



Health-related quality of life of adult, non-surgically treated patients with idiopathic scoliosis and curves above 45°: a cross-sectional study at an average follow-up of 30 years

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Abstract

Background context Previous studies on the natural history of moderate to severe idiopathic scoliosis show contradictory results. Some studies reported an increased incidence of back pain and disability in severe curves, while other studies reported no difference in health-related quality of life (HRQoL) compared to age-matched adult controls. None of these studies addressed HRQoL using currently recommended and validated questionnaires.

Purpose To examine the long-term HRQoL in non-surgically treated adult idiopathic scoliosis patients with a curve of 45° or higher.

Methods In this retrospective cohort study, all patients were retrospectively identified in the hospital's scoliosis database. Patients (1) with idiopathic scoliosis; (2) born before 1981 (to ensure 25-year follow-up after skeletal maturity); (3) with a curve of 45° or more by Cobb's method at the end of growth; and (4) no spinal surgical treatment were selected.

Patients received digital questionnaires of the Short Form-36, Scoliosis Research Society-22, Oswestry Disability Index and Numeric Rating Scale. Outcomes of the SF-36 were compared with a national reference cohort. Additional measures with questions regarding choice of education and occupation were used.

Results Forty-eight of 79 (61%) eligible patients completed the questionnaires, at an average follow-up time of 29.9 ± 7.7 years. Their average age was 51.9 ± 8.0 , and median Cobb angle at adolescence was 48.5° . Five of the eight SF-36 subdomains were significantly lower in the scoliosis group compared to the nationwide cohort: physical functioning (73 vs 83, $p=0.011$), social functioning (75 vs 84, $p=0.022$), role physical functioning (63 vs 76, $p=0.002$), role emotional functioning (73 vs 82, $p=0.032$), and vitality (56 vs 69, $p < 0.001$). The scoliosis-specific SRS-22r score of the patients was 3.7 ± 0.7 on a 0–5 scale. The mean NRS score for pain of all patients was 4.9 ± 3.2 , and eight patients (17%) reported a NRS of 0 and 31 (65%) a NRS above 3. At the Oswestry Disability Index, 79% of the patients reported minimal disabilities. Thirty-three patients (69%) reported that their scoliosis had influenced their choice of education. Fifteen patients (31%) reported that their scoliosis had influenced their choice of work.

Conclusion Patients with idiopathic scoliosis and curves of 45° or higher have reduced HRQoL. Although many patients experience back pain, the disability reported on the ODI was limited. Scoliosis had noteworthy effect on choice of education.

Keywords Adolescent idiopathic scoliosis · HRQoL · Quality of life · Non-surgically treated · Conservative treatment · Long-term follow-up

Introduction

Idiopathic scoliosis is a complex three-dimensional deformity of the spine defined as a lateral curvature of the spine greater than 10° without an underlying cause. The deformity arises during skeletal growth and affects 1–2% of the children [1]. Although many children with idiopathic scoliosis are asymptomatic, progressive curves are treated to alter

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the natural history of the deformity [2]. Surgical treatment is indicated for curves exceeding 45°–50° to prevent curve progress after skeletal maturity and a subsequent negative impact on adulthood [3].

Although treatment aims to prevent future problems in adulthood, information on the natural course of non-operated curves of 45° or higher in adulthood is scarce and inconclusive [4]. Two early studies about the natural history of scoliosis presented a grim prognosis and concluded that it might lead to severe back pain, lack of social participation, lower marriage rates, cardiopulmonary compromise and early death [4, 5]. However, one of these studies also included patients with other etiologies (e.g., congenital scoliosis or poliomyelitis), and both studies did not present outcomes related to spinal curve severity. None of these studies addressed health-related quality of life (HRQoL) using currently recommended and validated questionnaires [4, 5]. More recent studies, which included only idiopathic patients, show a more favorable course without increased mortality. The prevalence of back pain increased as patients get older [6–8]. The pain was often mild, and most patients function well, become employed, get married, have children and grow to become active adults. Although the prognosis of untreated idiopathic scoliosis seems good, these studies included mainly moderate curves [6, 8, 9]. Studies specifically focusing on long-term outcomes in patients with curvatures above 45 degrees are scarce since most patients in this category have been treated surgically.

Therefore, the primary aim of this study was to compare the HRQoL of non-surgically treated idiopathic scoliosis patients with severe curvatures (> 45 degrees) more than 25 years after skeletal maturity, measured using the Short Form-36, to a Dutch national reference cohort to investigate the burden of a severe spinal curve. The secondary aim was to assess scoliosis-specific HRQoL, back pain, disability and other relevant outcomes as reported by the patients.

Materials and methods

This study was a single-center cross-sectional cohort study which was performed in accordance with the *STROBE guidelines* for improving quality in reporting of observational studies in epidemiology [10]. Approval was obtained from the local medical ethics committee (WO15.017). Since not all eligible patients participated, there was a risk of selection bias. The patients all had a conservative treatment during childhood and had a spinal X-ray at the end of growth.

Participants

Eligible patients were identified in the local scoliosis database, a single-center registry of the Department of Orthopedic Surgery at the OLVG Hospital in Amsterdam that was initiated in 1976. Inclusion criteria consisted of (1) idiopathic scoliosis patients; (2) born before 1981 (to ensure a minimum of 25-year follow-up after skeletal maturity); (3) a curve of 45° or more by Cobb's method at the end of growth; and (4) without any spinal surgical treatment. Patients with other forms of scoliosis (e.g., neuromuscular, syndromic, congenital, or secondary scoliosis) were excluded. Curve size and type of curve were determined on historic spinal X-rays at the end of adolescence. Curve types were defined according to the Lenke classification [11]. All eligible patients were traced and contacted by mail or by phone. Before contacting the patients, the hospital records were updated using the Dutch Personal Records Database to check whether patients were still alive and avoid the risk of approaching family members of deceased patients. If contact details were incorrect and there was no possibility to obtain correct address or phone number using the Dutch Personal Records Database, or if patients did not respond to letters of information, patients were defined as lost to follow-up. After providing informed consent, participants received online questionnaires using secured survey software (Questmanager, VitalHealth software, Ede, the Netherlands) which could be filled out at home. The scoliosis characteristics were extracted from the original medical charts, which were all still available. The coronal curve magnitude was quantified using the Cobb angle.

Outcome assessment

The primary outcome of this study was the HRQoL measured using the Short Form-36 item Health Survey (SF-36). The SF-36 consists of four domains regarding physical health and four domains regarding mental health. The SF-36 results of the adult scoliosis patients were compared with Dutch scores of a random nationwide cohort. These nationwide scores were collected during the International Quality of Life Assessment Project (IQOLA), which aimed to translate, adapt and validate the SF-36 in various countries and generate normative or reference group data within each participating country [12]. For this nationwide cohort, a random sample of 2800 households received the SF-36 Health Survey, and 1742 respondents, with a mean age of 47.6 ± 18.0 , completed it.

The secondary outcomes consisted of the scoliosis-specific health-related quality of life determined by the

Scoliosis Research Society-22 questionnaires (SRS-22r), and severity of low back pain was determined by the Numeric Rating Scale (NRS) for back pain and the Oswestry Disability Index (ODI) [14]. The SRS-22 is a scoliosis-specific questionnaire, addressing function, pain, self-image, mental health and satisfaction [12, 13]. The NRS is a scale to determine pain intensity and ranges from zero to ten. The ODI was used to measure the disability due to low back pain and ranges from zero to hundred with subscales ranging from zero to five. Validated Dutch versions of all questionnaires were used [12–14]. Additional, non-validated, questions were included regarding frequency of back pain, marital status, education, occupation, the influence of scoliosis on the choice of education and occupation as well as potential surgical treatment as adults. For the SRS-22r, NRS and ODI questionnaires, no local or nationwide reference values were available.

Statistical analysis

All relevant historical and questionnaire data were entered into a database, and statistical analysis was performed using SPSS software (version 23.0; SPSS, Chicago, Illinois). Demographic and scoliosis-specific factors such as gender, mean age, education, occupation, mean Cobb angle and mean ODI score were reported descriptively. Continuous variables were summarized using the appropriate measures of central tendency (i.e., mean and median) and dispersion (i.e., standard deviation and interquartile range), depending on their distribution. Categorical data were presented by counts and percentages. HRQoL scores measured with the SF-36 were compared with the reference scores of the nationwide cohort using the unpaired Student's *t* test. The significance level was set at $\alpha < 0.05$.

Results

Patient identification

In the local scoliosis database, 83 non-surgically treated idiopathic scoliosis patients born before 1981 were identified with a curve of 45° or more at the end of growth. Four patients (4.8%) were deceased. The 79 living patients were traced and contacted. Of those patients, 21 could not be reached; they did not respond to the invite to participate by mail and/or phone. Three patients initially agreed to participate, but eventually withdrew. One patient did not want to participate, for no particular reason. Fifty-four patients were willing to participate and completed the questionnaire. Questions regarding previous spinal surgery were included. Six patients completed the questionnaire and reported spinal procedures during adulthood. These patients were excluded

from the statistical analyses, as our study focused on patients who were not surgically treated. As a result, 48 of 79 living (61%) eligible patients were included in this study (Fig. 1).

Patient characteristics

The patient cohort consisted of 38 women and 10 men with a mean age at completion of the questionnaires of 51.9 ± 8.0 years. (Table 1) The mean of the follow-up was 29.9 ± 7.7 , and the number of follow-up years ranged from 13 to 45 years. The median of the Cobb angle was 48.5°, with a range from 45° and 96° and an interquartile range (IQR) of 9° (mean age of Cobb angle measurement 20.1 ± 4 years). The mean age at diagnosis of the deformity was 12.9 ± 2.8 years, and the population included nine juvenile and 39 adolescent idiopathic scoliosis cases. According to the Lenke classification, 27 patients had a type 1, three a type 2, four a type 3, one a type 4, five a type 5, two a type 6, and 6 an unknown type of scoliosis due to missing X-rays.¹⁰ During childhood, 22 patients (46%) were treated with a Boston brace, four patients (8%) with a Milwaukee brace, and three patients (6%) with a cast. Five patients (11%) had an unknown type of brace. Fourteen patients (29%) had no brace treatment. The 29 non-participants (also listed in Table 1) had a median Cobb angle of 53.0° with an IQR of 16. The mean age at diagnosis was 14.4 ± 3.6 . Eighteen patients were female (62%). The reason that patients were not treated surgically was not clear in all cases. Some patient charts reported non-surgical management because of patient preferences, inappropriate patient circumstances and stable curves during follow-up. The six patients who reported surgical treatment during adulthood are also listed in Table 1. Their median Cobb angle was 58.5° with an IQR of 17.5°.

Health-related quality of life

The scores for the different domains of the SF-36 questionnaire for the non-surgically treated scoliosis group and the national reference cohort are presented in Table 2. The score of the scoliosis group was significantly lower compared to the national reference cohort in the domains physical functioning, social functioning, role physical functioning, role emotional functioning and vitality. There were no statistically significant differences between the scoliosis group and reference cohort in the domains mental health, bodily pain and general health. The scoliosis-specific SRS-22r scores are summarized in Table 3. The sum score was 3.7 ± 0.7 , with domain scores varying between 3.0 ± 0.8 for satisfaction with management and 4.0 ± 0.9 for function.

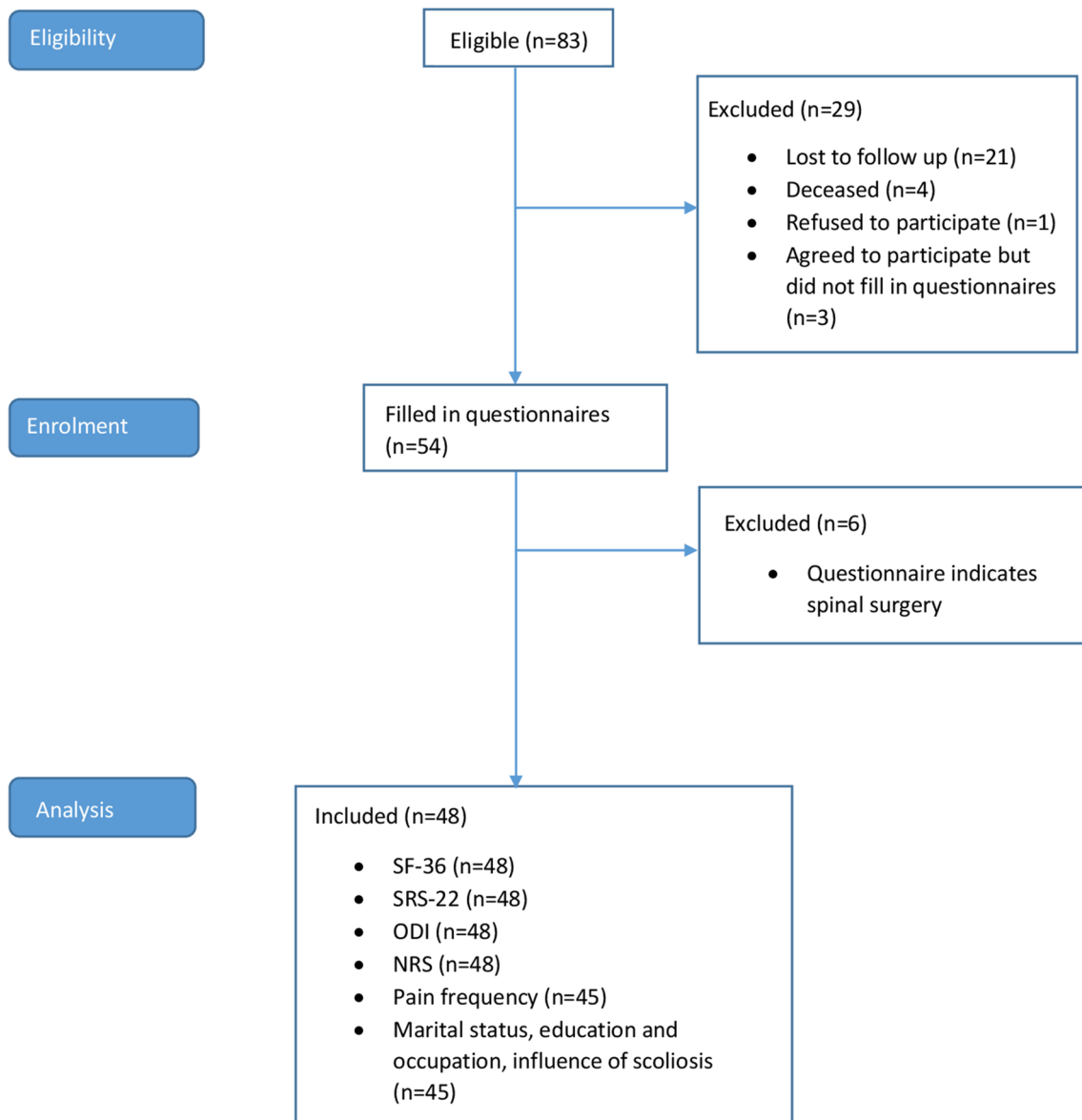


Fig. 1 Flowchart of patient inclusion

Back pain and Oswestry disability index

According to the question regarding pain frequency, five patients (10%) never experienced pain and 17 patients (35%) reported to have sometimes pain for short periods of time. Four patients (8%) reported to have intermittent pain for longer periods of time. Seven patients (15%) reported to have pain on a weekly basis, and twelve patients (23%) reported to have pain daily. The answer to this question was missing in three patients (6%). The mean pain on the NRS was 4.9 ± 3.2 . Eight patients (17%) reported a NRS of 0 and 31 (65%) a NRS above 3 (Fig. 2).

The ODI score ranged from 0 to 54. The mean was 13.6, with a standard deviation of 15.2. Of the 48 patients, 38 patients reported minimal disabilities (ODI scores between 0 and 20), five patients moderate disabilities (scores between 21 and 40), and five patients severe disabilities (scores between 41 and 60) (Fig. 3). The mean score on every item was as follows; patients scored highest on the question regarding pain intensity (1.2 ± 3) and scored lowest on the questions regarding functioning of personal care (0.2 ± 0.6). Problems with lifting, walking and sitting (score > 0) were reported by 18 (38%), 15 (31%), and 26 (54%) patients, respectively. For standing, the average pain

Table 1 Patient demographics

| | Participants (<i>n</i> = 48) | Non-participants (<i>n</i> = 29) | Surgically treated (<i>n</i> = 6) |
|--|-------------------------------|-----------------------------------|------------------------------------|
| Women | 38 (79%) | 18 (62%) | 4 (67%) |
| Juvenile/adolescent scoliosis | 9 / 39 | 3/26 | 4/2 |
| Average age of diagnosis (years) | 12.9 ± 2.8 | 14.4 ± 3.6 | 11 ± 3 |
| Lenke classification (number of cases) | | | |
| Type 1 | 27 | 6 | 5 |
| Type 2 | 3 | 3 | 0 |
| Type 3 | 4 | 8 | 0 |
| Type 4 | 1 | 2 | 0 |
| Type 5 | 5 | 3 | 0 |
| Type 6 | 2 | 5 | 1 |
| Not known | 6 | 2 | 0 |
| Number of patients treated with a brace | 34 (71%) | 13 (45%) | 4 (67%) |
| Average age end of adolescent follow-up (years) | 20.4 ± 4.3 | 21.7 ± 4.6 | 21.3 ± 5.7 |
| Cobb angle at the end of adolescent follow-up (°) | 48.5, IQR 9 | 53.0, IQR 16 | 58.5, IQR 17.5 |
| Average age at completion of the questionnaire (years) | 51.9 ± 8.0 | – | 49.8 ± 5.9 |
| Average follow-up (years) | 29.9 ± 7.7 | – | 27.9 ± 9.2 |

Table 2 SF-36 scores

| | Scoliosis cohort (<i>n</i> = 48) | National cohort (<i>n</i> = 1742) | Mean differences (95% CI) | <i>p</i> -value |
|----------------------------|-----------------------------------|------------------------------------|---------------------------|-----------------|
| Domain (range 0–100) | Mean age 51.9 ± 8.0 | Mean age 47.6 ± 18.0 | | |
| Physical functioning | 73.4 ± 25.1 | 83.0 ± 22.8 | 9.6 (– 17.5 to – 2.9) | 0.011* |
| Social functioning | 75.0 ± 26.4 | 84.0 ± 22.4 | 9.0 (– 17.7 to – 2.4) | 0.022* |
| Role physical functioning | 63.1 ± 28.1 | 76.4 ± 36.3 | 13.3 (– 22.5 to – 6.4) | 0.002* |
| Role emotional functioning | 73.1 ± 28.9 | 82.3 ± 32.9 | 9.2 (– 18.6 to – 1.9) | 0.032* |
| Mental health | 71.3 ± 19.5 | 76.8 ± 17.4 | 5.5 (– 11.9 to – 0.6) | 0.055 |
| Vitality | 55.7 ± 19.1 | 68.6 ± 19.3 | 12.6 (– 18.6 to – 7.4) | <.001* |
| Bodily pain | 69.8 ± 24.4 | 76.4 ± 36.3 | 6.6 (– 13.7 to 0.5) | 0.067 |
| General health | 65.9 ± 20.8 | 70.7 ± 20.7 | 4.8 (– 11.6 to 0.6) | 0.119 |

Data are presented as mean and S.D. * The score is significant (*P* < 0.05)

Table 3 SRS-22r scores

| Domain (range 1–5) | <i>n</i> = 48 |
|------------------------------|---------------|
| Total score | 3.7 ± 0.7 |
| Function/activity | 4.0 ± 0.9 |
| Pain | 3.7 ± 0.9 |
| Self-image | 3.4 ± 0.8 |
| Mental health | 3.8 ± 0.8 |
| Satisfaction with management | 3.0 ± 0.8 |

score on the ODI was 1.2 ± 1.2, and seven patients (15%) reported pain during sleep. Seven participants (15%) reported problems with sex life, 19 (40%) reported problems with social life, and problems with traveling were reported by 15 patients (31%) (Table 4).

Social life and work

Regarding social life, half of the patients reported to be in a relationship. (Table 5) The highest level of education was for most patients vocational training (35%), followed by university (35%) and high school (11%). Thirty-three patients (69%) reported that their scoliosis had influenced their choice of education. Most patients reported to be employed (58%), and seven patients were sick-listed due to any disease (15%). Fifteen patients (31%) reported that their scoliosis had influenced their choice of work.

Surgically treated patients

Six patients reported in the questionnaire that they had undergone spinal surgery during adulthood. Five out of the six patients underwent surgery because of curve progression,

Fig. 2 NRS histogram

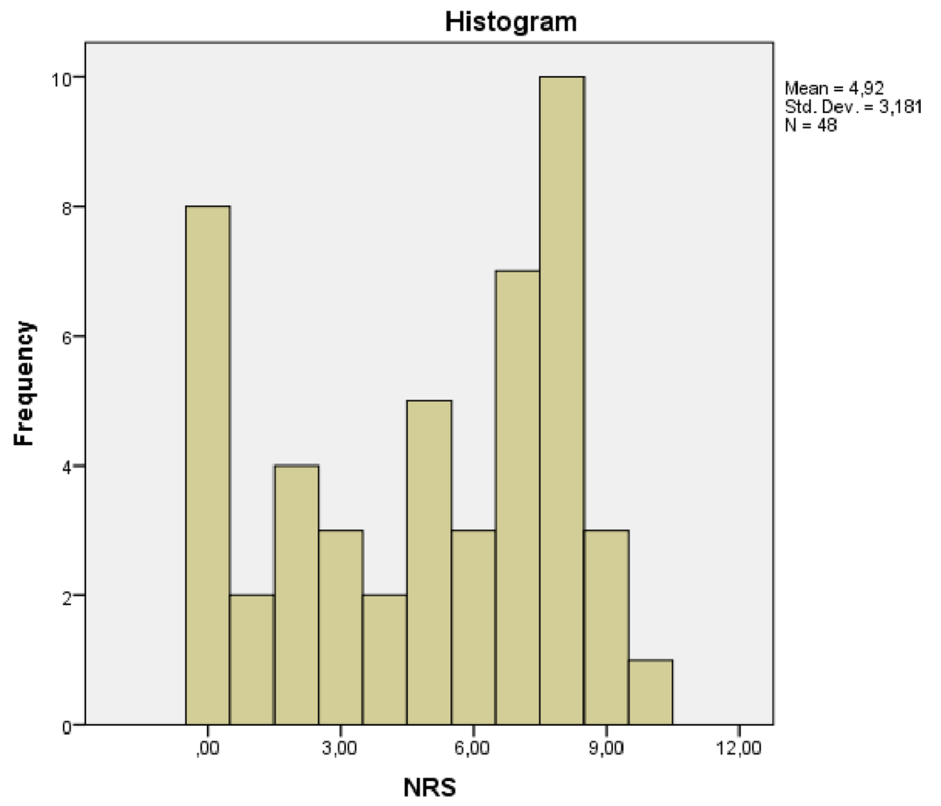


Fig. 3 ODI histogram

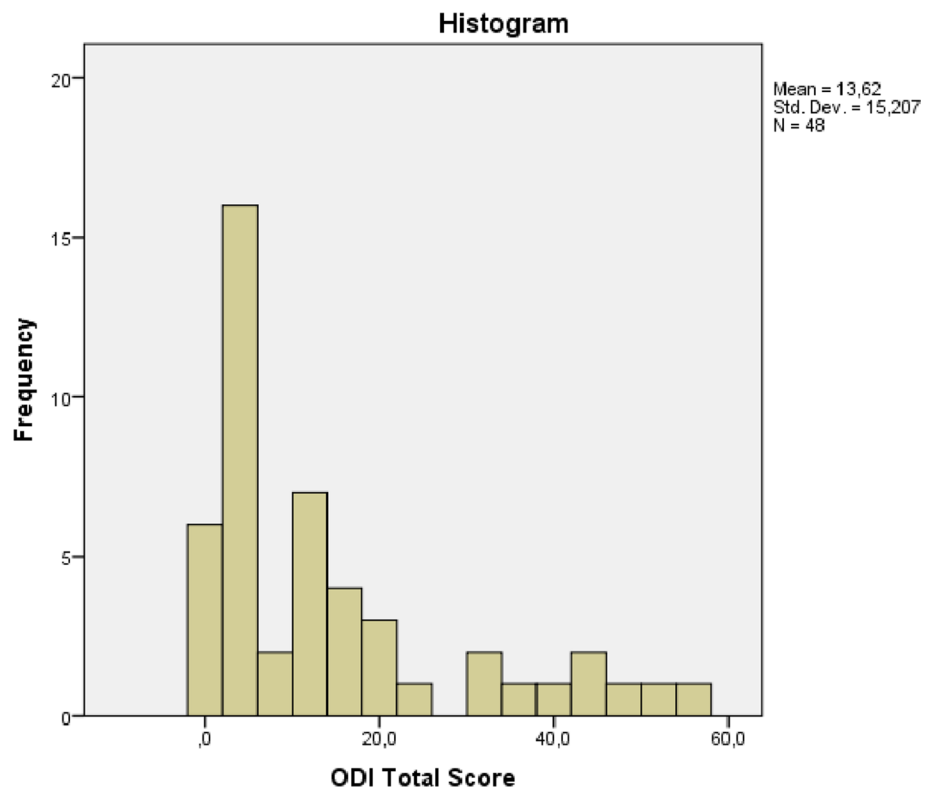


Table 4 Pain frequency, NRS and ODI scores

| Pain frequency | |
|--|-------------|
| Never had pain | 5 (10%) |
| Sometimes, short periods | 17 (33%) |
| Sometimes, longer periods | 4 (8%) |
| Weekly | 7 (15%) |
| Daily | 12 (23%) |
| Missing | 3 (6%) |
| Average numeric rating scale for pain (range 0–10) | 4.9 ± 3.2 |
| Oswestry disability index (range 0–100) | 13.6 ± 15.2 |
| ODI subscores | |
| <i>Pain intensity</i> | 1.2 ± 1.7 |
| <i>Personal care</i> | 0.2 ± 0.6 |
| <i>Lifting</i> | 0.9 ± 1.3 |
| <i>Walking</i> | 0.5 ± 0.9 |
| <i>Sitting</i> | 0.9 ± 1.0 |
| <i>Standing</i> | 1.2 ± 1.2 |
| <i>Sleeping</i> | 0.3 ± 0.8 |
| <i>Sex life</i> | 0.4 ± 1.0 |
| <i>Social life</i> | 0.8 ± 1.2 |
| <i>Traveling</i> | 0.5 ± 0.9 |

Table 5 Social and work demographics (n = 48)

| <i>Marital status</i> | |
|---|-----------------|
| Single | 11 (23%) |
| Married/living together | 26 (22/4) (54%) |
| Divorced/widowed | 7 (5/2) (15%) |
| Not reported | 4 (8%) |
| <i>Educational level</i> | |
| No education | 1 (2%) |
| High school, completed or not | 5 (11%) |
| Vocational training | 21 (44%) |
| Higher education (college, university) | 17 (35%) |
| Not reported | 4 (8%) |
| <i>Scoliosis influenced the educational choice</i> | |
| Yes | 33 (69%) |
| No | 12 (25%) |
| Not reported | 3 (6%) |
| <i>Occupation</i> | |
| Employed | 28 (58%) |
| Housewife | 5 (11%) |
| Unemployed | 1 (2%) |
| Sick-listed | 7 (15%) |
| Retired | 3 (6%) |
| Not reported | 4 (8%) |
| <i>Scoliosis influenced the professional choice</i> | |
| Yes | 15 (31%) |
| No | 30 (63%) |
| Not reported | 3 (6%) |

Table 6 Outcomes surgically treated patients

| SF -36 | Domain | Domain scores 1–100 |
|----------------|--|---------------------|
| | Physical functioning | 85.8 ± 18.3 |
| | Social functioning | 72.9 ± 25.5 |
| | Role physical functioning | 69.8 ± 31.5 |
| | Role emotional functioning | 77.8 ± 25.6 |
| | Mental health | 57.5 ± 18.1 |
| | Vitality | 45.8 ± 19.6 |
| | Bodily pain | 91.2 ± 12.7 |
| | General health | 55.8 ± 19.1 |
| SRS-22 | Domain | Domain scores 1–5 |
| | Function / activity | 4.1 ± 0.7 |
| | Pain | 4.4 ± 0.3 |
| | Self-image | 3.4 ± 0.8 |
| | Mental health | 3.1 ± 0.9 |
| | Satisfaction with management | 4.0 ± 0.7 |
| ODI | Domain | Domain scores 1–5 |
| | Pain intensity | 0.0 ± 0.0 |
| | Personal care | 0.0 ± 0.0 |
| | Lifting | 0.2 ± 0.4 |
| | Walking | 0.0 ± 0.0 |
| | Sitting | 0.5 ± 0.8 |
| | Standing | 0.5 ± 0.8 |
| | Sleeping | 0.0 ± 0.0 |
| | Sex life | 0.0 ± 0.0 |
| | Social life | 0.0 ± 0.0 |
| | Traveling | 0.0 ± 0.0 |
| ODI | Total score (0–100) | 2.3 ± 3.7 |
| NRS | Average numeric rating scale for pain (range 0–10) | 1.8 ± 2.0 |
| Pain frequency | Number of patients | |
| | Never had pain | 1 |
| | Experience pain | 2 |
| | Not reported | 3 |

one patient because of pain. The mean age of surgery was 30, and the range was 25–40 years. These patients were not included in our non-surgically treated study population, but their outcomes are listed separately (Table 6).

Discussion

This study shows that non-surgically treated adults with idiopathic scoliosis with a curve of > 45° at the end of adolescence have a worse HRQoL than the reference cohort. At an average follow-up of 30 years, patients scored significantly lower on five of the eight subscales of the SF-36 compared

to a national reference cohort. These reduced scores of 6–14 points were larger than the minimal clinically important difference (MCID 4–7 points) and can therefore be considered clinically relevant [15]. Seventeen percent of the patients reported no pain at all (NRS of 0) but the average NRS score was 4.9 and 65% had a NRS above 3. A study by Mannion et al. defined a cutoff point at which patients are still satisfied with quality of life, called the acceptable state. They classified symptoms as acceptable if the NRS was below 4 [16]. Despite the high prevalence of back pain, the average ODI score was 13.6. Only 10 patients reported to have moderate to severe disabilities due to their back pain. Regarding the ODI, the normative score of patients with lower back pain without disabilities is 11.9 and with disabilities is 22.1. The cutoff point of lower back pain with disabilities is 12 [17]. Regarding the SRS-22, Mannion et al. classified the acceptable state if the SRS-22 was above 3.5, our population had an average total score of 3.8. Specifically, 69% of the patients reported an acceptable symptom state based on the threshold of 3.5 for the total SRS-22 score. Regarding the SRS subdomains the percentages of patients with acceptable symptoms were 81% for function, 64% for pain, 60% for self-esteem and 69% for mental health [16].

Most recent reviews describe a benign natural history of untreated idiopathic scoliosis with a similar HRQoL as the general population and some increase in mild or occasional back pain and cosmetic problems [18]. However, many studies, including those by Watanabe et al. with 107 patients and Farshad et al. with 20 patients, reported the HRQoL of mixed populations with curve sizes below and above the 45° surgical threshold [9, 19]. As a result, it has been suggested that idiopathic scoliosis is a cosmetic disorder, and surgical intervention should only be considered in patients with substantial psychological problems or restrictions in socialization due to the deformity [20]. Since clinical decision making is still based on curve severity, it is important to have a better insight in the natural history of untreated surgical candidates excluding non-surgical candidates with curves below 45 degrees. Furthermore, most of the natural history studies are before the era of validated HRQoL questionnaires. In contrast to previous reports, this Dutch group of non-surgically treated patients with severe curves above 45 degrees had significantly lower scores on five of the eight SF-36 domains at an average follow-up of 30 years compared to a random Dutch reference cohort. These results show that a severe scoliosis is not just a cosmetic disease, but a deformity which influences the patients' HRQoL. Unfortunately, this study could not provide any information whether surgical treatment would change the impact on HRQoL in these patients which are nowadays considered as candidates for operative treatment at childhood.

In previous studies, social life was the most important indicator for living a normal life. Marriage was one of the

measures of social success, and the reported marriage rate ranged from 42 to 98% [4, 5]. Furthermore, 53 to 98% of the patients were able to work, and the level of disability was the same as a sex-matched control group.^{4,5} In our study, we focused on validated measures of HRQoL that are currently widely used, but also observed that more than half of the patients was married or living together, as these questions were used to measure social life in older studies [4, 5]. Seven patients (15%) reported not being able to work; however, the cause of incapacitation was not mentioned. Most of the patients (69%) reported that the scoliosis deformity influenced the choice of their education or work. Combined with our findings on HRQoL, pain and disability, this study supports previous findings that most patients with untreated curves above 45 degrees can live normal lives with limited disabilities. However, scoliosis does influence choice of education and career.

Previous studies describe a higher mortality due to scoliosis. In this study, four patients out of 83 (4.8%, 95%CI: 1.3–11.9%) were deceased. The average age of deceased was 50.8. The percentage of decease is higher than expected when looking at the number of deaths per age group. In the Netherlands, percentage of deaths in the age group 55–59 is 0.42% [21]. Unfortunately, we were not able to trace the causes of death, so we were not able to conclude whether this was related to scoliosis.

Several studies have evaluated the HRQoL of adults with spinal deformities that seek medical care for their complaints [22, 23]. Compared to large cohorts with > 61% idiopathic scoliosis patients, average ages of > 45 years and mean Cobb angles > 42°, physical component scores were almost similar [22, 23]. The SRS-22 activity, pain, appearance and total scores were also within the range of a previously published adult spinal deformity population [16, 22, 23]. The high prevalence of back pain, low ODI scores and high NRS for back pain suggest that many of our patients have learned to cope with the deformity and complaints.

This retrospective evaluation of the HRQoL and back pain in non-surgically treated idiopathic scoliosis patients has some strengths and limitations. A strength of this study is that patients were evaluated from a historical pediatric database and not from cohort patients seeking medical care as adults. This resulted in inclusion of patients who would not visit the hospital since they experience little to no complaints. Since patients could complete the questionnaires at home, a fairly good response rate of 61% could be reached. The non-participants have a slightly higher Cobb angle, and a slightly higher age at diagnosis, wore less braces and have relatively more men (Table 1). Furthermore, six patients had spinal surgery during adulthood. We provided their demographics and outcome data, but this group was too small to draw conclusions on the outcome of surgical treatment during adulthood.

When interpreting the results of this study, important limitations should be considered. The results of this study were not based on an experimental study design, but on observational data after treatment during childhood. Therefore, this uncontrolled study design represents level 3 evidence, and the conclusions are only based on patients who were not treated surgically. Furthermore, no radiologic follow-up was acquired. Another limitation, is the lack of HRQoL measures at adolescence. HRQoL questionnaires such as the SF-36 and SRS-22r were not available at that time, so unfortunately it was not possible to investigate changes over time.

Conclusion

This study shows that non-surgically treated scoliosis of more than 45° has a significant impact on the HRQoL in adulthood. Adult patients with idiopathic scoliosis had significantly lower SF-36 scores on five of the eight domains compared the national reference cohort. Differences were larger than the MCID and therefore considered clinically relevant. The prevalence of back pain was high. Despite the high prevalence of back pain, the reported disability was mild in more than half of the patients according to the ODI. Nevertheless, scoliosis had a noteworthy influence in choice of education and occupation.

Author contributions All authors were involved in the design. JH and AB performed the data collection. All authors reviewed and edited subsequent iterations of the manuscript.

Declarations

Conflict of interests Local ethical committee approval was granted for this study (registration number WO 15.017). We have nothing to disclose. All authors declare they have no commercial associations that might pose a conflict of interest in relation to the submitted manuscript. The author(s) received no specific funding for this work.

References

1. Simony A, Hansen EJ, Carreon LY, Christensen SB, Andersen MO (2015) Health-related quality-of-life in adolescent idiopathic scoliosis patients 25 years after treatment. *Scoliosis* 10:22. <https://doi.org/10.1186/s13013-015-0045-8>
2. Negrini S, Grivas TB, Kotwicki T, Maruyama T, Rigo M, Weiss HR, Members of the Scientific Society on Scoliosis Orthopaedic and Rehabilitation Treatment (SOSORT) (2006) Why do we treat adolescent idiopathic scoliosis? What we want to obtain and to avoid for our patients SOSORT 2005 consensus paper. *Scoliosis* 1:4
3. Weinstein SL, Zavala DC, Ponseti IV (1981) Idiopathic scoliosis: long-term follow-up and prognosis in untreated patients. *J Bone Jt surg. Am* 63(5):702–712
4. Nilsson U, Lundgren KD (1968) Long-term prognosis in idiopathic scoliosis. *Acta Orthop Scand* 39(4):456–465. <https://doi.org/10.3109/17453676808989663>
5. Nachemson A (1968) A long term follow-up study of non-treated scoliosis. *Acta Orthop Scand* 39(4):466–476. <https://doi.org/10.3109/17453676808989664>
6. Danielsson AJ, Wiklund I, Pehrsson K, Nachemson AL (2001) 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. *Eur Spine J Off Publ Eur Spine Soc Eur Spinal Deform Soc Eur Sect Cerv Spine Res Soc* 10(4):278–288. <https://doi.org/10.1007/s005860100309>
7. Danielsson AJ, Hasselius R, Ohlin A, Nachemson AL (2010) Health-related quality of life in untreated versus brace-treated patients with adolescent idiopathic scoliosis: a long-term follow-up. *Spine* 35(2):199–205. <https://doi.org/10.1097/BRS.0b013e3181c89f4a>
8. Rushton PR, Grevitt MP (2013) Comparison of untreated adolescent idiopathic scoliosis with normal controls: a review and statistical analysis of the literature. *Spine* 38(9):778–785. <https://doi.org/10.1097/BRS.0b013e31827db418>
9. Watanabe K, Ohashi M, Hirano T, Katsumi K, Mizouchi T, Tashi H, Minato K, Hasegawa K, Endo N (2020) Health-related quality of life in nonoperated patients with adolescent idiopathic scoliosis in the middle years: a mean 25-year follow-up study. *Spine* 45(2):E83–E89. <https://doi.org/10.1097/BRS.0000000000003216>
10. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP, Strobe Initiative (2007) The strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *Ann Intern Med* 147(8):573–577. <https://doi.org/10.7326/0003-4819-147-8-200710160-00010>
11. Lenke LG, Betz RR, Harms J, Bridwell KH, Clements DH, Lowe TG, Blanke K (2001) Adolescent idiopathic scoliosis: a new classification to determine extent of spinal arthrodesis. *J Bone Jt Surg Am* 83(8):1169–1181
12. Aaronson NK, Muller M, Cohen PD, Essink-Bot ML, Fekkes M, Sanderman R, Sprangers MA, te Velde A, Verrips E (1998) Translation, validation, and norming of the Dutch language version of the SF-36 health survey in community and chronic disease populations. *J Clin Epidemiol* 51(11):1055–1068. [https://doi.org/10.1016/s0895-4356\(98\)00097-3](https://doi.org/10.1016/s0895-4356(98)00097-3)
13. Schlösser TP, Stadhouder A, Schimmel JJ, Lehr AM, van der Heijden GJ, Castelein RM (2014) Reliability and validity of the adapted Dutch version of the revised Scoliosis research society 22-item questionnaire. *Spine J Off J North Am Spine Soc* 14(8):1663–1672. <https://doi.org/10.1016/j.spinee.2013.09.046>
14. van Hooff ML, Spruit M, Fairbank JC, van Limbeek J, Jacobs WC (2015) The Oswestry disability index (version 2.1a): validation of a Dutch language version. *Spine* 40(2):E83–E90. <https://doi.org/10.1097/BRS.0000000000000683>
15. Yuksel S, Ayhan S, Nabiyev V, Domingo-Sabat M, Vila-Casademunt A, Obeid I, Perez-Grueso FS, Acaroglu E, European Spine Study Group (ESSG) (2019) Minimum clinically important difference of the health-related quality of life scales in adult spinal deformity calculated by latent class analysis: is it appropriate to use the same values for surgical and nonsurgical patients? *Spine J Off J North Am Spine Soc* 19(1):71–78. <https://doi.org/10.1016/j.spinee.2018.07.005>
16. Mannion AF, Loibl M, Bago J, Vila-Casademunt A, Richner-Wunderlin S, Fekete TF, European Spine Study Group (ESSG) (2020) What level of symptoms are patients with adult spinal deformity prepared to live with? A cross-sectional analysis of the 12-month follow-up data from 1043 patients. *Eur Spine J* 29:1340–1352
17. Tonosu J, Takeshita K, Hara N, Matsudaira K, Kato S, Masuda K, Chikuda H (2012) The normative score and the cut-off value

- of the Oswestry Disability Index (ODI). *Eur Spine J Off Publ Eur Spine Soc Eur Spinal Deform Soc Eur Sect Cerv Spine Res Soc* 21(8):1596–1602. <https://doi.org/10.1007/s00586-012-2173-7>
18. Danielsson AJ (2013) Natural history of adolescent idiopathic scoliosis: a tool for guidance in decision of surgery of curves above 50°. *J Child Orthop* 7(1):37–41. <https://doi.org/10.1007/s11832-012-0462-7>
 19. Farshad M, Götschi T, Bauer DE, Böni T, Laux CJ, Kabelitz M (2022) Long-term outcome of patients with adolescent idiopathic scoliosis seeking nonoperative treatment after a mean follow-up of 42 years. *Spine deformity* 10(6):1331–1338. <https://doi.org/10.1007/s43390-022-00541-5>
 20. Weiss HR, Moramarco M (2013) Indication for surgical treatment in patients with adolescent idiopathic scoliosis—a critical appraisal. *Patient Saf Surg* 7(1):17. <https://doi.org/10.1186/1754-9493-7-17>
 21. Sterfte. [Volksgezondheinzorg.info](https://www.volksgezondheinzorg.info). <https://www.volksgezondheinzorg.info/onderwerp/sterfte/cijfers-context/huidige-situatie>. Accessed March 7, 2022
 22. Pellisé F, Vila-Casademunt A, Ferrer M, Domingo-Sàbat M, Bagó J, Pérez-Gruoso FJ, Alanay A, Mannion AF, Acaroglu E, European Spine Study Group, ESSG (2015) Impact on health related quality of life of adult spinal deformity (ASD) compared with other chronic conditions. *Eur Spine J Off Publ Eur Spine Soc Eur Spinal Deform Soc Eur Sect Cerv Spine Res Soc* 24(1):3–11. <https://doi.org/10.1007/s00586-014-3542-1>
 23. Glassman SD, Carreon LY, Shaffrey CI, Polly DW, Ondra SL, Berven SH, Bridwell KH (2010) The costs and benefits of non-operative management for adult scoliosis. *Spine* 35(5):578–582. <https://doi.org/10.1097/BRS.0b013e3181b0f2f8>

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