respiratory failure	9 (2.1)	164 (0.9)	.13
Pulmonary insufficiency	4 (0.9)	40 (0.2)	.04 <sup>b</sup>
Chronic respiratory failure	10 (2.3)	15 (0.1)	<.001 <sup>b</sup>
Acute posthemorrhagic anemia	74 (16.9)	2422 (14.0)	.34
Anemia, unspecified	13 (3.0)	878 (5.1)	.25
Ventilator requirement	8 (1.8)	103 (0.6)	.01 <sup>b</sup>
Hyponatremia	11 (2.5)	355 (2.0)	.85
Acidosis	14 (3.2)	275 (1.6)	.07
Volume depletion	9 (2.1)	215 (1.2)	.46
Cardiomyopathy	14 (3.2)	33 (0.2)	<.001 <sup>b</sup>
Cardiac arrhythmias	6 (1.4)	194 (1.1)	.90
Hypotension	17 (3.9)	303 (1.7)	.01 <sup>b</sup>
Tachycardia, unspecified	15 (3.4)	253 (1.5)	.01 <sup>b</sup>
Paralytic ileus	9 (2.1)	729 (4.2)	.16
Esophageal reflux or esophagitis	6 (1.4)	279 (1.6)	.92
Convulsions	5 (1.1)	793 (4.6)	.008 <sup>c</sup>
Sleep apnea	5 (1.1)	83 (0.5)	.25
Fever	6 (1.4)	415 (2.4)	.53

Abbreviation: NMD, neuromuscular disease.

<sup>a</sup> P values calculated using 2-sided  $\chi^2$  test for categorical variables.

<sup>b</sup>  $P < .25$  for positive tail (increased frequency of association among children with NMD).

<sup>c</sup>  $P < .25$  for negative tail (decreased frequency of association among children with NMD).

pair aims to reduce the rate of decline in pulmonary function over time,<sup>21</sup> vital capacity may worsen at the time of surgery in patients with NMD due to the abrupt changes to alveolar perfusion and aeration that occur during the immediate postoperative period.<sup>22</sup> Although scoliosis surgery can be safely and successfully performed even in patients with NMD complicated by respiratory failure,<sup>23</sup> this study further affirms the importance of expert pulmonary management in the care of these patients and the special attention that ventilatory function warrants in their operative and postoperative care, particularly in the context of scoliosis surgery and repair.

Among the scoliosis surgery data in the KID, there were several demographic differences between children with and without NMD. The significantly younger age of the NMD cohort likely reflects the often severe and progressive nature of the underlying disease, combined with an expectation of clinical progression of spine curvature that drives earlier and more aggressive management. Concerns about declining pulmonary function as children with NMD age may also contribute to the decision to intervene earlier. The high proportion of boys among the NMD cohort may relate to the X-linked nature of DMD, although this cannot be conclusively demonstrated given the lack of a specific ICD-9 code for this type of muscular dystrophy. Children with NMD undergoing scoliosis surgery are more likely to be white or Hispanic and are less likely to be African American; however, data on race/ethnicity were frequently omitted in the KID. Children with NMD are also much more likely to be insured through Medicaid. The high Medicaid insurance rate in the NMD cohort likely reflects the severe disabilities affecting many of these children; as a result of their functional impairments, these children often receive care through public insurance programs that carry more restrictive eligibility requirements for children with non-severe disabilities. Whether the observed racial/ethnic disparities stem from socioeconomic, individual, or other factors such as access to care cannot be determined based on the information available.

Our study is limited by the methods, specifically in that hospital discharge records are subject to coding errors and omissions. Using a similar method, an Italian study<sup>24</sup> of hospital discharge diagnoses for amyotrophic lateral sclerosis reports good sensitivity (91.6%) and specificity (99.9%) for coding the amyotrophic lateral sclerosis diagnosis. Given that the KID is deidentified, the validity of the data entered cannot be established. However, this database has been used in numerous neurologic<sup>25-30</sup> and orthopedic<sup>31-36</sup> studies and has been accepted as a nationally representative data set.<sup>37,38</sup> The database is limited to hospital admissions, and no identifiers are included that would allow for longitudinal follow-up. Also, given that the cases are identified as hospitalizations, it is possible that a given child is counted more than once if admitted several times in a given year for scoliosis surgery. Although this possibility cannot be excluded with the available data set, we assume that multiple admissions in a given year for the same procedure are uncommon, particularly for an extensive and invasive procedure such as scoliosis repair.

In conclusion, our study confirms previous evidence based on less rigorous criteria<sup>17</sup> that children with NMD are at increased risk of complications during hospitalizations for scoliosis surgery. There are important demographic differences between children with and without NMD who undergo scoliosis surgery, with children having NMD typically being younger and male and requiring longer hospital length of stay and greater hospitalization expenditures. Moreover, the in-hospital mortality risk seems greater than that previously reported.<sup>17</sup> In contrast to children with idiopathic scoliosis, children with NMD are at higher risk of in-hospital mortality and operative or postoperative (particularly pulmonary or ventilatory) com-

plications. Unaddressed by this study and the KID is the potential effect of recent medical advances in terms of refined noninvasive and invasive pulmonary management<sup>39</sup> and novel surgical techniques<sup>40</sup> on the morbidity and mortality of scoliosis surgery, particularly in this vulnerable population. Given the increased morbidity, in-hospital mortality, hospital length of stay, and hospitalization expenditures associated with scoliosis surgery in children with NMD, further research into outcomes and prognostic factors is important.

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