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ORIGINAL ARTICLE

The Relationship Between Function, Self-perception, and Spinal Deformity

Implications for Treatment of Scoliosis in Children With Spina Bifida

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Abstract: The purpose of this study was to determine the relationship of spinal deformity with physical function and self-perception in children with spina bifida. Ninety-eight eligible children with scoliosis and spina bifida were identified; 80 of them (82%) consented to participate. Spinal deformity was measured in many ways, including scoliosis, coronal balance, and pelvic obliquity. Measures of physical function included the Sitting Balance Scale, Jebsen Hand Scale, Hoffer Ambulation Scale, the Spine Bifida Spine Questionnaire, and the Activities Scale for Kids (ASK). Self-perception was determined with Harter's Self-Perception Profile. No relationship was found between spinal deformity and overall physical function (ASK). Of all aspects of spinal deformity, only coronal imbalance was significantly related to only one aspect of physical function (ie, sitting imbalance). No aspect of spinal deformity was related to self-perception. In conclusion, surgeons should be clear in their indications for surgery and recognize that in the short term the potential benefit of surgery may be, at best, to improve only sitting balance.

Key Words: spina bifida cystica, scoliosis, activities of daily living, health status, surgery

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Study conducted at Bloorview MacMillan Centre and The Hospital for Sick Children, Toronto, Canada.

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Scoliosis affects 30% to 50% of children with spina bifida.[34,35,37,38] Many children with spina bifida and scoliosis undergo spinal surgery. Although children with spina bifida experience many surgical procedures throughout their life, one of the most serious is spinal surgery, with reported complication rates of up to 58%.[5,29,31,36,48] The primary focus of most prior studies on spina bifida and scoliosis has been on the technical correction of spinal deformities,[1,5–7,9,16,18,28,29,31,36,41,48] with less attention to the functional outcomes. The few studies that have examined function have evaluated ambulation and suggest that spinal fusion adversely affects walking ability.[30,34] However, because most children who undergo spinal surgery are full-time sitters, surgery is generally believed to improve overall physical function and self-perception.[28,43]

The premise of surgery for scoliosis in children with spina bifida is that spinal deformity is related to physical function, and that by correcting spinal deformity, function is improved. Patients may also have expectations of improved physical appearance. The purpose of this study was to determine the relationship of spinal deformity with overall physical function and self-perception.

MATERIALS AND METHODS

All children with diagnoses of spina bifida and scoliosis who were seen at the Bloorview MacMillan Center Spina Bifida Clinic were considered. The Bloorview MacMillan Center is a regional rehabilitation unit primarily serving a large urban city and the surrounding rural areas. All English-speaking children aged 7 to 16 with spina bifida cystica (ie, meningomyelocele, meningocele, lipomeningocele, or lipomeningomyelocele) and scoliosis (ie, >10 degrees fixed lateral curvature on anteroposterior [AP] radiograph along with rotation of vertebrae) were evaluated. This group included some who had had spinal surgery. Subjects were excluded if they had not had a radiograph of their spine within 6 months or had had an orthopaedic operative procedure within the previous year. The study received ethical approval. Informed written consent and child assent was obtained.

Conceptual Framework

As shown in Figure 1, the International Classification of Impairment, Disability, and Handicap (ICIDH) model[39,49,50] of

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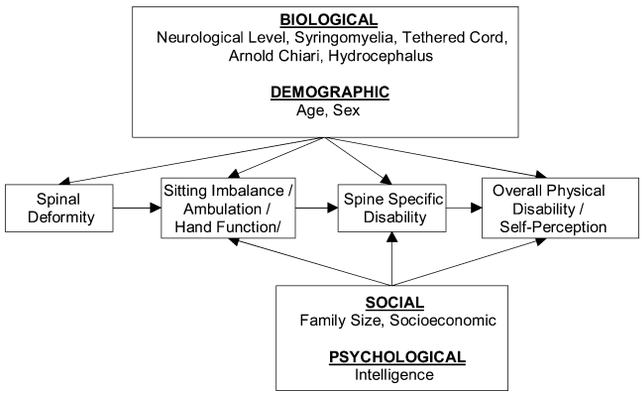

FIGURE 1. Conceptual framework for relationships.

the World Health Organization was used as the conceptual framework. In the ICIDH model, impairments are defined as abnormalities of structure or function. Disability (or activity restriction) refers to reduction in a person's ability to perform basic tasks.[39,49,50] We hypothesized that the impairment of spinal deformity would be related to specific aspects of physical function, such as sitting and hand function, which in turn would be related to overall physical function. Verbrugge's model of the disablement process[45] was used to consider factors that would act as intermediate steps or effect modifiers or confound the relationship of spinal deformity with function or self-perception.

Spinal Deformity

Because scoliosis is only one aspect of spinal deformity, deformity was measured in multiple ways. Radiographs were taken in a standardized fashion according to a set protocol with the child sitting on a flat surface with two vertical radiolucent bars for dorsal support. A single observer, blinded to the identity of the child and other measures, performed all radiographic measurements. A fine pencil, a protractor with single degree markings, and a 15-inch ruler were used for all measurements.[11,33] The Cobb technique was used to determine the magnitude of scoliosis, kyphosis, and lordosis in degrees on the AP and lateral radiographs.[12] Coronal imbalance, defined as millimeters of lateral deviation from the vertical center of gravity,[6] was measured by the amount of displacement between the midpoint of the superior aspect of the sacrum (the midpoint of a line connecting the cephalad-most point of both sacroiliac joints) to a vertical line drawn from the T1 spinous process. Sagittal imbalance was measured by the amount of displacement between a vertical line drawn from the anterior cortex of C7 to the anterior cortex of S1. Pelvic obliquity was measured in degrees using the technique described by Osebold et al.[34] Secondary scoliotic curves, axial shoulder rotation (the rotation of shoulders in relation to pelvis), and shoulder tilt were also assessed but were found to be highly correlated with the primary scoliotic curve (data not shown) and were not analyzed further.

Physical Function

Physical function was measured in multiple ways. Sitting balance was measured with a 10-grade ordinal scale, modified from Swank and Dias, representing sitting balance in a static and dynamic context.[42] With this scale, a score of 10 represented a well-balanced sitter. Ambulation was assessed with the 4-grade ordinal scale described by Hoffer for classifying children with spina bifida; a score of 4 represented the ability to walk in the community.[23] Hand function, evaluated with the Jebsen Hand Test for children,[44] is a timed structured assessment of six hand activities expressed in seconds and has been used previously in children with spina bifida.[31] Finally, we used a number of scales all developed for, or used extensively in, children with spina bifida. The Spina Bifida Spine Questionnaire (SBSQ)[47] was used to assess function specifically related to the spine. The SBSQ is a validated disease-specific, self-administered questionnaire. The SBSQ was developed by polling clinicians, parents, and children with spina bifida and scoliosis to generate a number of items related specifically to disability related to their spine. These items were then reviewed and ranked by a group of 40 children with spina bifida and scoliosis to produce the questionnaire. Items tested in the SBSQ included questions on mobility, sitting, back pain, appearance, and ability to self-catheterize. The SBSQ has been shown to have excellent test–retest reliability in children with spina bifida and correlates well with parents' global assessments of their child's spine-specific function.[47]

The Activities Scale for Kids (ASK)[51,52] was used to measure overall physical function. Although many instruments exist for assessment of overall physical function, most of these were not developed specifically for children or were developed exclusively by clinicians and thus may not reflect the activities that are important to the children.[46,47] The ASK, on the other hand, was developed from the child's and family's perspective and consists of eight subdomains in locomotion, dressing, eating, personal care, standing skills, stairs, play, and miscellaneous activities distributed over 30 self-administered questions. It has been previously validated and shown to be reliable in children with various physical afflictions and neurocognitive disabilities, including spina bifida.[46,47] Both the ASK and the SBSQ had a maximum score of 100, representing no disability.

Self-perception was measured with the Harter Self-Perception Profile for Children and Adolescents.[19–22] The Harter Profile is a validated, widely used, and accepted scale for use in both the pediatric[14] and the spina bifida population,[3,24] with subscales assessing perceived social competence, athletic competence, physical appearance, and global self-worth. Scores range from 5 to 25, with higher scores representing higher self-perception.

A single examiner determined the neurologic motor level using the International Myelodysplasia Study protocol.[38] Medical records were used to obtain information about other potential confounders, including demographic (age, sex), biologic (presence of hydrocephalus, number of ventricular-peritoneal shunt revisions, presence of tethered cord, syringomyelia and Arnold-Chiari malformation, along with any releases/decompressions), psychosocial (child's educational

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placement, family/household income before taxes, parent's educational level) and whether the child had had previous spinal surgery. Children's motivation was assessed with the Health Self-Determinism Index for Children (HSDI-C),[13] a self-administered questionnaire consisting of 29 items divided over four subscales representing the multidimensionality of intrinsic motivation (Health Behavior/Goals, Competency in Health Matters, Internal-External Cue Responsiveness, and Self-Determinism in Health Judgment).

Data Analyses

The analyses examined the correlation of spinal deformity with physical function and self-perception. In the first stage of analysis, separate linear regression models were used to examine the relationship between each aspect of spinal deformity with sitting balance, walking, and hand function. In the second stage we examined the relationship between each aspect of spinal deformity with the SBSQ, ASK, and self-perception. In the final stage, multivariable analysis was used to examine the relationship between scoliotic deformity and physical function while adjusting for confounding variables. Potential confounding factors were selected for the multivariable linear regression analyses using the change-in-estimate method described by Kleinbaum and other authors.[17,26,32] We included patients with the full range of spinal deformity. Thus, while adjusting for confounding variables, multivariable analyses allowed comparison of physical function between those with mild and those with severe deformity. Analyses were repeated in stepwise and backward fashion with no effect on the results. Tests for interactions, linearity, collinearity, and influential observations were conducted.[15] Two standards were used to examine the quantitative impact, or clinical importance, of the relationships tested. First, as suggested by Feinstein, a cutoff of at least 10% of the variance (R^2) explained by the independent variable was used as the lower boundary in regard to that variable having an important impact on the outcome.[10,15] Second, in multivariable analysis, where there is sharing of variance explained, a standardized beta coefficient estimate of at least 0.3 was used as the lower boundary of quantitative significance.[10,15]

RESULTS

Of 123 children with spina bifida and scoliosis, 13 had had a recent operation and 12 had not had recent spinal radiographs. Of the remaining 98 eligible children, 80 (82%) consented to participate. The baseline characteristics of the study and the exclusions/refusal group are shown in Table 1.

The mean age of the study patients was 12.5 (range 7–16) years. Fifty-one children (64%) were diagnosed previously with an Arnold-Chiari malformation, of which 16 required previous decompression. Thirty-one children (39%) had a documented syrinx and eight children required decompression of their syrinx. Fifty children (63%) were documented with a tethered cord and 37 had undergone previous release of their tethered cord. Seventy children (88%) had a ventricular-peritoneal shunt and 45 had had at least one revision of their shunt. Table 2 lists for the entire group the mean values of each test of physical disability and self-perception.

TABLE 1. Characteristics of Study and Refusal/Exclusion Groups*

	No. Children (%)	
	Study Cohort (n = 80)	**Exclusions Group (n = 25)**
Age (average in years, range 7–16)	12.5 SD = 2.7	12.1 SD = 2.9
Sex (no. males)	38 (47.5%)	9 (36.0%)
Neurologic motor level		
T12 or higher	39 (48.8%)	15 (60.0%)
L1 to L3	13 (16.3%)	4 (16.0%)
L4 to L5	15 (18.8%)	4 (16.0%)
Sacral	13 (16.3%)	2 (8.0%)
Scoliosis (Cobb angle)	38° SD = 25°	38° SD = 21°
Previous spinal operation	24 (30.0%)	12 (48.0%)
Special or integrated education	28 (35.0%)	10 (40.0%)
Ambulation classification		
Non-walker	46 (57%)	
Walks during exercise only	8 (10.1%)	
Walks in household	5 (6.3%)	
Walks in community	21 (26.6%)	

*None of the comparisons was significantly different (Student t test, $P > 0.05$).

Spinal Deformity

The average magnitude of the primary scoliotic curvature was 38 degrees (standard deviation [SD] = 25 degrees; range 10–108 degrees). The average amount of kyphosis and lordosis was 61 degrees (SD = 36 degrees; range 7–150 degrees) and 44 degrees (SD = 24 degrees; range 5–104 degrees), respectively. Pelvic obliquity averaged 9 degrees (SD = 8 degrees; range 0–38 degrees). On average, children were off balance by 16 mm (SD = 14.1 mm; range 0–60) in the coronal plane and 37 mm (SD = 36 mm; range = 32–135) in

TABLE 2. Outcomes of Physical Disability and Self-Perception for Entire Study Cohort

Self-perception (possible range: 5–25)	
Global	18.2 ± 3.3
Social	15.7 ± 3.2
Appearance	16.6 ± 4.3
Athletic	13.1 ± 4.3
Sitting Scale (possible range: 0–10)	8.1 ± 2.7
Ambulation (possible range: 1–4)	2.1 ± 2.7
Jebsen Hand Test (time for both hands in seconds, range 269–1,665)	513.3 ± 270.4
Spina Bifida Spine Questionnaire (possible range: 0–100)	65.8 ± 24.1
Activities Scale for Kids (possible range: 0–100)	62.4 ± 25.6

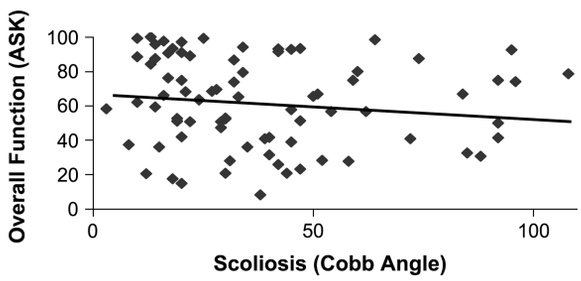
Data are given as mean ± SD.

the sagittal plane. None of the measures of spinal deformity (scoliosis, pelvic obliquity, sagittal balance, coronal balance, kyphosis, lordosis) was significantly correlated with any other deformity measure except, for a correlation between pelvic obliquity and scoliotic curvature (Pearson r = 0.33, $P = 0.05$).

Operative Results

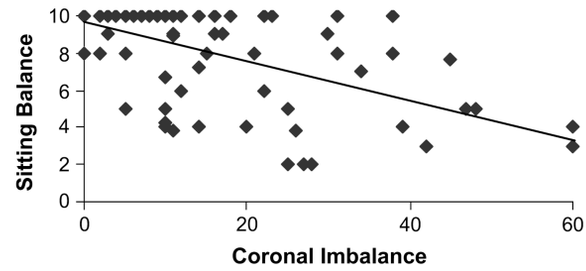
Twenty-four children had undergone spinal stabilization surgery consisting of anterior release and discectomy and posterior instrumentation to the pelvis with segmental unit rod fixation. Nineteen children had adequate preoperative radiographs available for comparison. The average preoperative Cobb angle was 73.7 degrees (SD = 18.0 degrees); after surgery the Cobb angle improved significantly (paired $t = 6.2$, $P < 0.001$) to an average of 39.0 degrees (SD = 24.8 degrees). Pelvic obliquity also significantly improved (paired $t = 2.4$, $P = 0.01$) from a preoperative average of 17.6 degrees (SD = 11.6 degrees) to a postoperative average of 11.3 degrees (SD = 7.9 degrees). Truncal malalignment improved minimally (paired $t = 0.4$, $P > 0.5$) from an average preoperative value of 21.3 mm (SD = 19.7 mm) to an average postoperative value of 19.2 mm (SD = 15.2 mm). In multivariable analyses with adjustment for confounding factors including neurologic level, amount of spinal deformity, or postoperative complications, on average children who underwent spinal stabilization surgery had significantly lower scores on the Sitting Scale (−1.3, $P = 0.003$), SBSQ (−11.0, $P = 0.002$), and ASK (−9.3, $P = 0.01$).

The relationship of scoliosis with the ASK is shown in Figure 2 and the relationship of coronal imbalance with sitting in Figure 3. No aspect of spinal deformity was related to the Harter Self-Perception Profile. In multiple linear regression, important factors related to function included more severe neurologic level, previous spinal surgery, older age, and the presence of hydrocephalus. After adjustment for those confounding factors, coronal imbalance (standardized beta parameter estimate = −0.31, $P = 0.002$; $R^2 = 0.42$) was the only aspect of spinal deformity significantly related, both quantitatively and statistically, to the Sitting Balance Scale. Scoliosis (standardized beta parameter estimate = −0.19, $P = 0.04$; $R^2 = 0.38$) was also statistically but not quantitatively significantly related to the Sitting Balance Scale. On average, sitting balance decreased 1 point (on the 10-point scale) for every 17-mm (95% confidence interval [CI] = 11–61 mm) shift in coronal imbalance, or for a 50-degree increase in the primary scoliotic Cobb angle (95% CI = 27–107 degrees). Thus, of all aspects of spinal deformity, only coronal imbalance was related to one aspect of disability (ie, sitting imbalance).



Unadjusted Pearsons Correlation Coefficient R = 0.1, P = 0.39

FIGURE 2. Relationship of overall function (ASK) with scoliosis.



Unadjusted Pearsons Correlation Coefficient R = 0.49, P = 0.0001

FIGURE 3. Relationship of sitting balance with coronal imbalance.

DISCUSSION

Spinal deformity in children with spina bifida is generally believed to cause severe disability.[1,8,30] Surgical correction of spinal deformity, however, is a serious undertaking, with long operating and recovery times. Given the magnitude of surgery and high complication rates,[5,29,31,36,48] some centers seldom recommend surgery.

Clinicians may attribute a child's disability to the severity of his or her scoliosis. However, scoliosis is more common in children with higher neurologic levels,[35,38] and it is this group that is most likely to be significantly disabled. After adjusting for neurologic level, this study showed no significant relationship between any aspect of spinal deformity with self-perception and overall physical function as measured by the ASK. The absence of relationship shown in this study suggests that spinal deformity may not have a substantial effect on overall physical function or self-perception in children with spina bifida.

Several aspects of spinal deformity have been suggested, in previous literature, to interfere with sitting ability. Increased kyphosis is believed to result in altered sitting posture and increased difficulty in the fitting of prostheses and braces.[27,36,40] Pelvic obliquity has been suggested to cause sitting imbalance and subsequent pressure sores.[27,34,40] Other authors have stated that scoliosis alters the position of the trunk so that it is no longer centered over the pelvis, which in turn affects the child's stability and sitting balance and may cause pressure sores.[4,25,31,40] In this study, coronal imbalance was the only aspect of spinal deformity found to affect one aspect of physical function (ie, sitting). The importance of this finding is that simple interventions, such as chair modifications, should be investigated as possible means to shift the trunk to improve coronal balance and sitting function. In patients in whom surgical therapy is chosen, specific attention should be directed toward achieving coronal balance, including correction of all curves and leveling pelvic obliquity.[2]

This study has several potential limitations. First, although the sample size was limited, virtually all the observed

relationships were quantitatively weak. For example, at the lower 95% CI, the Cobb angle would have to increase by 27 degrees for a 1-point change in the 10-point Sitting Balance Scale. Second is the issue of generalizability of the results. The results of this study cannot be extrapolated to those with scoliosis beyond 110 degrees, the upper limit of the range of scoliosis in this study. Third, the results of this study rely on the validity of the chosen measures in children with spina bifida. However, all the measures chosen were developed specifically for or extensively tested and validated in children with spina bifida. In addition, children's educational placement, presence of hydrocephalus, and number of shunts were assessed and adjusted for the multivariable analyses. Fourth, this study did not evaluate long-term outcomes of untreated spinal deformity. Many issues, such as pulmonary dysfunction, adult function, pressure sores, and cosmesis, may justify surgery in the long term. However, no study had addressed these issues in the adult population.

In conclusion, this study showed no relationship between spinal deformity and overall physical function or self-perception. Studies are required to show the benefits of spinal surgery in children with spina bifida. Surgeons should be clear in their indications for surgery and recognize that in the short term the potential benefit of surgery may be, at best, to improve only sitting balance.

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