CASE SERIES

Long-term outcome of patients with adolescent idiopathic scoliosis seeking nonoperative treatment after a mean follow-up of 42 years

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Abstract

Purpose Adolescent idiopathic scoliosis (AIS) affects up to 3% of otherwise healthy adolescents. The extreme long-term outcomes of nonoperative treatment are underreported. This study aimed to investigate the long-term outcome of nonoperative-treated AIS patients. Comparison between a bracing and an observation approach were performed.

Methods In a retrospective cohort study, 20 nonoperatively treated AIS patients were observed concerning patient-related outcome measures (PROM) (visual analog scale (VAS), Short Form Health Survey 36 item (SF 36), Scoliosis Research Society (SRS 24), Oswestry Low Back Pain Disability Index (ODI), Psychological General Well-Being Index (PGWBI)), radiological curve progression and health-related quality of life (HRQoL). Baseline characteristics and radiological imaging were collected. At follow-up, anteroposterior and lateral X-rays as well as questionnaires were analyzed.

Results Twenty patients (16 females, mean age: 14.6 ± 3.2 years) with a follow-up time of 42 ± 9 years were included. Nine patients (initial Cobb 35° ± 19°) were treated with bracing for a mean time of 26 ± 9 months, while the other 11 patients (initial Cobb 29° ± 11°) were observed. The primary curve progressed from 32° ± 15° to 52° ± 25° in average with no significant difference between the cohorts (p = 0.371). At final follow-up, a mean ODI score of 7 ± 7.9 points with no difference depending on the treatment (p = 0.668) was seen. No significant differences were observed for PROMs. Curve magnitude correlated neither at diagnosis (p = 0.617) nor at follow-up (p = 0.535) with the ODI score at final follow-up.

Conclusion After a mean of 42 years, patients with nonoperative treatment of moderate AIS demonstrated a good clinical outcome despite progression of the deformity.

Level of evidence Level IV, therapeutic study.

Keywords Adolescent idiopathic scoliosis · Bracing · Nonoperative treatment · Long-term results · Spinal deformity

Introduction

Adolescent idiopathic scoliosis (AIS) is a three-dimensional structural deformity of the spine developing during adolescence after the age of 10 years [1]. The etiopathogenesis of AIS is considered multifactorial and largely remains
unclear [2]. The prevalence of AIS, defined as a coronal curvature with a Cobb’s angle greater than 10°, is about 3% in healthy adolescents, mostly affecting female patients [3]. Even though typically asymptomatic during adolescence, AIS curves can progress and may cause back pain, shortness of breath, incapacity in conducting activities of daily living, psychological impairment and esthetic concerns in adulthood [4–6]. The choice of treatment depends on the magnitude of the primary curve, curve progression, patient age and symptoms, such as back pain and cardiac or respiratory compromises [7].

Operative treatment is traditionally reserved for adolescent patients with major curves exceeding 45° to stabilize the curves and prevent late progression and deterioration of cardio-pulmonary symptoms and health-related quality of life (HRQoL) [8]. Recent data show clinically relevant improvements in functional and health-related quality of life, self-image, and pain at the 2-year follow-up after fusion surgery for AIS, with only few adverse events [9]. Particularly in view of the good short-term surgical results in terms of patient-reported outcomes today, the question arises as to long-term treatment recommendations and the future value of nonoperative therapy.

Patients presenting a curve magnitude of ≥ 25° or a rapid curve progression (> 5° in 6 months) with bony immaturity (Risser sign < 3) and pre-menarchal status are subject to bracing therapy [10–12]. However, evidence on the influence of wearing time, patients’ age, curve flexibility or skeletal maturity on the results of bracing after a very long time is underreported [11, 13]. If untreated, one-third (32%) of patients with Risser 0–1 experience curve progression resulting in psychological complications [6]. In addition to the radiological and functional long-term outcome of nonoperative AIS treatment, the current research is focused on quality of life and patient satisfaction [14, 15]. However, increasing life expectancy is shifting interest to extreme long-term outcomes of different therapeutic modalities.

While there is long-term data on AIS published, most cohorts focus on clinical or patient-reported outcome data and do not always provide radiographic follow-up. The aim of this study was to present the extreme long-term outcome of patients with AIS treated with either bracing or observation regarding radiographic curve progression, associated pain, disability, and health-related quality of life (HRQoL).

Materials and methods

Study population

Patient files in the form of paper copies in the archive of our institution were searched for the diagnosis of “scoliosis”. Between 1960 and 1990, 597 patients with degenerative, congenital, neurogenic, or operatively treated scoliosis were treated in the outpatient clinic of our institution. Patients with AIS with a minimum Cobb angle of 10° in the major curve, age of 10–20 years at the time of diagnosis as well as nonoperative treatment, availability of a full standing anteroposterior X-ray of the spine at diagnosis and a minimum follow-up of 20 years were subject to this analysis. Accordingly, 332 patients not meeting the inclusion criteria were excluded from this study. From the remaining 265 patients, contact information could be obtained in 131 cases. These patients were contacted via mail or phone. However, 111 of these patients were excluded due to various reasons (e.g., emigration, refusal for participation, death, or nonresponse). Finally, a total of 20 patients could be included (Fig. 1). During follow-up, asymptomatic patients without relevant curve progression (> 5° per 6 months) were asked to present again whenever they had symptoms.

Radiographical examination

Plain film radiographs at diagnosis were digitized for measurement of radiographic parameters. Follow-up anteroposterior and lateral radiographs were performed with a microdose 3D imaging system (EOS™ imaging, SA, 10 rue de Mercoeur, 75011 Paris, France). The magnitude of the primary and secondary curve was measured using Cobb’s method. Radiological imaging was analyzed using IMPAX (version 6.4.0.6010) and IMPAX Orthopaedic Tools (Agfa-Gevaert N.V., Mortsel, Belgium).

Questionnaires

At the follow-up visit, patients were asked about their medical history and socio-demographic as well as disease-specific data. Further, the EQ-5D-5L, Short Form Health Survey 36 item (SF 36), Scoliosis Research Society (SRS 24), Oswesty Low Back Pain Disability Index (ODI) and Psychological General Well-Being Index (PGWBI) were recorded [16–21]. In addition, we asked all patients to remember their pain levels during adolescence and to rate them on the visual analog scale (VAS).

Ethics approval

The study was approved by the local ethics committee prior to patient enrollment and a signed informed consent was obtained from each patient. Patient data were retrieved from the local hardcopy archive and the electronic database. Study data were collected and managed using REDCap electronic data capture tools hosted at our institution for analysis [22].
Patient characteristics are presented with mean and standard deviation or median with range, as applicable. Predictor–outcome associations were assessed using Spearman rank correlation tests. Differences between the groups with/without brace were compared using the Mann–Whitney U test. Data analysis was conducted with SPSS (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.). p values below 0.05 were considered statistically significant.

Results

Twenty patients (80% female) with a mean age at diagnosis of 14.6 ± 3.2 years agreed to undergo follow-up examination in adulthood. Nine patients (45%) were treated with bracing therapy over an average time of 26 ± 16 months. The remaining 11 patients were treated without bracing. No crossover from the observation to the bracing cohort was documented. The follow-up periods were 29 years to a maximum of 58.8 years in the brace group and 33.4 years to a maximum of 55.3 years in the observation group, respectively. There was no statistical difference between the investigated cohorts regarding age, BMI, length of follow-up, pain at diagnosis or major curve Cobb angle at diagnosis (Table 1). During the entire time of follow-up, no patient underwent spinal surgery, neither corrective nor due to degenerative changes.

Radiologic findings

Baseline and follow-up anteroposterior whole spine radiographs were available for all included patients. During the observation period, the major curve progressed from 32° ± 15° to 52° ± 25° on average. Individuals without brace treatment had an average increase from 29° ± 11° to 45° ± 21°, whereas braced patients developed from 35° ± 19° to 59° ± 28° in their major curve. Secondary curves evolved in average by 10° ± 12° in unbraced and 12° ± 18° in braced patients. Tables 2 and 3, respectively, shows the individual patients’ baseline and follow-up measurements including patient-reported outcome measures of both patient cohorts. There were no differences in major curve progression between the two cohorts (p = 0.568) and between sexes (p = 0.91).

Disability and back pain

At final follow-up, the mean ODI score was 7 ± 7.9 points. The cohort treated with bracing showed a mean ODI of 8.5 ± 8.6 points compared to 6.2 ± 7.3 points in the observation group (p = 0.668). There was no correlation between ODI at follow-up and the magnitude of the major curve at
In addition, there was no correlation between the ODI at follow-up and the age at diagnosis \( (p = 0.771) \).

At the time of final examination, 15 patients (75%) showed a working ability of 100%. Among the others, one person was unable to work due to back pain. Four patients were already retired.

The median VAS for pain was 1 (range 0–7), which was consistent until follow-up without differences among the braced (1, range 0–5) and observed (1, range 0–7)) patients. Also, subcategories for pain in the EQ-5D, SF-36, SRS-24 and ODI questionnaire did not show statistically significant differences between both groups.

### Health-related quality of life

Considering the EQ-5D-5L, patients showed no or minor limitations in their mobility (median: 1 (IQR 0 versus median 1 (IQR 0), \( p = 0.842 \), self-care (1 (IQR 0) vs 1 (IQR 0), \( p = 1.000 \)) or daily activities (1 (IQR 0) vs 1 (IQR 0.5), \( p = 0.882 \)) (80%) at final follow-up. There was a slight, but statistically insignificant difference in pain with a median of 2 points (IQR 1.5) in the braced group compared to 1 point (IQR 1) in the observed group \( (p = 0.412) \).

The SRS-24 questionnaire generally yielded “good” (4 out of 5) to “very good” (5 out of 5) scores for all subcategories as shown in Tables 2 and 3, respectively. There was no subcategory showing statistically significant differences in scores when comparing the two cohorts. Some categories were more favorable for the observation group (e.g., “going out” 3.2 ± 0.6 vs. 2.8 ± 1.1 or “daily activities” 4.6 ± 1.2 vs. 4.1 ± 1.8), whereas two subcategories concerning pain showed a slight tendency to increased pain symptoms (“maximum pain” 3.4 ± 2.1 vs. 3 ± 1.7 and “everyday pain” 2.4 ± 1.5 vs. 2.2 ± 1.3). No patient reported to regularly require medication against back pain.

At the time of final follow-up, 80% of the overall cohort were ranked in the “being positive” subcategory of the PGWBI with a mean score of 86 ± 18 out of 110. Ten percent showed “moderate psychological distress” (scores 61–72) and 10% were classified as “experiencing severe psychological distress” (scores 0–60). No difference between the two observed groups could be identified (bracing 84 ± 20, observation 87 ± 20).

The results of the Short Form 36 survey are presented in Table 4 showing no statistical differences between cohorts for all subcategories.

### Discussion

We aimed to investigate extreme long-term follow-up study of nonoperatively treated patients diagnosed with mild or moderate AIS reporting radiological outcome and level of disability, pain and health-related quality of life after a minimum of 29 years and up to a maximum of 58.8 years of follow-up.

Starting with mild to moderate curves, the major curves progressed by 20° ± 20° within 42 ± 9 years. Patients treated with brace demonstrated a 24° ± 23° increase in curve magnitude, while those without brace treatment had an increase of 16° ± 15°. This is well explainable, as decision for brace treatment was made in younger patients with more potential for curve progression. On extrapolating the results of similar studies with a shorter follow-up time, they were found to coincide with the results of the present study with regard to curve progression \[23\]. We, however, do not want to claim
that brace treatment is ineffective, and we remind the
limitations due to age differences at first diagnosis within
the selected groups. Larger prospective randomized studies have
demonstrated the efficacy of bracing in patients with AIS
and bracing should be considered a valuable option in the
treatment of mild or moderate AIS [10].

Due to incomplete radiologic imaging of the iliac crests,
Risser’s staging at diagnosis could not be consistently
obtained for this study. Presumably, Risser stages were not
routinely determined at this time due to validation only
occurring in 1988 [24].

No patient underwent corrective surgery during the
observation period, even though some had extensive scoli-
otic deformities (curve magnitude: maximum: 109° in the
brace group and 84° in the observation group). Nevertheless
surprisingly, no patient underwent any kind of spine sur-
gery due to secondary degenerative changes. An interesting
observation is that all patients did not return to an orthope-
dic institution over the long course of their illness, although
some patients showed a considerable curve progression. In
female AIS patients, pregnancy—including the effect of the
peptide hormone relaxin—is a known risk factor for a peri-
partum curve progression, especially considering the long
observation period [25]. In our predominantly female study
population, however, there was no significant difference in
curve progression between both sexes.

This study has profound limitations. Since pain intensity
was not ranked at the time of diagnosis, patients were asked
to retrospectively remember their pain levels as accurately
as possible, which likely leads to recall bias. The data on
pain at diagnosis, therefore, must be interpreted cautiously.
The retrospective nature of the study itself, but also
the long enrollment period back to 1960 with signifi-
cant advancements in spinal deformity surgery, results in
additional limitations. We were not able to consistently
determine the frequency of follow-up and the reason for
its discontinuation. However, it can be assumed that they
were suspended only in the absence of curve progression
and symptoms. Also, the high proportion of non-included
patients was not reflected at the time of diagnosis, as patients
were asked to remember their pain levels accurately.

Table 2  Baseline and follow-up measurements and PROMs of patients with observation

| Patient | Gender | Duration follow-up (yr) | VAS diagnosis | Curve magnitude diagnosis (°) | Curve magnitude follow-up (°) | Dif-ference curve magnitude (°) | Working ability | Self-care | Usual activities | Pain | Anxiety/ Depression | VAS | EQ-5D-5L | PGWBI | SRS-24 | SF-36 | Physical functioning | Physical role | Bodily pain | General health | Vitality | Social functioning | Emotional role | Mental health |
|---------|--------|------------------------|---------------|-----------------------------|-------------------------------|--------------------------------|----------------------------|------------|------------------|------|------------------|-----|----------|--------|--------|--------|-------------------|-------------|-----------|-----------------|---------|------------------|--------------|------------|
| 1       | f      | 36.0                   | 0             | 30                          | 39                            | 9                              | 1                           | 2          | 1                | 2    | 2                | 2   | 68       | 4.5   | 5       | 3.7   | 4.7               | 100        | 100      | 62               | 32      | 75               | 67          | 60         |
| 2       | m      | 54.3                   | 0             | 38                          | 84                            | 46                             | 4                            | 0          | 0                | 0    | 1                | 2   | 85       | 3.7   | 4.7   | 4.3   | 4.7               | 100        | 100      | 100              | 67      | 100              | 100         | 96         |
| 3       | m      | 41.5                   | 6             | 15                          | 23                            | 8                              | 1                            | 0          | 1                | 1    | 1                | 1   | 95       | 4     | 4.3   | 5     | 5                 | 100        | 100      | 100              | 92      | 100              | 100         | 96         |
| 4       | f      | 35.8                   | 3             | 44                          | 52                            | 7                              | 1                            | 20         | 7                | 2    | 1                | 3   | 65       | 4.8   | 4.3   | 3.3   | 3.3               | 80         | 22       | 55               | 25      | 88               | 33          | 56         |
| 5       | f      | 2.27                   | 0             | 26                          | 52                            | 26                             | 1                            | 8          | 2                | 1    | 1                | 1   | 90       | 3.8   | 4     | 4.7   | 4.7               | 95         | 100      | 62               | 87      | 80               | 100         | 96         |
| 6       | m      | 33.0                   | 0             | 29                          | 65                            | 36                             | 1                            | 0          | 0                | 1    | 1                | 1   | 90       | 3.5   | 4.7   | 4.3   | 5                 | 100        | 100      | 90               | 87      | 100              | 100         | 94         |
| 7       | f      | 37.8                   | 4             | 20                          | 28                            | 8                              | 1                            | 2          | 1                | 1    | 1                | 1   | 100      | 3.7   | 5     | 4.3   | 5                 | 100        | 100      | 84               | 75      | 100              | 100         | 76         |
| 8       | m      | 35.1                   | 0             | 14                          | 15                            | 1                              | 1                            | 0          | 1                | 1    | 1                | 1   | 90       | 3.8   | 5     | 4.3   | 5                 | 100        | 100      | 87               | 65      | 100              | 100         | 72         |
| 9       | f      | 55.3                   | 0             | 31                          | 64                            | 27                             | 4                            | 0          | 0                | 1    | 1                | 1   | 80       | 3.7   | 5     | 4.3   | 5                 | 95         | 100      | 75               | 77      | 80               | 100         | 100        |
| 10      | f      | 41.7                   | 0             | 41                          | 45                            | 4                              | 2                            | 16         | 3                | 1    | 1                | 1   | 90       | 4.2   | 4.7   | 4.7   | 4.7               | 85         | 74       | 92               | 70      | 100              | 100         | 84         |
| 11      | f      | 38.5                   | 0             | 23                          | 30                            | 7                              | 1                            | 4          | 0                | 1    | 1                | 2   | 80       | 4.5   | 4.3   | 4.3   | 4.7               | 90         | 100      | 62               | 57      | 55               | 88          | 100        |
| Patient | Gender | Duration follow-up (yr) | VAS diagnosis | Curve magnitude diagnosis (°) | Curve magnitude follow-up (°) | ODI | VAS back | Mobility | Self-care | Usual activities | Pain | Anxiety/Depression | VAS Pain | Self-image | Function | Activity | Physical functioning | Physical role | Bodily pain | General health | Vitality | Social functioning | Emotional role | Mental health |
|---------|--------|------------------------|---------------|-----------------------------|------------------------------|-----|----------|----------|----------|-----------------|------|----------------|----------|------------|----------|---------|-------------------|------------|-----------|---------------|---------|------------------|--------------|-------------|
|         |        | 38.1                   | 28            | 47                          | 19                           | 1   | 0        | 1        | 1        | 1               | 1    | 1               | 95       | 96         | 3.8      | 2.3      | 4.3               | 5          | 100       | 100           | 92      | 80               | 100         | 100         |
|         |        | 29.0                   | 6             | 27                          | 24                           | −3  | 1        | 14       | 3        | 1               | 1    | 2               | 90       | 65         | 4.2      | 5.7      | 3.3               | 3.7         | 95        | 75            | 51      | 92               | 70          | 100         |
|         |        | 35.4                   | 0             | 31                          | 57                           | 26  | 1        | 14       | 2        | 1               | 3    | 3               | 90       | 78         | 4.2      | 4.4      | 5                 | 4.7         | 80        | 100           | 62      | 97               | 80          | 88          |
|         |        | 41.0                   | 0             | 26                          | 29                           | 3   | 1        | 10       | 2        | 1               | 1    | 2               | 98       | 97         | 3.8      | 4.7      | 4                 | 4.7         | 85        | 100           | 72      | 92               | 70          | 100         |
|         |        | 57.8                   | 3             | 26                          | 35                           | 9   | 4        | 10       | 0        | 1               | 1    | 1               | 100      | 108        | 2.8      | 5.3      | 4.3               | 4.7         | 85        | 100           | 100     | 90               | 90          | 100         |
|         |        | 29.9                   | 0             | 73                          | 78                           | 5   | 1        | 0        | 0        | 1               | 1    | 1               | 90       | 87         | 3.7      | 4        | 4                 | 4.3         | 100       | 100           | 82      | 60               | 100         | 100         |
|         |        | 49.5                   | 0             | 23                          | 79                           | 56  | 1        | 0        | 0        | 1               | 1    | 1               | 95       | 95         | 3.7      | 4        | 3.7               | 4           | 100       | 100           | 87      | 65               | 100         | 100         |
|         |        | 56.3                   | 7             | 61                          | 109                          | 48  | 1        | 2        | 1        | 1               | 1    | 2               | 100      | 41         | 3.8      | 6.3      | 4                 | 3.7         | 95        | 100           | 74      | 97               | 75          | 100         |
|         |        | 52.3                   | 0             | 20                          | 75                           | 55  | 4        | 27       | 5        | 2               | 1    | 2               | 60       | 88         | 4.5      | 4        | 4                 | 3           | 60        | 50            | 51      | 32               | 75          | 100         |

Yr, year; VAS, visual analog scale; ODI, Oswestry Disability Index; EQ-5D-5L, European Quality of Life 5 Dimensions 5 Levels; PGWBI, Psychological General Well-Being Index, SRS-24, Scoliosis Research Society 24-item questionnaire; SF-36, Short Form-36 questionnaire
showing significantly more degenerative disc changes than the controls, no correlation between pain and its localization and curve size or an increase of 10° or more since end of treatment could be found [26]. Another study, recently conducted by Watanabe et al., showed similar results after a mean follow-up of 25 years (range 12–39) for nonoperatively treated (bracing and/or observation) AIS [27]. In 107 subjects, no significant difference was verified concerning ODI and three out of four domains (pain, function, mental health) of the SRS-22 questionnaire compared to a control group. Such and other reports, including our current report, raise the question whether differences of treatment options are clinically less relevant than expected or if the measures that are used to find clinically relevant differences are not adequate enough [28]. Although it is known that younger patients with AIS may develop greater deformities with potentially more severe secondary degenerative changes, we did not find an association of age at diagnosis with long-term poor back function \( p = 0.771 \) in our collective [29].

Keeping the above-mentioned limitations in mind, we conclude that AIS patients undergoing nonoperative treatment of mild to moderate AIS reported good clinical outcomes despite progression of the sciotic deformity after 29–58.8 years.

### Conclusion

After a mean of 42 years, patient with a desire for nonoperative treatment of mild to moderate AIS demonstrated a good clinical outcome despite substantial progression of the sciotic deformity.

### Author contributions
MF: design conception, analysis, and data interpretation. TG: analysis and data interpretation. DEB: analysis and data interpretation. TB: analysis and data interpretation. CJL: design conception, acquisition, analysis, and data interpretation. MK: design conception, acquisition, analysis, and data interpretation.

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### Declarations

#### Conflict of interest
The authors have no relevant financial or non-financial interests to disclose.

#### Ethics approval
This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the local ethics committee (Cantonal Ethics Committee Zurich, ref. 2017-01596).

#### Consent to participate
Prior to patient enrollment, a signed informed consent was obtained from each patient.

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