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Health-related quality of life in patients with adolescent idiopathic scoliosis: a matched follow-up at least 20 years after treatment with brace or surgery

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Abstract No results on long-term outcome in terms of health-related quality of life (HRQL) have previously been presented for patients treated for adolescent idiopathic scoliosis. A consecutive series of patients with adolescent idiopathic scoliosis, treated between 1968 and 1977 before the age of 21, either with distraction and fusion using Harrington rods [surgical treatment group (ST), $n=156$; 145 females and 11 males] or with a brace [brace treatment group (BT), $n=127$; 122 females and 5 males] were followed at least 20 years after completion of the treatment. Ninety-four percent of ST and 91% of BT patients filled in a questionnaire comprising the SF-36, Psychological General Well-Being Index (PGWB), Oswestry Disability Back Pain Questionnaire, parts of SRS/MODEM'S questionnaire and study-specific questions concerning the treatment, as a part of an unbiased personal follow-up examination including radiography and clinical examination. An age- and sex-matched control group of 100 persons was randomly selected and subjected to the same examinations. The results showed no differences in terms of sociodemographic data between the groups. Both ST and BT patients had a slightly, but significantly, reduced physical function using the SF-36 subscales,

SF-36/Physical Component Summary (PCS) score as well as the Oswestry Disability Back Pain Questionnaire compared to the controls. Neither the mental subscales and the Mental Component Summary (MCS) score of SF-36 nor the PGWB index showed any significant difference between the groups. Forty-nine percent of ST, 34% of BT and 15% of controls admitted limitation of social activities due to their back [$P<0.001$ ST vs controls, $P=0.0010$ BT vs controls, and n.s. ($P=0.024$) ST vs BT], mostly due to difficulties with physical participation in activities or self-consciousness about appearance. Pain was a minor reason for limitation. No correlation was found between the outcome scores and curve size after treatment, curve type, total treatment time or age at completed treatment. Patients treated for adolescent idiopathic scoliosis were found to have approximately the same HRQL as the general population. A minority of the patients (4%) had a severely decreased psychological well-being, and a few (1.5%) were severely physically disabled due to the back.

Keywords Scoliosis · Treatment outcome · Long-term effect · Physical fitness · Mental health · Quality of life

Introduction

During the last decade, interest in assessing how patients perceive the impact of a disease has increased. This is commonly referred to as health-related quality of life (HRQL). HRQL is defined as a subjective multidimensional construct that captures the impact of health status, including disease and treatment, on three core domains: physical, psychological and social functioning [32]. By assessing HRQL, a perspective beyond traditional biomedical markers of disease activity is obtained, which is regarded as complementary to the objective signs and symptoms of disease.

There has been an increasing interest in HRQL assessment after treatment of scoliosis. New questionnaires have been developed [2, 7, 29] and are currently being evaluated [29]. A number of previous studies have discussed quality of life (QL) in general terms [12, 17, 21, 34]. So far, only a few studies using modern, validated questionnaires have been published. These relate to respiratory failure and scoliosis [38], the impact of the type of brace treatment [6], and the results of the Scoliosis Research Society (SRS) instrument used for evaluation of surgical outcome [29] and for presenting short-term outcome in adolescent [47] and adult [1, 23, 31] scoliosis surgery. With limited economic means for health care and need for proof of the efficacy of treatment given, there will be an increasing need for outcome studies that focus not only on strictly medical, objectively measured outcomes, but also on HRQL.

Treatment of scoliosis, which often lasts for a long time period, requires considerable contributions from the health care system. The treatment is also demanding, presenting a possible risk for stigmatization of the patient. Therefore, in this long-term follow-up of patients treated for adolescent idiopathic scoliosis, our intention was to focus on disease-specific aspects of HRQL. Special emphasis was put on the following questions: How has the treatment affected the psychological well-being during the past years and at present? Does the condition and its related problems affect the self-image or personal relationships? Do scoliotic patients have a social life equal to non-scoliotic subjects? Do treatment variables correlate with HRQL? Was there any difference between surgically and brace treated scoliotic patients?

In order to make comparisons more reliable, an age- and sex-matched control group was solicited at random from the Swedish population registry and subjected to the same questionnaires and examinations.

Materials and methods

Patients

A total of 283 consecutive patients treated for adolescent idiopathic scoliosis between 1968 and 1977 under the direction of the

senior author (A.L.N.) were invited to an unbiased follow-up. Until 1975, the majority of patients in Sweden needing treatment for scoliosis were referred to Sahlgrenska University Hospital in Gothenburg. There were 156 patients who underwent surgical treatment (ST) and 127 who underwent brace treatment (BT), with all treatments being completed before the patient reached 21 years of age. In all cases, the scoliosis had not been detected before 10 years of age and was not combined with any other related disorders or major spine anomalies. A minimum of 20 years had passed since completion of the treatment.

During the treatment period, thoracic, thoracolumbar or double primary curves of between 24° and 50°, and lumbar curves of less than 60° were treated with a brace. Brace treatment, of at least 12 months' duration, consisted of a Milwaukee brace (CTLSO) (until 1974) [4] or a Boston brace (TLSO) (1974 and onward). The brace was worn 22–24 h daily until skeletal maturity [25, 39]. All patients received psychological support during the initial treatment period from a specially trained physiotherapist and a social worker. Curves of larger magnitude were treated surgically, in either one- or two-stage procedures, with Harrington distraction and fusion. The postoperative bracing time ranged from 6 to 12 months. The patients were not allowed to attend school for the initial 6 postoperative months and were advised either to have teaching at home or to repeat a year in school. The detailed treatment protocol has been described in an earlier study with a shorter (7–10 years) follow-up [9, 10] and the radiographic and clinical results from the present follow-up are presented in a separate article [14].

Originally there were 156 ST and 127 BT patients. At follow-up, 146 (93.6%) of the ST group and 116 (91.3%) of the BT group completed the questionnaires (four ST and six BT patients answered questionnaires without undergoing re-examination). Patients lost to follow-up during the more than 20 years were very few. For the ST and BT groups respectively, three and four patients refused, two and zero had died for reasons not related to scoliosis, and five and seven could not be traced, which led to a 6.4% loss to follow-up in the ST group and 8.7% in the BT group.

The re-examinations were performed by the unbiased first author (A.J.D.), without the presence of the senior orthopaedic author (A.L.N.). Re-examinations comprised radiography with curve size on present and previous radiographs measured using the Cobb method [8]; trunk rotation, assessed by a Bunnell's scoliometer [5]; and body mass index (i.e. weight/length²), using the present height and weight. Data concerning former treatment regimens were gathered both from the Gothenburg Scoliosis Data Bank and from chart reviews, if the required information was not available in the Data Bank.

Control group

One hundred individuals of the same sex and age distribution and living conditions as the patients were randomly selected through the Swedish Postal Registry. The exclusion criteria for the control group were previous back surgery or significant scoliosis, which was ruled out by clinical examination, including the Bunnell's scoliometer [5]. None of the controls had a trunk rotation of more than 5° (Bunnell). They were examined using the same protocol as the patients. The control group consisted of 90 females and 10 males, with a mean age of 40 (range 35–45) years, matching the age profile of the patient groups.

Questionnaire

In order to capture the impact of the disease and its treatment, generic and specific questionnaires were selected (Table 1). All questionnaires were well documented in terms of psychometric properties [11, 49] and had previously been used in similar patient populations [1, 26, 30]. At the time the study was initiated, no sco-

Table 1 Questionnaires used in the follow-up of 262 patients with adolescent idiopathic scoliosis (*HRQL* health-related quality of life) and 100 healthy controls

Questionnaire	No. of items	Purpose
SF-36 [43, 46]	36	General HRQL, measuring the physical, social and mental components
The Psychological General Well-Being (PGWB) Index [16] ^a	22	Stigmata caused by the treatment
The Oswestry Low Back Pain Disability Questionnaire [18]	10	General back function
MODEM'S Spine Outcomes Data Collection Questionnaires, Scoliosis Questionnaire ^b (Table 6) [2]	5	Scoliosis-specific problems (self-image, personal relationships and social limitations)
Study-specific questionnaire ^c (Table 7)	13	Stigmata caused by the treatment
WHO questionnaire [40]	5	Smoking, alcohol intake, psychological stress, physical activity during work and leisure time

^a Norm values for PGWB: 98–104 [15]

^b MODEM'S was the only questionnaire not previously used in Sweden. The questions intended for use were modified for Sweden by using the guidelines for the cross-cultural adaptation process proposed by Guillemin [28]

^c Previous studies at our clinic had shown a negative impact of the treatment on the patients [19]. These aspects were not considered

liosis-specific QL instrument was available, which led us to choose among the already existing different outcome instruments. The Scoliosis Research Society Outcomes Instrument has since been developed and evaluated [29]. A standardized procedure for questionnaire administration was followed [48]. All questionnaires were checked for completeness in order to avoid missing answers.

Ethics

The study was approved by the Human Research Ethical Committee at the Medical Faculty, Gothenburg University.

Statistical methods

Distributions of variables are given as means, standard deviations (SD) and ranges. For comparison between the three groups in terms of continuous and ordered variables, the Kruskal-Wallis non-parametric one-way analysis of variance was first used. If significant, the three groups were then compared pairwise against each other. For comparison between two groups, the Mann-Whitney non-parametric U-test was used.

For comparison of dichotomous variables between the three groups, an overall Chi-square test was first used. If significant differences were found, the three groups were then compared pairwise against each other. For comparison of proportions between two groups, Fisher's exact test was used.

The Spearman rank correlation coefficient (r_s) was used for correlation analysis. For comparison with the Swedish SF-36 norm values, Student's *t*-test was used.

All significance tests were two-tailed and, in order to avoid type I error due to the multiple statistical analyses performed, all were conducted at the 1% significance level.

adequately covered through the already chosen and existing instruments, and a study-specific questionnaire was constructed. This questionnaire was tested for comprehension by a separate group. The control group did not answer these questions

Results

General measures

The main characteristics for all patients are presented in Table 2. Surgically and brace treated patients were comparable in terms of age and curve size at follow-up. The mean time from termination of treatment to the present follow-up was 23 years for the ST group and 22 years for the BT group. The mean values for the 21 patients who did not answer the questionnaire did not differ significantly with regard to age, sex, curve severity, curve type, length of treatment or complications of treatment from those of patients who answered the questionnaire (Table 2).

Demographic and clinical background data

Selected demographic and clinical data are depicted in Table 3. No differences in terms of background data could be found, except for educational level. Only 31% of ST patients had passed graduate school compared with 50% of BT patients and controls (ST vs BT $P=0.0022$, ST vs controls $P=0.0033$ and BT vs controls n.s., $P=0.99$). The frequency of other self-reported diseases was not significantly different in the three groups (41% in ST patients, 44% in BT patients and 29% in controls, $P=0.058$, overall test). For example, pulmonary disease occurred in eight ST patients, six BT patients and three controls (n.s., $P=0.18$, overall test), coronary heart disease in five subjects in each group (n.s., $P=0.82$, overall test) and neo-

Table 2 Characteristics of both the 262 surgically-treated (ST) and brace-treated (BT) patients with adolescent idiopathic scoliosis who answered the HRQL questionnaires, and of the 21 drop-outs of the consecutive series (values presented as mean \pm SD above and range below). *P*-values indicate the differences on each parameter between the ST and the BT study groups

	Study subjects		<i>P</i> -value ST (study group) vs BT (study group)	Drop-outs	
	ST (<i>n</i> =146)	BT (<i>n</i> =116)		ST (<i>n</i> =10)	BT (<i>n</i> =11)
Age at the present follow-up	39.7 (2.5) (33.9–45.8)	39.3 (2.2) (34.4–45.4)	n.s. (<i>P</i> =0.31)	–	–
Age at the start of treatment	15.0 (1.8) (11.3–19.3)	14.4 (1.4) (11.0–18.4)	n.s. (<i>P</i> =0.012)	15.5 (1.9) (13.6–19.2)	15.1 (1.7) (11.8–17.1)
Total treatment time (years)	1.4 (0.2) (0.6–2.1)	2.7 (1.0) (1.0–5.9)	<i>P</i> =0.0001	1.5 (0.2) (1.3–1.8)	2.4 (0.6) (1.1–3.4)
Follow-up after completed treatment, (years)	23.3 (1.6) (20.3–26.6)	22.3 (1.9) (19.4–28.3)	<i>P</i> =0.0001	–	–
Sex, <i>n</i> (%)			n.s. (<i>P</i> =0.43)		
Female	136 (93.1%)	111 (95.7%)		9 (90%)	11 (100%)
Male	10 (6.9%)	5 (4.3%)		1 (10%)	0
Curve size of the major curve ^a					
Before treatment	61.8 (13.2) (38–122)	33.2 (9.6) (12–60)	<i>P</i> =0.0001	59.6 (9.4) (50–78)	36.7 (7.8) (25–48)
At present follow-up ^b	36.5 (9.7) (14–66)	37.6 (14.7) (5–71)	n.s. (<i>P</i> =0.48)	–	–
Rotation of the upper/major curve (Bunnell scoliometer) at present follow-up ^b	11.4 (5.2) (0–30)	10.3 (5.3) (0–25)	n.s. (<i>P</i> =0.16)	–	–

^a In patients with double curves, the upper curve is considered as the major curve

^b Presented values are for 139 ST patients and 109 BT patients who underwent radiography at the present follow-up

plasm, both malignant and benign, in seven ST patients, four BT patients and three controls (n.s., *P*=0.74, overall test).

General health

The results of the SF-36 QL questionnaire with subscales, Physical Component Summary (PCS) and Mental Component Summary (MCS) scores for patients and controls are shown in Fig. 1 and Table 4. Both patient groups had reduced physical functioning and more bodily pain compared to the controls. The ST patients had significantly worse general health than the controls, and between BT patients and controls a small, but not significant, difference was found. No difference between the groups was found in any of the other subscales.

There was a significant difference in terms of the PCS score between the patient groups and controls. All groups had mean values (49.2 for ST, 49.5 for BT patients and 53.1 for controls) around the Swedish age-related norm values. There was no difference between the groups in terms of the MCS score (50.9 for ST patients, 50.2 for BT patients and 50.1 for controls).

The results of the eight subscales as well as the PCS and MCS scores of the female subgroups of the ST and

BT patients were compared with the Swedish norm scales for females aged 35–44 years. A significant difference was found only between the physical functioning scores of ST patients and controls (*P*=0.00015).

The mean Psychological General Well-Being (PGWB) Index at present follow-up was 106.8 (SD 14.2) in ST patients, 104.7 (SD 16.1) in BT patients and 109.3 (SD 13.5) in controls (n.s., *P*=0.062, overall test).

Disease-specific Quality of Life

Both ST patients and BT patients had significantly more back problems compared to the control group, measured by the Oswestry Disability Questionnaire as well as occurrence of previous sick-leave due to their back (Table 5). The ST and the BT patient groups did not differ regarding those problems. Within the Oswestry Disability Back Pain Questionnaire, only four patients, all surgically treated, had severe disability, with scores of 40–50. Three of these patients were sick-listed or retired and, in addition to their back problems, also had definite psychiatric diagnoses; the fourth, who was unemployed at the time of the follow-up, had spinal stenosis, verified on computed tomography (CT), four levels below her scoliosis. The mean PGWB

Table 3 Distribution of selected demographic and clinical data in 262 patients with adolescent idiopathic scoliosis and 100 controls (CTR)

	ST (n=146)	BT (n=116)	CTR (n=100)	P-value (overall test)
Marital status ^a				n.s. ($P=0.99$)
Never married	24 (16.4%)	19 (16.4%)	17 (17.0%)	
Married	113 (77.4%)	91 (78.4%)	71 (71.0%)	
Divorced/widowed	9 (6.2%)	6 (5.2%)	12 (12.0%)	
No. of children per female: mean (SD)	1.8 (1.1)	1.9 (1.1)	2.0 (1.1)	n.s. ($P=0.25$)
Attained educational level				$P=0.0014^b$
High school, completed or not	32 (21.9%)	12 (10.3%)	12 (12.0%)	
Vocational school	7 (4.8%)	6 (5.2%)	1 (1.0%)	
College	62 (42.5%)	40 (34.5%)	37 (37.0%)	
Graduate school	45 (30.8%)	58 (50.0%)	50 (50.0%)	
Occupation				n.s. ($P=0.35$) ^c
Employed (outside your own house)	109 (74.7%)	94 (81.0%)	81 (81.0%)	
On current education or maternity leave	12 (8.2%)	12 (10.4%)	9 (9.0%)	
Not currently employed or housewife	1 (7.6%)	6 (5.1%)	5 (5.0%)	
Sick-listed or retired	14 (9.6%)	4 (3.4%)	5 (5.0%)	
Working time ^d (% of fulltime): mean (SD)/range	73.3 (33.9) (0–120)	79.6 (29.1) (0–125)	79.6 (30.2) (0–100)	n.s. ($P=0.42$)
Strain during working time				n.s. ($P=0.85$)
Sedentary	36 (24.6%)	35 (30.2%)	26 (26.0%)	
Light work with some physical activity	56 (38.3%)	38 (32.8%)	41 (41.0%)	
Relatively heavy work	53 (36.3%)	42 (36.2%)	31 (31.0%)	
Heavy manual work	1 (0.7%)	1 (0.9%)	2 (2.0%)	
Strain during spare time (hobby and sports)				n.s. ($P=0.17$)
Mainly sedentary	12 (8.2%)	12 (10.3%)	10 (10.0%)	
Light exercises and training at least 4 h/week	106 (72.6%)	72 (62.0%)	56 (56.0%)	
Regular training and exercise	26 (17.8%)	31 (26.7%)	33 (33.0%)	
Serious training and competitive sports	2 (1.4%)	1 (0.9%)	1 (1.0%)	
Stress				n.s. ($P=0.43$) ^e
No stress	61 (41.8%)	45 (38.8%)	32 (32.0%)	
Minor stress	70 (47.9%)	61 (52.6%)	54 (54.0%)	
Heavy stress	15 (10.3%)	10 (8.6%)	14 (14.0%)	
Cigarette smoking ^f				n.s. ($P=0.25$) ^g
Non-smokers	81 (55.5%)	65 (56.0%)	46 (46.0%)	
Regular smokers	36 (24.6%)	21 (18.1%)	35 (35.0%)	
Ex-smokers	29 (19.9%)	30 (25.9%)	19 (19.0%)	
Pack-year of cigarettes ^h (ever-smokers): mean (SD)/range	11.9 (7.5) (0.3–29.0)	8.1 (5.6) (1.0–19.5)	11.0 (7.3) (0.02–29.0)	n.s. ($P=0.026$)
Alcohol				
Consumption per month ⁱ : mean (SD)/range	14.1 (12.2) (1.5–60.4)	15.2 (18.6) (1.5–138.7)	12.9 (11.5) (0.7–59.7)	n.s. ($P=0.70$)
Do not drink alcohol	28 (19.2%)	22 (19.0%)	17 (17.0%)	n.s. ($P=0.90$)
Body Mass Index: mean (SD)/range	23.8 (3.8) (16.0–42.1)	23.3 (3.5) (18.1–39.8)	24.4 (4.2) (17.9–39.3)	n.s. ($P=0.20$)

^a Cohabitant is equal to married^b Comparison between those who have completed graduate school or not^c Comparison between subjects with and without current employment^d Among those who have current employment^e Comparison between subjects with and without heavy stress^f No subjects used any other tobacco than cigarettes^g Comparison between ever smokers or not^h One pack-year indicates a cigarette consumption equal to a packet of cigarettes every day for 1 yearⁱ Measured in ml 100% pure alcohol

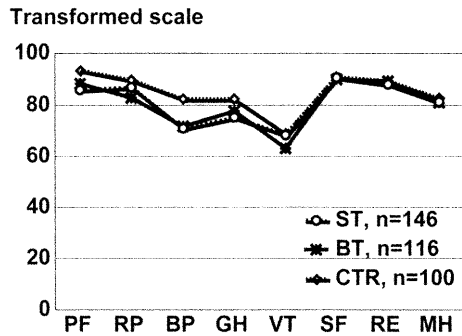


Fig. 1 Results of the eight subscales of the SF-36 in 262 patients with adolescent idiopathic scoliosis and 100 controls. There was significantly reduced physical functioning in both patient groups compared to the controls. The surgically treated (ST) patients had significantly more bodily pain and poorer general health than the controls; between brace-treated (BT) patients and controls, small, but not significant, differences were found. There were no differences found between the groups in any of the other subscales. (*PF* Physical Functioning, *RP* Role Physical, *BP* Bodily Pain, *GH* General Health, *VT* Vitality, *SF* Social Functioning, *RE* Role Emotional, *MH* Mental Health)

Index for these four patients was 74, i.e., well below the normal mean of 101. Fourteen ST patients were sick-listed or retired (Table 3), more than in the other groups,

although not significantly so ($P=0.10$, overall test). The back, alone or in combination with other, mainly psychiatric, diagnoses, was the reason for being sick-listed or having retired in 11 of these 14 ST patients.

Table 6 shows answers to questions on self-esteem and social activities. Major complaints in both patient groups were related to appearance in a bathing suit. The back was a limitation for social activities in 49% of ST and 35% of BT patients, significantly more than in the control group (15%), mostly due to difficulties with physical participation in activities, fear of injury, or self-consciousness about their appearance. Pain was a minor limiting factor in all groups.

Impression of the treatment period

There was a difference between the treatment groups in terms of how they experienced their treatment period. In the ST group, 40% experienced a negative effect on their life, while in the BT group this was reported by 65% ($P<0.0001$) (Table 7). Although the treatment period for ST patients was shorter (mean 1.4 years vs 2.7 years for BT patients), they felt much more taken care of and helped out than did the BT patients ($P=0.0027$) and felt they received greater sympathy than the BT patients did

Table 4 Outcome of the SF-36 scales^a in 262 patients with adolescent idiopathic scoliosis compared with 100 healthy controls (*PCS* Physical Component Summary, *MCS* Mental Component Summary)

	ST (<i>n</i> =146) Mean (95% CI)	BT (<i>n</i> =116) Mean (95% CI)	<i>P</i> -value ST vs BT	CTR (<i>n</i> =100) Mean (95% CI)	<i>P</i> -value		
					ST vs CTR	BT vs CTR	Overall Chi-square test
Physical Functioning	85.8 (83.1–88.5)	88.2 (85.5–90.9)	n.s. ($P=0.22$)	93.4 (90.9–95.9)	$P<0.0001$	$P=0.0005$	$P=0.0001$
Role Physical	86.8 (81.9–91.7)	82.8 (76.7–88.9)		89.7 (84.6–94.8)			n.s. ($P=0.14$)
Bodily Pain	70.8 (66.5–75.1)	71.5 (66.6–76.4)	n.s. ($P=0.73$)	82.3 (77.8–86.8)	$P=0.0003$	$P=0.0018$	$P=0.0007$
General Health	75.1 (71.8–78.4)	77.6 (74.3–80.9)	n.s. ($P=0.49$)	82.2 (78.5–85.9)	$P=0.0016$	n.s. ($P=0.012$)	$P=0.0044$
Vitality	68.4 (65.1–71.7)	63.1 (59.2–67.0)		68.7 (64.6–72.8)			n.s. ($P=0.039$)
Social Functioning	90.7 (87.8–93.6)	90.0 (86.7–93.3)		90.9 (87.6–94.2)			n.s. ($P=0.97$)
Role Emotional	88.1 (83.6–92.6)	89.1 (84.6–94.4)		89.3 (84.2–94.4)			n.s. ($P=0.95$)
Mental Health	81.0 (78.5–83.5)	80.8 (77.7–83.9)		82.6 (79.7–85.5)			n.s. ($P=0.75$)
PCS score ^b	49.2 (47.7–50.7)	49.5 (47.7–51.3)	n.s. ($P=0.41$)	53.1 (51.7–54.5)	$P<0.0001$	$P=0.0042$	$P=0.0002$
MCS score ^c	50.9 (49.4–52.3)	50.2 (48.2–52.1)		50.1 (48.2–51.9)			n.s. ($P=0.67$)

^a Range 0–100 in each of the eight subscales, 100 is best possible function. A difference of 5–10% has been considered clinically significant [44]. See the Swedish Manual and Interpretation Guide for the SF-36 [43] for Swedish norm values

^b Swedish norm values for these age groups are 51.1 (females), 52.0 (males) [45]

^c Swedish norm values for these age groups are 49.0 (females), 50.4 (males) [45]

Table 5 Outcome in disease-specific questionnaires and sick-leave in 262 patients with adolescent idiopathic scoliosis and 100 healthy controls

	ST (n=146)	BT (n=116)	P-value ST vs BT	CTR (n=100)	P-value		
					ST vs CTR	BT vs CTR	Overall Chi- square test
Oswestry Disability Questionnaire ^a [18]: mean (SD)/range	8.3 (10.0) (0–50)	7.6 (9.0) (0–36)	n.s. (P=0.49)	4.2 (7.0) (0–36)	P<0.0001	P=0.0008	P=0.0001
Sick-leave ever due to back problems?: n (%)	63 (43.2%)	44 (37.9%)	n.s. (P=0.45)	19 (19.0%)	P=0.0001	P=0.0026	P=0.0003

^a Range 0–100. Zero is best possible function. There are five degrees of disability: 1. minimal disability (0–20), the subject can cope with most living activities; 2. moderate disability (21–40), there are certain problems with many living activities; 3. severe disability (41–60), when the pain is the main problem and affects many activities; 4. crippled patients (61–80), when the back impinges on all aspects of the patient's life; and 5. score 81–100, patients are either bed-bound or exaggerating the symptoms

Table 6 Self-esteem and social activity in 262 patients with adolescent idiopathic scoliosis and 100 healthy controls from the SRS/MODEM'S instrument for outcome of scoliosis treatment [2]

	ST (n=146) n (%)	BT (n=116) n (%)	P-value ST vs BT	CTR (n=100) n (%)	P-value		
					ST vs CTR	BT vs CTR	Overall Chi- square test
How do you look wearing clothes?							n.s. (P=0.079)
Unattractive, very or fairly	12 (8.2%)	7 (6.0%)		1 (1.0%)			
Neither attractive nor unattractive	71 (48.6%)	54 (46.6%)		44 (44.0%)			
Attractive, very or fairly	63 (43.2%)	55 (47.4%)		55 (55.0%)			
How do you look in a bathing suit?			n.s. (P=0.28)		P=0.0019	P<0.0001	P=0.0002
Unattractive, very or fairly	44 (30.1%)	40 (34.5%)		14 (14.0%)			
Neither attractive nor unattractive	76 (52.1%)	61 (52.6%)		57 (57.0%)			
Attractive, very or fairly	26 (17.8%)	15 (12.9%)		29 (29.0%)			
Does your back condition make it more difficult to have satisfying personal relationships?(affirmative answer)	12 (8.2%)	4 (3.4%)		7 (7.0%)			n.s. (P=0.28)
Does your back condition limit your social activity and ability to have satisfying relationships?	71 (48.6%)	40 (34.5%)	n.s. (P=0.024)	15 (15.0%)	P<0.0001	P=0.0010	P<0.0001
Reason for limitation in social activity ^a							
Pain limits me	15 (10.3%)	7 (6.0%)		5 (5.0%)			n.s. (P=0.24)
Can't physically participate in activities	43 (29.5%)	24 (20.7%)	n.s. (P=0.12)	8 (8.0%)	P<0.0001	n.s. (P=0.012)	P=0.0002
Self-conscious about appearance	25 (17.1%)	15 (12.9%)		5 (5.0%)			n.s. (P=0.018)
Don't feel accepted	7 (4.8%)	2 (1.7%)		0			n.s. (P=0.049)
Fear of injury	34 (23.3%)	13 (11.2%)	n.s. (P=0.011)	5 (5.0%)	P<0.0001	n.s. (P=0.14)	P=0.0002
Too old	0	0		1 (1.0%)			
Other	2 (1.4%)	5 (4.3%)		2 (2.0%)			

^a Several items may be chosen

Table 7 Influence of the treatment on 262 patients with adolescent idiopathic scoliosis

	ST (n=146) n (%)	BT (n=116) n (%)	P-value
How did you experience the treatment period?			<i>P</i> <0.0001
The treatment had a major positive effect on my life	37 (25.3%)	6 (5.1%)	
The treatment had a minor positive effect on my life	33 (22.6%)	18 (15.5%)	
The treatment in no way affected my life	18 (12.3%)	17 (14.6%)	
The treatment had a minor negative effect on my life	37 (25.3%)	43 (37.1%)	
The treatment had a major negative effect on my life	21 (14.4%)	32 (27.6%)	
How did the treatment affect you during the treatment time?			
I was very often depressed and sad	37 (25.3%)	35 (30.2%)	n.s. (<i>P</i> =0.41)
Because of the treatment I was more noticeable and I was helped out	106 (72.6%)	63 (54.3%)	<i>P</i> =0.0027
People around me and my mates were more sympathetic	96 (65.7%)	52 (44.8%)	<i>P</i> =0.0007
I was often teased because of the scoliosis	18 (12.3%)	5 (4.3%)	n.s. (<i>P</i> =0.027)
I was intentionally ignored	15 (10.3%)	11 (9.5%)	n.s. (<i>P</i> =0.99)
Often I kept to myself	31 (21.2%)	21 (18.1%)	n.s. (<i>P</i> =0.64)
I stopped all my spare time activities	52 (35.6%)	37 (31.9%)	n.s. (<i>P</i> =0.60)
Because of the treatment I faced a lot of conflicts at home	6 (4.1%)	5 (4.3%)	n.s. (<i>P</i> =0.99)
The treatment programme ruined my teenage period	34 (23.3%)	31 (26.7%)	n.s. (<i>P</i> =0.57)
The treatment programme did not bother me much	53 (36.3%)	46 (39.6%)	n.s. (<i>P</i> =0.61)
Because of the treatment programme my contacts with the opposite sex became limited	62 (42.5%)	50 (43.1%)	n.s. (<i>P</i> =0.99)
The treatment programme made me become independent sooner and mature earlier	73 (50.0%)	45 (38.8%)	n.s. (<i>P</i> =0.80)

(*P*=0.0007). Approximately 25% of each treatment group thought that their teenage period had been “ruined”, over 30% of the patients had stopped all their spare time activities and over 40% thought they had become limited in their contacts with the opposite sex because of the treatment programme. In contrast, nearly 40% in each group had not been much bothered by the treatment, and 50% of ST and 39% of BT group thought they had matured earlier as a consequence.

Correlation between the scoliotic curve and HRQL

Patients describing themselves as having been depressed and sad during the treatment period had significantly lower mental health scores in the SF-36 (75.8 vs 82.9, *P*=0.0047) and also lower (but not significant at the 1% level) scores in the SF-36/physical functioning and the PGWB Index. The same trend with lower scores of mental health in the SF-36 could be seen among those who said that “the treatment programme had ruined their teenage period”.

No correlations were found between variables concerning the scoliosis (curve size after treatment, total treatment time or age at completed treatment) and the PGWB (Psychological General Well-Being) Index as well as the three subscales of SF-36: physical functioning, general health and mental health. Furthermore, neither curve type (single or double) nor whether “the treatment pro-

gramme had a major negative effect on my life” influenced the HRQL scores.

In addition, no difference was found in these scores between patients who had a curve size of over 50° and those with curves of less than 50° (n.s., *P*=0.27 Physical Functioning, *P*=0.99 General Health, *P*=0.85 Mental Health and *P*=0.80 PGWB, all patients) at current follow-up or between patients whose curves had increased by more than 20° (only BT patients) and those in whom the increase had been less than 20° from the end of treatment (n.s., *P*=0.81 Physical Functioning, *P*=0.72 General Health, *P*=0.88 Mental Health and *P*=0.42 PGWB).

There were no correlations between the degree of trunk rotation measured using a Bunnell scoliometer and the PGWB ($r_s=-0.069$, *P*=0.27), the MCS ($r_s=0.009$, *P*=0.89) or the PCS ($r_s=0.12$, *P*=0.051) scores of the SF-36, or how the patients rated their self-appearance in a bathing suit ($r_s=-0.086$, *P*=0.17). Nor was there a difference in terms of rotation between patients with and those without social limitations, where the self-appearance was regarded as a limiting factor [mean 12.0° (SD 6.4°) and mean 10.7° (SD 5.1°) respectively, n.s., *P*=0.19].

Discussion

The physical well-being according to the SF-36 showed differences of a magnitude considered to reflect clinically

meaningful differences, i.e., a difference of 5 points [44] between the patient groups and controls, mainly in terms of the physical function. The same trend was seen regarding physical disability (the Oswestry Back Pain Disability Score) and having been on sick-leave due to back problems.

Recent studies have compared the functional impairment in different diseases. Fanuele et al. [20] reported a mean value of 30.4 of the PCS (Physical Component Summary) scores of 17,774 patients with spinal conditions collected from the National Spine Network, the majority of them having diagnoses with pain as the dominant symptom. They were compared with patients prior to primary hip arthroplasty, who had a mean PCS score of 29.0 and with chronic obstructive pulmonary disease, with a mean PCS score of 33.9. Sprangers et al. [41] similarly reported that the majority of studied disease clusters were associated with physical and mental dysfunction; in particular, a profound physical impairment for musculoskeletal conditions in general. Compared to these findings, our groups of previously treated scoliosis patients, with a mean PCS score of 49, can be considered to have a near normal function, even though 4 out of 262 exhibited severe disability due to physical limitations from their spinal disorder. Also, compared with patients aged between 50 and 60 years with rheumatoid arthritis, fibromyalgia or Sjögrens syndrome in a recent Swedish study [42], the patients with scoliosis reported better functioning in all subscales of the SF-36.

The scoliosis patients did not deviate from controls in any of the psychological measures. The treatment rationale was to save the patient from a presumed risk of respiratory failure, premature death and severe cosmetic deformity with psychological burden. For the patients, and especially for those surgically treated, who had larger curve improvement from treatment, this appeared to have been a positive factor for their feelings regarding the treatment. Some degree of coping with the disease in the long term might also have contributed positively to their well-being.

However, some patients, especially in the brace-treated group, experienced a psychological burden during and after the treatment period. Treatment time was not correlated to the outcome scores. However, those who had expressed feelings of depression at the time of treatment scored worse in psychological outcome scores at follow-up (Mental Health subscale of the SF-36). Additionally, the treatment period in general had a more negative effect on the brace-treated patients than on the surgically treated patients.

Psychological well-being has previously been shown to be influenced by the scoliosis and the appearance of the curve itself [17, 21]. The treatment per se may also impact on the quality of life and psychological well-being in a negative way [19, 33, 35, 37]. The negative effects experienced during the treatment period might also be related

to the patient's personality or to lack of support or poor family relations. The present study did not, however, establish a causal relationship for these findings. Another recent study [36] showed that brace wearing did not affect the self-image during the treatment of adolescents with idiopathic scoliosis, except in patients with low scores for relations with family.

No major impact on marriage, childbearing, degree of physical strain during work or leisure time was observed. The finding that scoliosis patients do not differ significantly in terms of sociodemographic measures has been reported in previously published studies [3, 9, 10, 22, 27, 34]. The same results have also been found for other chronic diseases during adolescence. In a study from 1993 by Gortmaker et al. [24], reviewing a large nationally representative sample, a great majority of subjects with different and chronic physical health conditions during youth were found to be remarkably successful in their transition to adulthood in terms of sociodemographic measures. Only the educational level in the surgically treated patients was significantly lower than in the other two groups. ST patients, but not BT patients, lost at least 6 months from school due to the time required for the treatment, and they sometimes had to repeat a year in school, which might be an explanation for this finding. Time off from school during the treatment period nowadays is considerably less (approximately 3 weeks).

Significantly more subjects in both patient groups in the present study were concerned about their appearance, leading to some restriction of social activities and also to some restriction of the sexual activity in some patients, previously reported [13].

We present results from patients treated more than 20 years ago; nevertheless, these results should also be applicable for treatment given today. The treatment time with the brace is similar, and both types of braces are still used. However, a recent study [6] has shown that the Milwaukee brace leads to a significantly greater impairment of the patient's QL during the treatment. The Harrington instrumentation has to a great extent been replaced by more modern devices, offering the possibilities of a somewhat shorter fusion and no need for postoperative bracing – both factors that each might influence the QL in a positive direction. The surgical principles, however, remain the same: correction and fusion.

Conclusions

We conclude that psychological well-being is quite good in patients with adolescent idiopathic scoliosis 20 years after surgery or brace treatment, and is equal to the general population. Even the physical function is equal to the general population, except in a minority of the patients. It is reasonable to expect some physical disability due to the disease, and this was similar for both patient groups.

A certain amount of psychological impact due to the cosmetic deformity is also to be expected, and this was equal for both groups in the present study. However, compared with the control group, both BT and ST patients displayed a lower cosmetic well-being, not correlated to curve size or chest deformity.

Overall positive results of this study indicate that there is no need for hesitation over the proposal of an indicated

treatment for scoliosis. Current treatment regimens, with the additional benefits of, for instance, shorter treatment times and better psychological support than 20 years ago, ought to have an even less negative impact on the well-being of the patients.

References

- Albert TJ, Purtill J, Mesa J, McIntosh T, Balderston RA (1995) Health outcome assessment before and after adult deformity surgery. A prospective study. *Spine* 20:2002–2004; discussion p 2005
- American Academy of Orthopaedic Surgeons/Council of Spine Societies (1996) Outcomes Data Collection Questionnaire. American Academy of Orthopaedic Surgeons, Council of Spine Societies, Rosemont, Illinois
- Ascani E, Bartolozzi P, Logroscino CA, Marchetti PG, Ponte A, Savini R, et al (1986) Natural history of untreated idiopathic scoliosis after skeletal maturity. *Spine* 11:784–789
- Blount W, Moe J (1980) *The Milwaukee brace*, 2nd edn. Williams and Wilkins, Baltimore
- Bunnell WP (1984) An objective criterion for scoliosis screening. *J Bone Joint Surg Am* 66:1381–1387
- Climent JM, Sanchez J (1999) Impact of the type of brace on the quality of life of adolescents with spine deformities. *Spine* 24:1903–1908
- Climent JM, Reig A, Sanchez J, Roda C (1995) Construction and validation of a specific quality of life instrument for adolescents with spine deformities. *Spine* 20:2006–2011
- Cobb J (1948) Technique for study of scoliosis. In: W. P. Blount WP (ed) *AAOS Instructional Course Lectures*. J Edwards, Ann Arbor, pp 261–275
- Cochran T, Nachemson A (1985) Long-term anatomic and functional changes in patients with adolescent idiopathic scoliosis treated with the Milwaukee brace. *Spine* 10:127–133
- Cochran T, Irstam L, Nachemson A (1983) Long-term anatomic and functional changes in patients with adolescent idiopathic scoliosis treated by Harrington rod fusion. *Spine* 8:576–584
- Cook DJ, Guyatt GH, Juniper E, Griffith L, McIlroy W, Willan A, et al (1993) Interviewer versus self-administered questionnaires in developing a disease-specific, health-related quality of life instrument for asthma. *J Clin Epidemiol* 46:529–534
- Cordover AM, Betz RR, Clements DH, Bosacco SJ (1997) Natural history of adolescent thoracolumbar and lumbar idiopathic scoliosis into adulthood. *J Spinal Disord* 10:193–196
- Danielsson A, Nachemson A (1986) Child-bearing, curve progression, and sexual function in women 22 years after treatment for adolescent idiopathic scoliosis. A case-control study. *Spine* (in press)
- Danielsson A, Nachemson A (2001) Radiologic findings and curve progression 22 years after treatment for adolescent idiopathic scoliosis. Comparison of brace and surgical treatment and with matching control group of straight individuals. *Spine* 26:516–525
- Dimenas E, Carlsson G, Glise H, Israelsson B, Wiklund I (1996) Relevance of norm values as part of the documentation of quality of life instruments for use in upper gastrointestinal disease. *Scand J Gastroenterol Suppl* 221:8–13
- Dupuy H (1984) *The Psychological General Well-Being (PGWB) Index*. In: Wenger N, Mattson M, Furberg C, Elinson J (eds) *Assessment of quality of life in clinical trials of cardiovascular therapies*. le Jacq, New York, pp 170–183
- Edgar MA, Mehta MH (1988) Long-term follow-up of fused and unfused idiopathic scoliosis. *J Bone Joint Surg Br* 70:712–716
- Fairbank JC, Couper J, Davies JB, O'Brien JP (1980) *The Oswestry Low Back Pain Disability Questionnaire*. *Physiotherapy* 66:271–273
- Fallstrom K, Cochran T, Nachemson A (1986) Long-term effects on personality development in patients with adolescent idiopathic scoliosis. Influence of type of treatment. *Spine* 11:756–758
- Fanuele J, Birkmeyer N, Abdu W, Tostesson T, Weinstein J (2000) The impact of spinal problems on the health status of patients. *Spine* 25:1509–1514
- Fowles JV, Drummond DS, L'Ecuyer S, Roy L, Kassab MT (1978) Untreated scoliosis in the adult. *Clin Orthop* 134:212–217
- Goldberg MS, Mayo NE, Poitras B, Scott S, Hanley J (1994) *The Ste-Justine Adolescent Idiopathic Scoliosis Cohort Study*. I. Description of the study [see comments]. *Spine* 19:1551–1561
- Goldstein JM, Nash CL Jr, Wilham MR (1991) Selection of lumbar fusion levels in adult idiopathic scoliosis patients. *Spine* 16:1150–1154
- Gortmaker S, Perrin J, Weitzman M, Homer C, Sobol A (1993) An unexpected success story: transition to adulthood in youth with chronic physical health conditions. *J Res Adolesc* 3:317–336
- Greulich W, Pyle S (1950) *Radiographic atlas of the skeletal development of the hand and wrist*, 2nd edn. Stanford University Press, Stanford
- Grevitt M, Khazim R, Webb J, Mulholland R, Shepperd J (1997) The Short Form-36 health survey questionnaire in spine surgery. *J Bone Joint Surg Br* 79:48–52
- Grouw AV, Nadel CI, Weierman RJ, Lowell HA (1976) Long term follow-up of patients with idiopathic scoliosis treated surgically: a preliminary subjective study. *Clin Orthop* 117:197–201
- Guillemin F, Bombardier C, Beaton D (1993) Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines [see comments]. *J Clin Epidemiol* 46:1417–1432

29. Haheer TR, Gorup JM, Shin TM, Homel P, Merola AA, Grogan DP, et al (1999) Results of the Scoliosis Research Society instrument for evaluation of surgical outcome in adolescent idiopathic scoliosis. A multicenter study of 244 patients. *Spine* 24:1435–1440
30. Hozack WJ, Rothman RH, Albert TJ, Balderston RA, Eng K (1997) Relationship of total hip arthroplasty outcomes to other orthopaedic procedures. *Clin Orthop* 344: 88–93
31. Hu SS, Holly EA, Lele C, Averbach S, Kristiansen J, Schiff M, et al (1996) Patient outcomes after spinal reconstructive surgery in patients ≥ 40 years of age. *J Spinal Disord* 9:460–469
32. Leidy N, Revicki D, Genesté B (1999) Recommendations for evaluating the validity of quality of life claims for labeling and promotion. *Value Health* 2: 113–127
33. MacLean WE Jr, Green NE, Pierre CB, Ray DC (1989) Stress and coping with scoliosis: psychological effects on adolescents and their families. *J Pediatr Orthop* 9:257–261
34. Moskowitz A, Moe JH, Winter RB, Binner H (1980) Long-term follow-up of scoliosis fusion. *J Bone Joint Surg Am* 62:364–376
35. Noonan KJ, Dolan LA, Jacobson WC, Weinstein SL (1997) Long-term psychosocial characteristics of patients treated for idiopathic scoliosis. *J Pediatr Orthop* 17:712–717
36. Olafsson Y, Saraste H, Ahlgren RM (1999) Does bracing affect self-image? A prospective study on 54 patients with adolescent idiopathic scoliosis. *Eur Spine J* 8:402–405
37. Payne WK 3rd, Ogilvie JW, Resnick MD, Kane RL, Transfeldt EE, Blum RW (1997) Does scoliosis have a psychological impact and does gender make a difference? *Spine* 22:1380–1384
38. Pehrsson K, Olofson J, Larsson S, Sullivan M (1994) Quality of life of patients treated by home mechanical ventilation due to restrictive ventilatory disorders. *Respir Med* 88:21–26
39. Risser J (1958) The iliac apophysis: an invaluable sign in the management of scoliosis. *Clin Orthop* 11:111–119
40. Rosengren A, Orth-Gomer K, Wedel H, Wilhelmsen L (1993) Stressful life events, social support, and mortality in men born in 1933 [see comments]. *BMJ* 307: 1102–1105
41. Sprangers M, de Regt E, Andries F, et al (2000) Which chronic conditions are associated with better or poorer quality of life? *J Clin Epidemiol* 53:895–907
42. Strömbek B, Ekdahl C, Manthorpe R, Wikström I, Jacobsson L (2000) Health-related quality of life in primary Sjögrens syndrome, rheumatoid arthritis and fibromyalgia compared to normal population data using SF-36. *Scand J Rheumatol* 29:20–28
43. Sullivan M, Karlsson J, Ware J (1994) SF-36, Swedish manual and interpretation guide. Gothenburg University and Sahlgrenska Hospital, Gothenburg
44. Ware J, Snow K, Kosinski M, Gandek B (1993) SF-36 Health Survey: manual and interpretation guide. The Health Institute, New England Medical Center, Boston
45. Ware J, Kosinski M, Keller S (1994) SF-36 Physical and Mental Health Summary Scores: a user's manual. The Health Institute, Boston
46. Ware JE Jr, Sherbourne CD (1992) The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 30: 473–483
47. White SF, Asher MA, Lai SM, Burton DC (1999) Patients' perceptions of overall function, pain, and appearance after primary posterior instrumentation and fusion for idiopathic scoliosis. *Spine* 24:1693–1699; discussion 1699–1700
48. Wiklund I (1993) Practical issues in the design and inclusion of quality of life in multicentre clinical trials. *Br J Med Econ* 6C:45–48
49. Wiklund I, Karlberg J (1991) Evaluation of quality of life in clinical trials. Selecting quality-of-life measures. *Control Clin Trials* 12:204S-216S