Thoracogenic spinal deformity: a rare cause of early-onset scoliosis

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OBJECTIVE Surgery for severe congenital defects, such as congenital diaphragmatic hernia, congenital heart defects, and tracheoesophageal disorders, are life-saving treatments for many infants. However, the incidence of scoliosis following thoracoabdominal surgery has been reported to range from 8% to 50%. Little is known about severe scoliosis that occurs after chest wall procedures in infants. The authors sought to determine the prevalence of thoracogenic scoliosis, disease severity, and need for scoliosis surgery in patients who underwent chest wall procedures in early childhood.

METHODS A multicenter database of patients with early-onset scoliosis was queried to identify patients with a history of thoracogenic or acquired iatrogenic scoliosis. Patients with significant congenital spine deformities were excluded. Forty-one patients (1.6%) were noted to have thoracogenic scoliosis. Of these patients, 14 patients were observed; 10 received casts and/or braces; and 17 underwent treatment with rib-based distraction rods, Shilla procedures, or spine-based growing rod devices. Radiographs, complications, and patient characteristics were reviewed.

RESULTS The mean age at scoliosis diagnosis for the 41 patients was 6.0 years. The mean time to follow-up was 2.9 years (4.5 years in the 17 surgical patients). The mean preoperative coronal Cobb angle in the surgical group was 65° and improved to 47° postoperatively ($p = 0.01$). The mean Cobb angle for the nonoperative group was 31° initially and 32° at follow-up ($p = 0.44$). Among the 17 patients undergoing surgery for scoliosis, there were 13 complications in 7 patients, including a brachial plexus palsy following rib-based distraction rod placement. This resolved with revision of the rib hooks. There were no known complications in the nonoperative cohort.

CONCLUSIONS Severe scoliosis can develop after thoracoabdominal surgeries during infancy. Further work is needed to understand the pathogenesis of scoliosis in this population so as to implement measures for prevention and early diagnosis and to guide appropriate treatment.

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KEYWORDS acquired scoliosis; early-onset scoliosis; diaphragmatic hernia; thoracotomy; deformity

THORACOGENIC scoliosis is defined as a spinal curvature attributable to iatrogenic disease or operative trauma to the thoracic cage. The disease mechanism behind this phenomenon is not well understood. Classically, surgeries for severe birth defects, such as congenital diaphragmatic hernia, congenital heart defects, and tracheoesophageal disorders, are life-saving treatments for many infants. Although dwarfed by the obvious benefits and necessity of intervention, thoracoabdominal surgery may have unforeseen sequelae, such as the development

of severe scoliosis. Scoliosis affects 2% to 4% of the general pediatric population,^{7,17} but it is much more prevalent in children after thoracoabdominal surgical intervention. Scoliosis has been reported in 13% to 33% of children surviving congenital diaphragmatic hernia repair,^{6,13,16} 8.5% of children following cardiac surgery,¹¹ and as many as 50% of children following tracheoesophageal fistula repair.³ Severe scoliosis has also been noted to occur following chest wall resection or laminectomy for spinal cord tumor and is often progressive.^{5,8}

ABBREVIATIONS VEPT = vertical expandable prosthetic titanium rib.

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Early-onset scoliosis can range in severity and may result from a number of etiologies, most of which are poorly understood, although some do appear to be mechanical in nature.^{10,14} Patient age, underlying diagnoses, and curve characteristics all play a role in evaluating treatment strategies, which may include observation, bracing/casting, or surgical interventions for more significant curves. In contrast to adolescent idiopathic scoliosis, early-onset scoliosis is a potentially life threatening diagnosis. Historically, severe scoliosis in children younger than 10 years was managed by fusion surgery. For young children, fusion caused a very short thorax, resulting in thoracic insufficiency syndrome and severe pulmonary disease. Growing rods were developed to allow for ongoing thoracic growth with regular lengthening of the spine, either through surgical lengthening procedures every 6 months or using a magnetically controlled growing rod device in the clinic. The vertical expandable prosthetic titanium rib (VEPTR, DePuy Synthes) was designed to treat children with rib deformity. The semiconstrained device attaches to the ribs proximally and to the rib, spine, or pelvis distally. Surgical lengthening procedures are performed twice yearly to maintain thoracic growth. The Shilla technique involves placement of rods that are not firmly tightened down to the screws, so as to allow vertical growth of the spine. Lengthening procedures are not required. Each of these techniques can be helpful interventions for severe curves in young children, despite high rates of complications.¹ Improved understanding of the development and progression of severe scoliosis following thoracoabdominal surgery is necessary to help providers, patients, and families navigate treatment options and expectations.

The purpose of this study was to evaluate and characterize patients with severe thoracogenic scoliosis from a large, multicenter database of children with early-onset scoliosis (prior to 10 years of age). We sought to 1) determine how frequently thoracogenic scoliosis was the cause of spine deformity; 2) characterize the severity of the curve pattern in children with thoracogenic scoliosis and how frequently surgical management was required; and 3) outline complications sustained by patients with thoracogenic scoliosis undergoing surgical management.

Methods

We queried a multicenter database that prospectively enrolls and follows patients with early-onset scoliosis. Twenty-six medical centers across the United States and other nations participate; patients were prospectively enrolled in the registry from 2002 to 2014 (*Appendix*). Institutional review board approval was obtained at each site, and informed consent was obtained from all study participants/parents. The prospective enrollment form asks the treating surgeon whether or not the child has a thoracogenic curve. We queried the database to identify patients with a history of thoracogenic scoliosis and reviewed radiographs, complications, and patient characteristics. Patients who underwent a prior medical procedure or surgery on the chest wall or spine (sternotomy, thoracotomy, chest wall resection, laminectomy, or chest wall radiation therapy) were included. Characteristics of patients with

scoliosis treated operatively versus nonoperatively were evaluated. Patients with congenital spine deformities were excluded from the current study.

Statistical analysis was performed using the Pearson chi-square test for nominal variables and the 2-tailed Student t-test for continuous variables. Matched pairs analysis was used to assess for change between pre- and postoperative values in the same patient. Observed differences that have a less than 5% likelihood of occurring by chance were considered significant.

Results

Between 2002 and 2014, 2555 patients with early-onset scoliosis were prospectively enrolled in the multicenter database. Of these patients, 43 were noted to have thoracogenic scoliosis. This represented 1.7% of patients in the entire cohort. Two surgical patients (one in whom the VEPTR was placed and another whose device was unspecified) had inadequate data available and were excluded. Of the 41 patients, 14 were observed, 10 received casts and/or braces, and 17 were treated surgically. Fifteen patients underwent treatment with VEPTR devices, one underwent a Shilla procedure, and another had growing rods implanted. All patients had bilateral devices placed. Six patients from the nonoperative group and 2 from the operative group had missing radiographs at the latest follow-up, but clinical and complications data were available.

The mean age at presentation for the 41 patients was 6.0 years. The mean time to follow-up was 2.9 years. Etiology for the scoliosis was heterogeneous. Diagnoses were similar between the operative and the nonoperative groups. In the operative group, 11 patients underwent a previous thoracotomy, 1 had a sternotomy, 3 had chest wall resections, and 2 patients had laminectomies. One patient diagnosed with congenital heart disease in the operative group had limited available data regarding the location of chest wall surgery (Case 5). In the nonoperative group, 11 patients underwent a previous thoracotomy, 3 had a sternotomy, 3 had chest wall resections, 6 patients had laminectomies, and 1 patient had radiation therapy alone.

In the nonoperative group, the mean age at presentation for the 24 patients was 5.4 years (Table 1). The mean Cobb angle for the nonoperative group was 31° initially and 32° at follow-up ($p = 0.44$). Curves in the nonoperative group progressed at least 10° in 3 patients (Cases 4, 22, and 23), and improved at least 10° in another 3 patients (Cases 7, 9, and 12). Of the patients with curves that progressed, 1 had a spinal cord tumor, 1 had congenital diaphragmatic hernia repair involving a left thoracotomy, and 1 had radiation treatment for leukemia. Ten patients had initial curves greater than 30°; 1 of these curves had improved to less than 30° by follow-up.

For the 17 patients in the operative group, the mean age at scoliosis surgery was 6.6 years with a mean 4.5 years of follow-up (Table 2). The mean preoperative coronal Cobb angle in the surgical group was 65° and improved to 47° postoperatively ($p = 0.02$, Fig. 1). Fifteen of the 17 patients in the operative group had initial curves greater than 30°. The mean Cobb angle at presentation was greater in the operative group than in the nonoperative group (65° vs 31°,

TABLE 1. Characteristics of the nonoperative group

Case No.	Age at Index (yrs), Sex	Diagnosis; Associated Intervention	Intervention	Cobb Angle (°)	Curve Levels	Follow-Up Cobb Angle (°)
1	0.5, M	Congenital diaphragmatic hernia; thoracotomy	Observed	23	T7–L3	NA
2	0.9, F	Congenital diaphragmatic hernia; thoracotomy	Cast	26	T3–9	24
3	1.1, F	Congenital heart defect; sternotomy, laminectomy	Observed	29	T2–6	36
4	1.4, F	Congenital diaphragmatic hernia; thoracotomy	Cast	34	T1–10	48
5	2.1, F	Chest wall resection	Observed	37	T4–10	41
6	2.3, M	Spinal cord tumor; laminectomy	Cast (then brace)	41	T3–10	43
7	2.6, M	Tracheoesophageal fistula; thoracotomy	Cast (then brace)	56	T7–L2	34
8	3.1, F	Spinal cord tumor; laminectomy	Brace	16	T2–11	8
9	3.3, M	Congenital heart defect/trisomy 21; thoracotomy	Cast	40	T9–L2	30
10	3.6, M	Congenital heart defect; sternotomy	Observed	7	T3–L3	4
11	4.1, M	Chest wall resection	Observed	35	T5–11	NA
12	5.1, F	Congenital diaphragmatic hernia	Cast (then brace)	90	T5–L5	65
13	5.2, M	Congenital heart defect; thoracotomy	Observed	13	T3–6	NA
14	6.1, F	Congenital heart defect; thoracotomy	Brace	47	T12–L4	41
15	6.5, F	Congenital diaphragmatic hernia; thoracotomy	Observed	21	L1–5	NA
16	6.8, M	Chest wall resection	Observed	15	T3–7	NA
17	6.9, M	Congenital heart defect; sternotomy	Brace	26	T6–11	27
18	7.8, M	Spinal cord tumor; laminectomy	Observed	18	T3–L1	10
19	8.0, M	Congenital diaphragmatic hernia; thoracotomy	Observed	20	T1–9	NA
20	8.6, M	Neuroblastoma; thoracotomy, laminectomy	Observed	32	T7–11	26
21	10.0, M	Spinal cord tumor; laminectomy	Brace	NA	NA	20
22	10.2, M	Spinal cord tumor; laminectomy	Observed	21	T3–T6	32
23	10.8, F	Leukemia; radiation therapy	Observed	47	T4–12	63
24	11.4, M	Pulmonary hypoplasia; thoracotomy	Observed	22	T4–7	21
Mean (SD)	5.4 (3.2)			31 (17)		32 (16)

NA = not available.

$p < 0.001$). Over the study period, patients underwent a mean of 7.5 surgeries (range 2–21), including a mean of 4.75 lengthening procedures (range 0–14).

Among the 15 VEPTR patients, there were 13 complications in 7 patients, including pneumonia (in 5), brachial plexus palsy (in 1), spine infection (in 3), device migration (in 1), implant failure (3 times in 1 patient). Three of the patients with pneumonia required hospitalization, and 2 were treated on an outpatient basis. All infections and device problems required revision surgery. The most serious perioperative complication was in a patient with previous chest wall tumor resection who developed a brachial plexus palsy following VEPTR placement. This resolved with revision of the rib hooks. The 2 patients with Shilla and a growing rod had no reported complications. Among the nonoperative patients, one patient died and another patient had cast problems requiring trimming of the cast in clinic.

Discussion

The development of scoliosis following rib resection has been well documented^{5,8,10} and is often studied in experimental models.^{2,9,10} Severe scoliosis has also been identified after thoracotomy and other pediatric surgical procedures but is less well understood.^{3,5,12,15} The present

study characterizes the underlying diagnoses in a cohort of children with thoracogenic scoliosis from a large registry of patients with early-onset scoliosis.

The exact timeline and pathophysiology for development of scoliosis after thoracotomy or similar procedures remains unclear. Despite the increased incidence and significant burden to patients and their families, little is known about severe scoliosis that is acquired after surgery in infancy. Van Biezen and colleagues evaluated 160 patients undergoing thoracotomy for aortic coarctation and noted the development of scoliosis in 22% of patients, despite the absence of scoliosis prior to surgery.¹⁵ Additional data may be helpful for surgeons as they counsel families about possible long-term sequelae of chest wall surgery performed at a young age. If children most at risk for scoliosis could be identified, screening measures could be put in place to ensure early access to nonoperative scoliosis treatment, although the efficacy of bracing or casting for treatment of thoracogenic scoliosis is not known. Based on this study, scoliosis following chest wall surgery can be severe. Parents should be warned about the possible development of scoliosis after chest wall surgery, and regular screening should be instituted.

Furthermore, it is uncertain whether thoracogenic scoliosis is due solely to an underlying diagnosis, such as a

TABLE 2. Characteristics of the surgical group

Case No.	Age at Treatment (yrs), Sex	Diagnosis; Associated Intervention	Intervention	Cobb Angle (°)	Curve Levels	Follow-Up Cobb Angle (°)
1	1.4, M	Chest wall resection	VEPTR	30	T1–6	52
2	2.4, M	Congenital diaphragmatic hernia; thoracotomy	VEPTR	53	T7–L1	63
3	2.5, F	Spinal cord tumor; laminectomy	VEPTR	72	T5–11	55
4	2.5, F	Congenital heart defect, pulmonary hypoplasia; thoracotomy	VEPTR	97	T4–10	NA
5	3.2, F	Congenital heart defect	VEPTR	86	T7–L2	34
6	3.3, M	Congenital diaphragmatic hernia, pulmonary hypoplasia	VEPTR	81	T6–13	71
7	3.8, M	Chest wall resection	VEPTR	62	T4–L1	50
8	4.7, F	Congenital heart defect; thoracotomy	VEPTR	76	T6–L1	68
9	4.8, F	Spinal cord tumor; laminectomy	VEPTR	56	T9–L4	58
10	7.6, F	Congenital heart defect; thoracotomy	VEPTR	57	T3–10	46
11	7.7, M	Chest wall resection, thoracotomy	VEPTR	29	T2–9	13
12	9.1, F	Nemaline myopathy; pneumonectomy, thoracotomy	Growing rod	95	T12–L5	NA
13	9.3, F	Congenital heart defect/trisomy 21; sternotomy	Shilla	53	T7–12	28
14	9.5, F	Congenital heart defect; thoracotomy	VEPTR	83	T6–12	56
15	9.8, F	Esophageal atresia; thoracotomy	VEPTR	62	T4–10	44
16	13.2, M	Tracheoesophageal fistula	VEPTR	72	T10–L3	49
17	17.9, F	Tracheoesophageal fistula; thoracotomy	VEPTR	33	T3–10	22
Mean (SD)	6.6 (4.3)			65 (21)		47 (16)

unifying defect in development resulting in both congenital diaphragmatic hernia and scoliosis, for example, or due to surgical interventions for the underlying diagnosis. Spinal cord tumor or chest wall tumor can result in scoliosis, and it is unclear whether the tumor or the surgical intervention causes the scoliosis. These patients were included in the study nevertheless, since they fall in the category of having iatrogenic or thoracogenic scoliosis, or scoliosis that develops after a medical intervention. Russell et al. evaluated a number of patients undergoing congenital diaphragmatic hernia repair with a variety of surgical techniques and found no significant influence of repair technique on subsequent development of scoliosis.¹³ Glotzbecker et al. reported severe curves (mean 26°, maximum 70°) following childhood resection of chest wall tumors, with tumor resection above the 6th rib at increased risk for developing scoliosis.⁵ This illustrates the need for further investigation and understanding of the mechanisms and pathogenesis of scoliosis development.

This study has a number of limitations; it provides no information regarding what percentage of children undergoing chest wall procedures will ultimately develop scoliosis. Rather, we sought to find the percentage of children with thoracogenic scoliosis from a large early-onset scoliosis registry. Although data were collected prospectively, limited information regarding the index chest wall surgery was available for analysis, especially for the nonoperative group. Some centers only enroll surgical patients, so potentially some nonoperative patients with thoracogenic scoliosis were not entered in the database. Curve location was well characterized, but laterality of the thoracotomy or surgical intervention was not reliably reported, nor was direction of the curve. Additionally, the lack of a control group limits interpretation in the context of managing pa-

tient expectations and outcomes with regard to incidence of scoliosis as a result of the described procedures. In some instances, patients had more than 1 diagnosis, such as a syndrome, congenital heart disease, and a thoracotomy. Syndromic or neuromuscular diagnoses, such as myopathy and Down syndrome, as well as spinal cord tumors may contribute to scoliosis progression. Treatment strategies may vary by center, and there are no clear indications as to when surgical treatment was initiated. For instance, some institutions may not offer casting for early-onset scoliosis or prefer surgical techniques over casting.⁴ Magnetically controlled growing rods are now frequently used for the treatment of thoracogenic disease, but due to the timespan of the study, no patients in this study were treated with these rods. Follow-up to skeletal maturity would be ideal, but, given the rarity of this condition, follow-up was limited to a mean of 2.9 years (4.5 years in the surgical cohort). Data were collected at 26 sites over a 12-year period and included a sample size of 2555 patients. Thus, this is a unique data set providing novel information on the presentation and treatment course of thoracogenic scoliosis before age 10 years.

Conclusions

Despite these limitations, this study does provide significant information regarding underlying diagnoses, as well as the development and progression of thoracogenic scoliosis. The natural history and treatment of scoliosis related to childhood thoracic surgery and interventions has not been well described, and, to our knowledge, this is the first prospective study on this topic. This condition is frequently unrecognized, and families are seldom counseled prior to chest wall surgery to watch for scoliosis later

FIG. 1. Case 7. **Left:** Preoperative radiograph demonstrating left-sided rib resection and 62° curve. **Right:** Postoperative radiograph obtained following VEPTR placement, demonstrating a 24° curve.

in life. In our patient population, thoracogenic scoliosis represented less than 2% of patients with early-onset scoliosis. Nevertheless, the resultant disease can be severe, requiring childhood surgical management in over 40% of patients. In this series, patients with severe early-onset scoliosis were successfully treated with rib-based growing devices. However, surgically treated patients underwent a mean of 7.5 surgeries during the study period, with surgical complications in 41% of patients. Thus, thoracogenic scoliosis can present as severe early-onset scoliosis, which is a potentially life-threatening diagnosis. Prospective studies may illuminate what surgical characteristics are associated with the development of scoliosis after early treatments in childhood. This project reports on the incidence and severity of thoracogenic scoliosis in the early-onset scoliosis population and may raise awareness of the association between severe scoliosis and childhood chest wall procedures.

Appendix

Children's Spine Study Group Enrolling Sites

Children's Hospital of Boston, MA; Primary Children's Medical Center, Salt Lake City, UT; Shriners Hospital for Children, Philadelphia, PA; Children's Hospital of Philadelphia, PA; Morgan Stanley Children's Hospital of New York–Presbyterian, New York, NY; Hospital De La Concepcion, San Germán, Puerto Rico; Central Texas Pediatric Orthopedics & Scoliosis Surgery, Austin, TX; Shriners Hospital for Children, Los Angeles, CA; Shriners Hospital for Children, Portland, OR; Shriners Hospital for Children, Chicago, IL; LeBonheur Children's Hospital, Memphis, TN; Children's Mercy, Kansas City, MO; IWK Health Centre, Halifax, Nova Scotia, Canada; Nemours–A.I. duPont Hospital for Children, Wilmington, DE; Washington University in St. Louis, MO; Upstate Medical University, Syracuse, NY; Cincinnati Children's Hospital Medical Center, Cincinnati, OH; Shriners Hospital for Children, Salt Lake City, UT; Children's Hospital Colorado, Aurora, CO; Children's Hospital of Wisconsin, Milwaukee, WI; Mayo Clinic, Rochester, MN; Orlando Health, Orlando, FL; Shriners Hospital for Children Canada, Montreal, Québec, Canada; Seattle Chil-

dren's, Seattle, WA; Emory University, Atlanta, GA; and Shriners Hospital for Children Twin Cities, Minneapolis, MN.

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