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JAMA. 2003;289(5):559-567 (doi:10.1001/jama.289.5.559)

http://jama.ama-assn.org/cgi/content/full/289/5/559

Health and Function of Patients With Untreated Idiopathic Scoliosis
A 50-Year Natural History Study

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Context Previous long-term studies of idiopathic scoliosis have included patients with other etiologies, leading to the erroneous conclusion that all types of idiopathic scoliosis inevitably end in disability. Late-onset idiopathic scoliosis (LIS) is a distinct entity with a unique natural history.

Objective To present the outcomes related to health and function in untreated patients with LIS.

Design, Setting, and Patients Prospective natural history study performed at a midwestern university with outpatient evaluation of patients who presented between 1932 and 1948. At 50-year follow-up, which began in 1992, 117 untreated patients were compared with 62 age- and sex-matched volunteers. The patients' mean age was 66 years (range, 54-80 years).

Main Outcome Measures Mortality, back pain, pulmonary symptoms, general function, depression, and body image.

Results The estimated probability of survival was approximately 0.55 (95% confidence interval [CI], 0.47-0.63) compared with 0.57 expected for the general population. There was no significant difference in the demographic characteristics of the 2 groups. Twenty-two (22%) of 98 patients complained of shortness of breath during everyday activities compared with 8 (15%) of 53 controls. An increased risk of shortness of breath was also associated with the combination of a Cobb angle greater than 80° and a thoracic apex (adjusted odds ratio, 9.75; 95% CI, 1.15-82.98). Sixty-six (61%) of 109 patients reported chronic back pain compared with 22 (35%) of 62 controls ($P = .003$). However, of those with pain, 48 (68%) of 71 patients and 12 (71%) of 17 controls reported only little or moderate back pain.

Conclusions Untreated adults with LIS are productive and functional at a high level at 50-year follow-up. Untreated LIS causes little physical impairment other than back pain and cosmetic concerns.

JAMA. 2003;289:559-567 www.jama.com

Late-onset idiopathic scoliosis (LIS) is a structural lateral curvature of the spine arising in otherwise normal children usually during puberty. The diagnosis is made when other causes of scoliosis, such as neuromuscular disorder, vertebral malformation, trauma, or tumor, have been ruled out. Epidemiological and natural history studies estimate that 1% to 3% of the at-risk population will have some degree of curvature, with the vast majority of curves requiring no intervention.[1-7] Applying these estimates to current population figures, LIS affects more than 60 000 adolescents in the United States.[8] In 1995, there were an estimated 602 884 visits to private physician offices associated with the *International Classification of Diseases, Ninth Revision (ICD-9)*[9] code 737.30 for idiopathic scoliosis.[10] Of these visits, 37% were to physicians other than orthopedic surgeons, making the clinical course of idiopathic scoliosis of importance to multiple disciplines.

Previous long-term studies of idiopathic scoliosis[1,11-23] presented a grim prognosis, perpetuating the common misperception that all types of idiopathic scoliosis inevitably lead to disability from back pain and cardiopulmonary compromise. The shortcomings of these earlier studies have been previously described[23]; of particular concern is the inclusion of patients with congenital, neuromuscular, or early-onset idiopathic scoliosis, and the failure to evaluate outcome in terms of the location of the curvature. However, according to Dickson,[24] the presence of a significant thoracic deformity prior to age 5 years indicates a real risk of cardiopulmonary compromise, whereas LIS is most commonly a matter of de-

For editorial comment see p 608.

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Table 1. History of Cohort*

Source	Eligible Population	Included in Analysis	Excluded From Analysis: Fusions	Deaths	Other†	Not Located	Refused Participation
Ponseti and Friedman,[26] 1950	444	394	50	0	0	0	0
Collis and Ponseti,[27] 1969	394	195	3	17	42	113	24
Weinstein et al,[23] 1981	332	161	2	16	0	133	20
Current study	314	117	3	36	4	127	27

*Some persons in the not located and refused participation groups in previous study were located or accepted enrollment in subsequent study.
†Includes misdiagnosis and mental impairment.

formity without any serious organic health problems. For these reasons, inferences about the natural history of LIS from uncontrolled studies of heterogeneous groups are questionable.

Treatment of any condition is an attempt to alter its natural history; therefore, long-term studies are necessary to provide benchmarks for clinicians and policymakers. The most common treatment of LIS involves early, conservative treatment to prevent curve progression. This forms the basis of school screening programs and the use of bracing in skeletally immature patients. Curves that progress to between 40° and 50° in skeletally immature patients have been shown to continue progression throughout adulthood, most often at the rate of approximately 1° per year.[22] Consequently, a Cobb angle[25] of between 40° and 50° has become the threshold indicating need for instrumentation and arthrodesis to correct the curvature, and to additionally prevent the sequelae of deformity, pain, and disability associated with this condition. Since the goal of both conservative and operative treatment of LIS is preventative, all decision makers must be aware of exactly what it is they are trying to prevent. To this aim, we present outcomes related to health and function in a long-term cohort of untreated patients at 50-year follow-up.

METHODS

Study Population

Between 1932 and 1948, 444 patients diagnosed as having LIS were seen at our facility. This group was first described by Ponseti and Friedman[26] in 1950 and subsequently at 30-year[27] and 40-year follow-up.[22,23] TABLE 1 summarizes the history of the cohort, noting the number of fusions, exclusions due to misdiagnosis, deaths, missing patients, and refusals to participate.

The current target population consisted of 314 eligible patients from the original cohort who had not been fused, excluded for other reasons, or had died. Human subjects' review board approval was obtained prior to beginning searching for the patients. Informed consent was obtained as patients were enrolled. We were unable to determine the disposition of 127 patients (88 had not been located since the 1950 report[26]) despite a search of the National Death Index[28] and letters and telephone calls to the last known address and to relatives. Of the remaining patients, 36 were dead, 3 had undergone fusion for scoliosis, 2 had been misclassified, and 2 were excluded due to decreased mental functioning. Thus, 144 were located and eligible. All were asked to return for evaluation and radiographs, or if unable to return to have these procedures performed locally. Twenty-seven patients refused to participate, often citing the length of the questionnaires as the reason for not participating. Hence, 117 patients are included in this study.

Sixty-two individuals participated in the study as control subjects. These volunteers were sought at various local sites (hospital clinics, senior citizen centers, retirement homes). Volunteers were examined by the Adams forward bend test for the presence of spinal curvature and/or were questioned concerning any history of spinal curvature. None were noted to have any evidence of non–age-related spinal deformity. The control group was age-matched (<65 years, ≥65 years) and sex-matched at a 100% target rate for men (n=13) and 50% target rate for women (n=49).

Outcomes

Mortality, back pain, pulmonary symptoms, general function, depression, and body image are the outcomes presented here. Details of the radiographic history of this cohort will be reported in a separate article. Outcomes used in the 30-year[27] and 40-year[23] follow-up studies were included for longitudinal comparisons.

All radiographs were taken in the standing position using a posterior-anterior projection. Evaluation included the Cobb angle[25] of the primary and compensatory curves along with other standard measures of spinal balance and rotation. Evidence of thoracic and/or lumbar osteoarthritis and other radiographic changes was noted. All dependent variables were examined for a relationship with curve type, and when appropriate, the magnitude of the curve. For certain analyses, the magnitude of the primary angle was used to classify patients as either having small or large curves relative to other patients with the same curve type. For patients with double major curves, the thoracic measurement was used except in cases where the lumbar curve was more than 10° larger than the thoracic curve.

The physical examination included vital signs, height, weight, spinal range of motion, chest expansion, reflexes, evaluation of motor-sensory function, and tests for nonorganic physical signs.[29] Pulmonary function testing was not repeated as this was reported on extensively in the last study.[23]

Statistical Analysis

The number of usable responses for each variable varies due to missing or ambiguous data. For the longitudinal analyses, only responses from those who participated in all 3 studies are included. No attempt was made to interpolate or otherwise replace missing data.

The Kaplan-Meier method was used to calculate survival probabilities. Fisher exact tests, odds ratios, Wilcoxon rank-sum tests, and logistic regression were used for nominal or ordinal variables. For interval or ratio variables, Pearson correlations, *t* tests, and analysis of variance with corresponding post-hoc tests were conducted. All analyses were performed using SAS statistical software (Version 8; SAS Institute Inc, Cary, NC). Tests were conducted as 2-tailed and the significance level was set at $P=.05$. All dependent variables were tested for differences due to curve type or size and for differences between the scoliosis and control groups. Unless otherwise noted, no statistically significant differences were found.

RESULTS

Sample Characteristics

Of the 117 patients, 104 (89%) were women (compared with 84% of those included in the 1950 article[26]). This ratio is comparable with the expected 10:1 ratio based on prevalence literature.[1-3,7,30-40] The mean age was 66 years (range, 54-80 years) and the mean follow-up since diagnosis was 51 years (range, 44-61 years). Forty-eight patients (41%) had thoracic curves, 14 (12%) thoracolumbar, 32 (27%) lumbar, and 23 (20%) had double major curves. Curve characteristics of 79 patients with current radiographs are summarized in TABLE 2. The Cobb angles ranged between 23° and 156° degrees in thoracic curves (mean, 85°); between 50° and 155° in thoracolumbar curves (mean, 90°); and between 15° and 90° in lumbar curves (mean, 49°). The thoracic components of the double major curves ranged between 30° and 104° (mean, 79°). The lumbar component ranged between 32° and 110° (mean, 76°). Measurements at skeletal maturity are provided in the table to demonstrate average progression of the curves. Using the current median as the threshold, those curves with a thoracic apex and a Cobb angle of 80° or higher and lumbar curves of 50° or higher were classified as large.

Representativeness of the sample was evaluated by comparing the age, sex, and curve type and size at maturity of the sample with that of the patients who refused to participate (n=27) or those who participated in the 1981 study[23] but were not located for the current study (n=17). Radiographs taken at skeletal maturity were available for 35 of these 44 nonparticipants. There were no significant differences in the mean Cobb angle at maturity between the groups, except in the case of the double major curves, in which the nonparticipating group had a mean Cobb angle of 66° compared with 44° in the sample ($P=.04$). There was no difference in the distribution of curve types between the 2 groups, or in the mean age or sex. If differences in the dependent variables are indeed related to age, sex, type of curve, or curve magnitude at maturity, the above comparisons provide little evidence for bias in the results due to these characteristics in the participating sample.

All patients completed questionnaires. Fifty-four patients returned for a physical examination and radiographs; 3 patients had radiographs taken locally in conjunction with an orthopedic examination; and 23 patients had radiographs taken locally but did not have physical examinations.

Demographics

The scoliosis patient and control groups were demographically similar (TABLE 3). Seventy-one (61%) of 117 patients were

Table 2. Cobb Angles by Curve Type and Period

Curve Type	No. (%)	Current Cobb Angles, Degrees	Cobb Angles at Skeletal Maturity, Degrees
		Mean (SD) [Range]	Mean (SD) [Range]
Thoracic	34 (43)	84.50 (30.17) [23-156]	60.48 (26.79) [26-108]
Thoracolumbar	11 (14)	89.54 (32.69) [50-155]	43.63 (8.70) [36-64]
Lumbar	22 (28)	49.41 (26.38) [15-90]	35.05 (13.18) [15-63]
Double major			
Thoracic component	12 (15)	79.08 (21.92) [30-104]	66.00 (21.53) [28-97]
Lumbar component	12 (15)	76.42 (21.88) [32-110]	60.75 (18.06) [26-83]

Table 3. Demographics of Patients With Scoliosis and Control Group

Demographic	No./Total (%) Scoliosis	No./Total (%) Control	*P* Value
Sex			
Women	104/117 (89)	49/62 (79)	.12
Men	13/117 (11)	13/62 (21)	
Mean (SD) age, y			
<65	46/117 (39)	23/62 (37)	.87
≥65	71/117 (61)	39/62 (63)	
Education			
High school or less	55/108 (51)	26/62 (42)	.07
Some college	28/108 (26)	13/62 (21)	
Undergraduate degree	14/108 (13)	7/62 (11)	
Graduate work	11/108 (10)	16/62 (26)	
Marital status			
Never married	11/107 (10)	6/62 (10)	>.99
Married once	81/107 (76)	47/62 (76)	
Married ≥1	15/107 (14)	9/62 (15)	
No. of children, median (range)			
Women	3/96 (0-8)	3/48 (0-9)	.34
Men	2/96 (0-4)	2/48 (0-4)	.91

older than 65 years and 97% were white. Fifty-five (47%) had a high school education or less, and 25 (21%) were college graduates. Ninety-six patients (90%) had been married at least once, while 11 (10%) had never been married. The median number of children was 3. The cesarean rate in scoliotic women was 3% compared with 10% in the control group.

Mortality

Deaths since 1981 are summarized in TABLE 4. Information on other deaths has been previously published,[23,27] and the mean age at death for these 36 patients was 65 years. Despite the National Death Index search and contacts with relatives, the cause of death was not confirmed in 13 cases. To our knowledge, scoliosis potentially contributed to the death of 3 patients (case-patient 6, 11, and 31). There was no difference between the age at death and the mean age of the living sample, nor was there a difference between the 2 groups in curve type or size from the last available radiograph.

Survival probability estimates for this cohort were 0.44 (95% confidence interval [CI], 0.36-0.52) if all patients not located are dead; 0.70 (95% CI, 0.63-0.78) if all patients not located are alive; and 0.55 (95% CI, 0.47-0.63) if half of the patients not located are alive. TABLE 5 includes the number of known dead, the number not located, and the estimated survival probability under these 3 assumptions. According to the 1994 US life tables,[41] women born between 1929 and 1931 have a 0.57 probability of surviving until age 65 years, a rate not dissimilar to ours under the third assumption.

Table 4. Mortality Cases Since 1981*

Case No.	Age at Death, y	Cobb Angle†	Cause of Death
Thoracic Curve			
1	Unknown	102°	Unknown
2	Unknown	42°	Cancer
3	Unknown	78°	Unknown
4	49	128°	Bronchial cancer
5	57	Unknown	Embolus
6‡	63	140°	Respiratory failure, pneumonia, kyphoscoliosis
7	64	34°	Cardiopulmonary arrest
8	66	99°	Septic shock
9	67	95°	Unknown
10	67	32°	Myocardial infarction
11‡	69	148°	Narcotic-induced respiratory arrest
12	69	78°	Farm accident
13	72	100°	Emphysema
14	73	35°	Respiratory failure, COPD
Thoracolumbar Curve			
15	Unknown	48°	Unknown
16	Unknown	69°	Unknown
17	Unknown	59°	Cancer
18	Unknown	15°	Unknown
19	Unknown	25°	Unknown
20	Unknown	Unknown	Unknown
21	Unknown	45°	Unknown
22	55	90°	Cardiopulmonary arrest, cerebral aneurysm
23	64	62°	Myocardial infarction, COPD
24	65	68°	Cardiopulmonary arrest
Lumbar Curve			
25	Unknown	31°	Unknown
26	63	15°	Respiratory failure, leukemia
27	64	30°	Cardiopulmonary arrest, lung cancer
28	73	20°	Unknown
Double Major Curve			
29	Unknown	37°/32°	Unknown
30	Unknown	37°/30°	Unknown
31‡	53	102°/70°	Respiratory failure, breast cancer
32	54	Unknown	Cardiopulmonary arrest, cancer
33	59	82°/83°	Atherosclerotic cardiovascular disease
34	63	73°/68°	COPD
35	75	60°/56°	Lung cancer
36	81	49°/45°	Cancer

Abbreviation: COPD, chronic obstructive pulmonary disease.
*Data are from Weinstein et al.[23]
†Measurement from last radiograph.
‡Scoliosis may have contributed to death.

Physical Examination

The results of the physical examination are shown in TABLE 6. Except for diminished chest expansion (<2.5-cm increase in chest circumference on inspiration) in some patients with thoracic-level curves, physical examination results were within normal limits.

Forty-five (79%) were able to forward bend to at least ankle level, and 52 (91%) had no pain with this motion. There were no lower extremity motor deficits and sensory examination was likewise unremarkable. Test results for nonorganic signs were all negative. The straight leg raise in both the seated and supine positions was negative in all examinations.

Radiographic Examination

Of the 79 patients with current radiographs, 72 (91%) had evidence of arthritis or other radiographic changes. Two patients (1 thoracic and 1 thoracolumbar curve) had thoracic endplate abnormalities; 13 had evidence of

Table 5. Survival Probabilities Under 3 Assumptions

	Assumption											
	All Not Located Are Alive				All Not Located Are Dead				Half Not Located Are Alive			
Year	No. Dead	No. Not Located	No. Survived	Survival Probability (95% CI)	No. Dead	No. Not Located	No. Survived	Survival Probability (95% CI)	No. Dead	No. Not Located	No. Survived	Survival Probability (95% CI)
1950	0	0	350	1.00 (Referent)	0	0	350	1.00 (Referent)	0	0	350	1.00 (Referent)
1968	17	88	245	0.94 (0.90-0.97)	105	0	245	0.70 (0.64-0.76)	61	44	245	0.80 (0.75-0.85)
1978	16	22	207	0.87 (0.82-0.91)	38	0	207	0.59 (0.52-0.66)	27	11	207	0.71 (0.64-0.77)
1992	36	17	154	0.70 (0.63-0.78)	53	0	154	0.44 (0.36-0.52)	45	8	154	0.55 (0.47-0.63)

Abbreviation: CI, confidence interval.

thoracic osteoarthritis (4 with thoracic, 2 with thoracolumbar, 2 with lumbar, and 5 with double major curve); 7 had osteopenia (6 with lumbar and 1 thoracolumbar curve); and 1 had lumbar endplate abnormalities (lumbar curve). Sixty-nine (87%) of 79 patients had evidence of lumbar osteoarthritis (28 thoracic, 10 thoracolumbar, 20 lumbar, and 11 double major curves).

Self-reported Health and Function

Pulmonary Function. Scoliosis was not associated with an increased risk of self-reported history of smoking, asthma, bronchitis, or pneumonia. All 4 patients with chronic obstructive pulmonary disease had large curvatures involving the thoracic spine (one 82° double major curve and 3 thoracic curves averaging 101°).

Twenty-two (22%) of 98 patients reported shortness of breath during everyday activities compared with 8 (15%) of 53 controls. Thirty-five (39%) of 89 patients and 15 (31%) of 48 controls had shortness of breath while walking 1 city block. Smoking status was not related to shortness of breath in either the patient or control group.

Although there were no significant differences in reported shortness of breath with activities between groups, there was a relationship between shortness of breath and the size and location of the curve (unadjusted odds ratio [OR], 2.13; 95% CI, 0.72-6.28). For patients with relatively small curves (<80° with thoracic involvement or <50° lumbar), those with a thoracic apex were at no greater risk for shortness of breath with activities than those with a single lumbar curve (adjusted OR, 0.43; 95% CI, 0.08-2.44). However, patients with the combination of a large (>80°) curve and a thoracic apex had significantly greater odds of shortness of breath than did those with large (>50°) lumbar curves (adjusted OR, 9.75; 95% CI, 1.15-82.98). A similar pattern of ORs was noted for shortness of breath while walking 1 block.

The effect of apical rotation was also examined. Using logistic regression, we found that curve apex and Cobb angle were not significant predictors of shortness of breath when rotation was simultaneously evaluated. Larger degrees of rotation were significantly associated with shortness of breath (adjusted OR, 1.16; 95% CI, 1.04-1.30; $P=.008$).

Of the 79 patients who participated in 1968, 1981, and 1992, 15 (19%) reported daily shortness of breath in 1968, as did 22 (28%) in 1978, and 19 (24%) in 1992. A Cobb angle of greater than 50° at skeletal maturity was associated with significantly increased odds of developing shortness of breath (1968: OR, 14.58 [95% CI, 2.28-93.46]; 1978: OR, 5.01 [95% CI, 1.23-20.99]; 1992: OR, 3.67 [95% CI, 1.11-12.12]). A thoracic curve apex was not an independent predictor of shortness of breath in these analyses.

Back Pain. Both chronic and acute back pain were more prevalent in patients relative to controls. However, for those subjects with pain, there was no significant difference in intensity or duration between the patients and controls (TABLE 7).

Table 6. Selected Results of Physical Examination

Variable	Value
	Mean (Range)
Height, cm	157.57 (145-178)
Weight, kg	68.62 (41-156)
Pulse, beats/min	78 (60-132)
Respiratory rate, breaths/min	17 (12-32)
Blood pressure, mm Hg	
Systolic	143 (110-196)
Diastolic	86 (66-118)
Prominence magnitude, mm	
Rib	36 (3-90)
Lumbar	24 (5-54)
	No./Total (%)
Forward bend to ankles	45/57 (79)
Forward bend without pain	52/57 (91)
Pelvic tilt	44/48 (92)
Reflexes	
Triceps	48/56 (86)
Biceps	49/56 (88)
Brachial radialis	48/56 (86)
Knee jerk	41/57 (72)
Ankle jerk	32/56 (57)
Chest expansion (>2 cm on inspiration)	24/57 (42)

Specifically, 66 (61%) of 109 patients reported chronic back pain at any level of the spine compared with 22 (35%) of 62 controls ($P=.003$). Current pain was measured by intensity (none=0; unbearable pain=5),[42] and duration (<1 month=1; ≥2 years=6). Currently, 71 (77%) of 92 patients report back pain compared with 17 (35%) of 48 controls ($P=.001$). Of those with pain, the intensity was similar: 48 (68%) of 71 patients and 12 (71%) of 17 controls had little or moderate pain ($P>.99$). Duration of pain was also similar between the 2 groups: 61 (91%) of 67 patients and 13 (76%) of 17 controls have had back pain for at least 2 years ($P=.12$). We additionally summed the intensity and duration

Table 7. Onset and Intensity of Current Back Pain

Description of Pain	Score	No./Total (%) Scoliosis	No./Total (%) Control	*P* Value
Overall Pain				
None	0	21/92 (23)	31/48 (65)	<.001
Some	1-5	71/92 (77)	17/48 (35)	
Intensity				
Little/moderate	1-2	48/71 (68)	12/17 (71)	>.99
Quite bad/unbearable	3-5	23/71 (32)	5/17 (29)	
Duration				
<2 y	2-5	6/67 (9)	4/17 (24)	<.12
≥2 y	6	61/67 (91)	13/17 (76)	

scores to create a more complete pain composite. The median score was 7 in the scoliosis group compared with 6 in the control group ($P = .08$).

Of 78 patients responding to the question in all 3 studies, 22% had never or rarely had pain, 38% have had occasional pain, 21% have had frequent pain, and 19% have had daily pain. The median response was occasional pain in all 3 studies. Of 25 patients without back pain in 1968, 11 still are without pain, 11 have occasional pain, 2 have frequent pain, and 1 has daily pain.

Both acute back pain scores and current radiographic data were available for 60 patients. Of these, 9 (15%) had evidence of thoracic osteoarthritis and 53 (88%) had lumbar osteoarthritis. Neither thoracic ($P = .89$) nor lumbar osteoarthritis ($P = .12$) was significantly related to the pain composite scores.

The majority of both the patient (61%) and control (54%) groups rarely use pain medication of any type. No one with scoliosis reported using strong narcotics more than rarely, while 2 (7%) of 30 controls used 1 to 2 doses of strong narcotics per day. When the patient group was asked specifically about pain medicine use for their backs, 48 (49%) of 97 patients stated they took no medications, 35% took aspirin or acetaminophen only, 6% took nonsteroidal anti-inflammatories, and 10% took varying combinations of the above. Only 1 scoliosis patient reported taking narcotic medication for back pain.

Activities of Daily Living. Respondents were asked to indicate their capacity (no = 0 and yes = 1) to perform each of 15 different activities of daily living, such as riding in a car, sitting for long periods, walking up or down stairs, making a bed, or cooking a meal. These responses were then summed to create an overall capacity score. The median capacity score was 14 for patients and 15 for controls. Additionally, the frequency with which individuals performed these activities was examined. Frequency was measured on a 0 (never) to 5 (daily) scale and scores were then summed to create a 0- to 75-point activity scale. The median performance score for the scoliosis group was 48 compared with 50 in the control group ($P = .03$). Therefore, there was no difference in the capacity to perform these activities, but the control group performed them slightly more frequently.

The acute back pain index was significantly related to the performance scores, but after controlling for back pain, there was no significant difference in performance scores between the groups. Shortness of breath during everyday activities was also related to performance ($P = .01$).

Cause and Effect of Disability on Work Hours and Activity Level. Thirty-seven (39%) of 94 patients felt they had a disability compared with 16 (30%) of 53 controls. Thirty-one (80%) of these 37 patients and 15 (94%) of these 16 controls said their disability was back-related. Of these, 25 patients and 15 controls were still working. Thirteen (52%) of these 25 patients reduced their work hours due to back pain, as did 6 (40%) of controls. Twenty-three (74%) of 31 patients and 8 (53%) of 15 controls reduced their activity level due to back pain.

Psychosocial Indices

Depression Index. The presence of clinical depression was evaluated using a modification of the Self-Rating Depression Scale.[43] The reliability and validity of this scale has been well documented for use as both a screening tool and in outcomes assessment.[43-45] The items describe symptoms related to the presence of depression and respondents rate the frequency with which they experience each symptom. Possible scores range from 0 to 100, with lower scores indicating less frequent depressive symptoms. The mean (SD) score for the scoliosis group was 47.53 (9.74) with a range of 24.21 to 69.00 compared with 48.17 (10.02) and a range of 29.63 to 66.00 in the control group ($P = .60$).

Body Satisfaction. Body satisfaction was measured using an adaptation of the Body Satisfaction Scale.[46] Subjects rated their satisfaction with 16 body parts (the original scale), as well as appearance from the front, side, and rear, and appearance in clothes and a swimsuit (added for this study) using a 6-point scale. The 21 ratings were then averaged to create 2 subscale scores and a total score. The first subscale included items concerning the axial skeleton (shoulders, upper back, lower back, and hips). The mean (SD) score for the scoliosis group was 3.02 (1.23) with a range of 1.30 to 6.00 compared with 4.47 (1.11) and a range of 1.75 to 6.00 in the control group ($P = .001$). The second subscale included the remaining items to determine if the effect of scoliosis on body satisfaction was localized to the back and hips, or if it affected perception of the rest of the body. The patient mean (SD) score was 3.74 (0.83) with a range of 1.38 to 6.00 compared with 4.15 (1.03) and a range of 1.73 to 6.00 in the control group ($P = .01$). The mean (SD) total score in the scoliosis group was 3.60 (0.84) with a range of 1.30 to 6.00 compared with

4.21 (1.00) and a range of 2.00 to 5.95 in the control group ($P = .001$). Therefore, on all scales, patients were slightly dissatisfied to slightly satisfied, and the controls were slightly satisfied to moderately satisfied.

Neither the current Cobb angle nor the degree of apical rotation was highly correlated with the body image subscales or total scores (Pearson correlation $r = -0.08$ to -0.32).

Perception of Limitation Due to Scoliosis. Patients responded to the open-ended prompt "Do you feel your back has limited your life, or in any way affected you, other than as discussed above?" [treatment, pain, medications, pulmonary complaints, apparent deformity]. Responses varied, but the majority dealt with such issues as difficulty in purchasing clothes, decreased physical capacity, and self-consciousness. In 1968, 33% of 73 respondents felt limited compared with 25% in 1978, and 32% in 1992.[23,27]

COMMENT

Patients with LIS and their families are often upset by misinformation about the condition and its ultimate effect on their lives. Although it is quite clear today that the natural history of scoliosis varies according to the etiology and the pattern of vertebral involvement, the results of studies following cases of mixed origin have been used to develop screening and treatment policy. For example, a state screening program has been supported because untreated scoliosis has been reported to result in changes in cardiopulmonary function and life expectancy, and that "delay in obtaining specialized care may lead to serious crippling."[47]

The current study completes the natural history study of untreated LIS patients first seen at the University of Iowa between 1932 and 1948. We did not find evidence to link untreated LIS with increased rates of mortality in general, or from cardiac or pulmonary conditions potentially related to the curvature. In LIS, only patients with thoracic apices and curves of more than 100° are at increased risk of death from cor pulmonale and right ventricular failure.[23] The cumulative death rate was approximately 54%, but not higher than that expected in the general population. Of the 36 deaths in the last 10 years, only 3 are possibly attributable to scoliosis. This points out the deficiency of previous research reporting a higher than expected mortality rate without properly controlling for the age at onset.[19] Furthermore, no patient with LIS in that study died of respiratory failure. Likewise, Branthwaite[48] found dyspnea solely due to the curvature to be extremely rare in patients with LIS. Therefore, respiratory failure and premature death may develop in idiopathic scoliosis, but there is no indication from any study that severe pulmonary compromise is common in those with LIS.

With respect to back pain, recent data from the National Health and Nutrition Examination Survey[49] estimate the annual prevalence of back pain in the population of persons aged 65 years or older to be 29%, while 75% to 85% of all people will experience some form of back pain during their lifetime.[50] Although the prevalence of back pain in untreated scoliosis likely exceeds that in the general population, it does not appear to cause excessive disability. For example, Dahlberg[51] found similar rates of surgery specifically for backache in both scoliotic and nonscoliotic patients. Horal[52] showed that patients with scoliosis did not represent a disproportionate number of disability pensions. Furthermore, the 3 Swedish long-term follow-up studies of idiopathic scoliosis, all with follow-up periods longer than 30 years and all with more than 90% of the patients traced, also demonstrated that low back pain was not a significant problem in these patients.[17,19,20]

On average, patients have been experiencing occasional back pain during the past 30 years, and the frequency of back pain has not significantly increased in this cohort since 1968. Although scoliosis patients report more chronic back pain, those with pain have similar profiles in terms of duration and intensity as their peers, and their ability to work and perform everyday activities is similar to their peers. Additionally, back pain had no larger impact on work and activities for scoliosis patients than it did for controls.

Late-onset scoliosis, and possible sequelae such as back pain and pulmonary limitations, must be viewed in light of its effect on function and self-esteem. The authors of the Ste-Justine series[14,18,53,54] conclude that patients with idiopathic scoliosis perceive themselves to be less healthy than their peers and experience limitations in certain activities such as lifting, walking long distances, standing and sitting for periods, and the traveling and socializing outside the home. The present study did not find the patients to be significantly different from controls in terms of ability to perform similar activities to those reported in the Ste-Justine studies. Our findings also conflict with those of Dickson et al[55] who found untreated patients to have decreased physical, functional, self-care, and positional abilities when compared with controls. Likewise, we found that back pain and shortness of breath had similar effects on the function and activity levels of both the control and patient groups.

A recent long-term study from Sweden corroborates our interpretations concerning back pain and function. Danielsson and Nachemson, in comparing previously braced patients[56] and patients who had undergone surgery[57] with the same set of age-matched controls, found little evidence that either patient group was significantly impaired relative to their peers when using the 36-item Short Form Health Survey (SF-36)[58] and the Oswestry Disability[59] questionnaire. The mean curve size in both groups was greater than 30°. Another recently reported follow-up of more than 20 years found no difference in quality of life, including back pain and function, between adolescent idiopathic patients who had undergone surgery and those who remained untreated, as inferred from multiple instruments including the Oswestry Disability, Roland-Morris, and the EuroQol-5D.[60] These studies do not confirm the necessity of intervening in LIS to prevent back pain and disability in late adulthood.

This series of Iowa studies[22,23,26,27] does not demonstrate a grim prognosis. In 1968, at the mean age of 42 years, 98% of the sample (n=195) were either homemakers or gainfully employed.[27] Sixteen percent restricted their activities due to their backs. The mortality rate of 7% was only slightly higher than that expected in the general population (5.4%). Sixty-nine percent only had occasional back pain compared with 72% in the control group. Ten years later,[23] a similar sample of 161 patients from the same cohort was reviewed at the mean age of 53 years. All but 4 were reported as normally active and 12% restricted activities due to their back, but none were receiving disability due to scoliosis. Sixty-three percent (101/161) of patients reported occasional back pain compared with 75% (75/100) of the controls. We have not been able to demonstrate a significant correlation between curve severity or curve location and back symptoms. At skeletal maturity, 2% of patients showed evidence of osteoarthritis of the spine. Currently, this rate is 75%. There was no evidence, however, for a relationship between the degree of back pain and osteoarthritis, or for a corresponding increase in back pain over the study period. Curve characteristics are, however, highly predictive of pulmonary symptoms. The current study found that having a Cobb angle of greater than 50° at skeletal maturity is a significant predictor of decreased pulmonary function. The fact that large curves with a thoracic apex have been associated with decreased vital capacity and more frequent shortness of breath was demonstrated in the 1981 follow-up.[23] Using suggested score criteria,[44,45] the depression indices for both the scoliosis and control groups compare closely with those for nondepressed patients. On average, patients were slightly dissatisfied to slightly satisfied with their bodies.

By closely studying this group of patients for more than 50 years, we have learned that patients with untreated LIS can function well as young adults, become employed, get married, have children, and grow to become active older adults. Unfortunately, patients with untreated LIS can develop significant deformity, and the cosmetic aspect of this condition cannot be disregarded. The physical outcomes demonstrated in this cohort born many decades ago can be used to predict the likely experience of a similar set of untreated patients born later in the century, although what is less sure is if a contemporary cohort (and their peers) would be as accepting of deformity as these patients have been.

It is essential that community physicians and the public recognize the difference in clinical course between early-onset scoliosis and LIS, and recognize that the latter is likely to cause little physical impairment other than back pain and cosmetic concerns. Curves less than 30° at skeletal maturity rarely get worse. However, back pain may arise in any patient regardless of curve size or location. School screening programs, if conducted at all, should aim for low false-positive rates, because the high error rates have led to undue concern for adolescents and their parents, as well as contributing to expensive, unnecessary radiographs and specialty consultations.[61,62]

Community physicians should be concerned with noticeable body asymmetries as noted on the forward bend test in the thoracic, thoracolumbar, and lumbar area, shoulder height discrepancies, and trunk shift, especially in skeletally immature patients. The recommendation of bracing and surgery must be made on an individual basis with the patient and family well-informed of the natural history of the disease.

Author Contributions: *Study concept and design:* Weinstein, Spratt, Ponseti.
Acquisition of data: Weinstein, Dolan, Spratt, Peterson, Spoonamore, Ponseti.
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Critical revision of the manuscript for important intellectual content: Weinstein, Dolan, Spratt, Peterson, Spoonamore, Ponseti.
Statistical expertise: Dolan, Spratt.
Obtained funding: Weinstein, Dolan.
Administrative, technical, or material support: Dolan, Peterson, Spoonamore.
Study supervision: Weinstein, Dolan, Ponseti.
Funding/Support: This study was supported by grants from the Orthopaedic Research and Education Foundation, grant RR00059 from the General Clinical Research Centers, and funding from the Libby Pink Foundation, Mr and Mrs Herb and Nancy Townsend, and the family of Mr Richard Greenlee.
Acknowledgment: The investigation was performed at the Department of Orthopaedic Surgery, University of Iowa Hospitals and Clinics, Iowa City. We thank Jose A. Morcuende, MD, PhD, and Sergio A. Mendoza, MD, for their critical review of the manuscript.

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