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HEALTH RELATED QUALITY OF LIFE IN JUVENILE VERSUS ADOLESCENT IDIOPATHIC SCOLIOSIS BEFORE AND AFTER SURGERY

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MASTER'S THESIS | ABSTRACT

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HEALTH RELATED QUALITY OF LIFE IN JUVENILE VERSUS ADOLESCENT IDIOPATHIC SCOLIOSIS BEFORE AND AFTER SURGERY

Aim of this study was to compare the clinical, radiographic, and health related quality of life outcomes of posterior spinal fusion in patients with juvenile (JIS) and adolescent idiopathic scoliosis (AIS). The aim was to assess which factors predict the quality of life in these patients (gender, age, back pain before surgery, curve correction, surgical technique, complications etc.) and to produce information that can be used to promote patient`s change in health. The aim of this study was also to obtain new knowledge to enable developing the nursing of scoliosis surgery patients.

Patients with juvenile idiopathic scoliosis with immature skeleton may experience crankshaft and adding on after posterior spinal fusion. Limited data exist comparing the clinical, radiographic, and health related quality of life outcomes after pedicle screw instrumentation with direct vertebral column derotation between juvenile and adolescent idiopathic scoliosis.

This was a prospective comparative study of 21 consecutive children with juvenile and 84 adolescent idiopathic scoliosis undergoing bilateral segmental pedicle screw instrumentation and direct vertebral derotation with a minimum of two-year follow-up. Outcome measures included clinical, radiographic, and SRS-24 parameters preoperatively, at six months, and at two-year follow-up.

Juvenile patients had a significantly larger main curve (58° vs. 53°, p=0.003), more fused levels (p=0.012) and posterior column osteotomies (p=0.014) than adolescent patients. Distal adding-on (>10°) was observed in one (4.7%) juvenile and three (3.6%) adolescent patients (p=0.80), without the need for revisions. SRS-24 total score averaged 101 in juvenile and 97 in adolescent group at two-year follow-up (p=0.047).

Posterior spinal fusion with bilateral segmental pedicle screw instrumentation using direct vertebral column derotation provides similar clinical and radiographic outcomes in juvenile patients as compared with adolescents with idiopathic scoliosis. Health related quality of life as measured using the SRS-24 questionnaire was significantly better for the juvenile than in the adolescent idiopathic scoliosis group at two-year follow-up. Both groups showed a statistically significant improvement in the back pain score from preoperative to six months and from preoperative to two-year follow-up.

KEYWORDS:

Juvenile idiopathic scoliosis, adolescent idiopathic scoliosis, posterior spinal fusion, rib hump, pedicle screw instrumentation, direct vertebral column derotation, health related quality of life

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IDIOPAATTISTA SKOLIOOSIA SAIRASTAVIEN LASTEN JA NUORTEN ELÄMÄNLAATU ENNEN JA JÄLKEEN SKOLIOOSILEIKKAUKSEN

Tämän opinnäytetyön tavoitteena oli vertailla idiopaattista skolioosia sairastavien lasten ja nuorten leikkaushoidon tuloksia sekä elämänlaatua kliinisten tutkimusten, radiologisten mittausten sekä SRS-24 elämänlaatukaavakkeen avulla. Tavoitteena oli lisäksi selvittää, mitkä tekijät vaikuttavat potilaiden elämänlaatuun (sukupuoli, ikä, selkäkipu ennen leikkausta, käyryyden korjaantuminen, leikkaustekniikka, komplikaatiot jne.) sekä tuottaa uutta tietoa skolioosipotilaiden hoitotyön kehittämiseen.

Kyseessä on prospektiivinen elämänlaatututkimus, jossa 105 idiopaattista skolioosia sairastavaa lasta ja nuorta hoidettiin Turun yliopistollisessa keskussairaalassa vuosien 2009-2015 välisenä aikana. Tutkimuksessa oli mukana 21 juveniilia ja 84 nuoruusiän idiopaattista skolioosia sairastavaa potilasta, joiden skolioosin suuruus preoperatiivisessa röntgenkuvassa ylitti 45 astetta. Seuranta-aika oli kaikilla potilailla kaksi vuotta.

Tutkimuksessa oli mukana 21 juveniilia idiopaattista skolioosia (JIS) ja 84 nuoruusiän idiopaattista skolioosia (AIS) sairastavaa potilasta, joiden skolioosin suuruus preoperatiivisessa röntgenkuvassa ylitti 45 astetta. Seuranta-aika oli kaikilla potilailla kaksi vuotta. Tuloksia arvioitiin kliinisten tutkimusten, radiologisten mittausten sekä SRS-24 elämänlaatukaavakkeen kautta.

Juveniilia idiopaattista skolioosia sairastavilla potilailla oli selkeästi suurempi skolioosin käyryys (58° vs. 53°), enemmän luudutettuja nikamia (p=0.012) sekä enemmän tehtyjä osteotomioita (p=0.014) kuin nuoruusiän idiopaattista skolioosia sairastavilla. SRS-24 lomakkeen kokonaispistemäärä oli juveniilipotilailla 101 ja AIS-potilailla 97 kahden vuoden seurantakäynnillä (p=0.047).

Skolioosin leikkaushoidolla saavutettiin erinomainen skolioosin radiologisen virheasennon korjaantuminen. Skolioosipotilaiden elämänlaatua arvioivan SRS-24- lomakkeen perusteella potilaat olivat tyytyväisiä leikkaushoidon lopputulokseen. Juveniilia idiopaattista skolioosia potilaat sairastavat kokivat elämänlaatunsa kahden vuoden seurannassa selkeästi paremmaksi SRS-24 elämänlaatulomakkeen perusteella. Molemmat ryhmät osoittivat kuitenkin tilastollisesti selkeän paranemisen mitattaessa selkäkipua ennen leikkausta sekä kuuden kuukauden että kahden vuoden kuluttua leikkauksesta. Tutkimuksen tuloksia voidaan tulevaisuudessa hyödyntää sekä käytännön hoitotyössä että sen kehittämisessä muun muassa lasten ja nuorten ohjauksessa sekä perheille tarkoitetun kirjallisen ohjausmateriaalin suunnittelussa.

ASIASANAT:

Juveniili idiopaattinen skolioosi, nuoruusiän idiopaattinen skolioosi, takakautta tehtävä leikkaus, kylkikohouma, pedikkeliruuvijärjestelmä, selkärangan derotaatio, terveyteen liittyvä elämänlaatu

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LIST OF ABBREVIATIONS

AIS	Adolescent idiopathic scoliosis
DVR	Direct vertebral column derotation
FU	Follow-up
HRQoL	Health-related quality of life
JIS	Juvenile idiopathic scoliosis
ODI	The Oswestry Disability Index
PedsQL	The Pediatric Quality of Life Inventory
PROM	Patient reported outcome measures
PSI	Pedicle screw instrumentation
QoL	Quality of Life
SRS	Scoliosis Research Society
WHO	World Health Organization

1 INTRODUCTION

In health care research, quality of life (QoL) is commonly conceptualised as health-related quality of life (HRQoL), which is a multidimensional construct encompassing domains such as physiological, psychological, social and spiritual areas of life. This is in line with the World Health Organization's (WHO) definition of health as the state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. (Helseth & Misvaer 2009, 1457.) Health related quality of life includes the subjectively perceived impact of a disease and its treatment on physical, psychological and social well-being (Edgar & Mehta 1988). Today, the patient`s own subjective opinion of the impact of the disease is recognized and used as an assessment of outcome. With the development of outcome tools for measuring general health-related quality of life and more disease-specific questionnaires, this outcome can now be evaluated. (Danielsson, Hasserius, Ohlin & Nachemson 2010, 199.)

Scoliosis is the most common deformity of the spine and it is defined as a lateral curvature of the spine that is 10 degrees or greater according to the Cobb method on a coronal radiographic image while the patient is in a standing position (James 1954, 37; Hresko 2013, 834). Scoliosis is typically categorized according to cause. Idiopathic scoliosis is subclassified as infantile (in children from birth up to 3 years of age), juvenile (in children 3 to 10 years of age) or adolescent (in children older than 10 years of age). (James 1954, 37; Hresko 2013, 834.) The primary goal of non-operative and operative treatment during idiopathic scoliosis is to prevent curve progression (Weinstein, Dolan, Cheng, Danielsson & Morcuende 2008, 1529). Secondary goals are curve correction and cosmetic improvement (Helenius, Remes, Lamberg, Schlenzka & Poussa 2008, 1231).

The aim of this study was to evaluate the quality of life in patients operated for juvenile (JIS) and adolescent idiopathic scoliosis (AIS) before and after surgery with minimum of two-year follow-up. The aim was to assess which factors predict the quality of life in these patients (gender, age, back pain before surgery, curve correction, surgical technique, complications etc.) and to produce information that can be used to promote patient`s change in health. The aim of this study was also to obtain new knowledge to enable developing the nursing of scoliosis surgery patients.

The thesis is a retrospective study using a prospectively collected register data of 105 juvenile and adolescent idiopathic scoliosis patients over two-year follow-up who were treated surgically at Department of Paediatric Orthopaedic Surgery, Turku University Hospital during 2009-2015. Data have been collected by the author of this study before and after surgery as well as at six month, and two-year follow-up visits. Eighty-four AIS patients and twenty-one JIS patients were investigated with 2 years follow-up. Data have been collected before surgery as well as at six months and two-year follow-up visits. The plan was to collect all the data of the SRS- 24 questionnaires from patients, X-rays information (back curvature before and after surgery) and all the required information of patient records: gender, age at time of surgery, complications and follow-up visit information.

This study will be performed in collaboration with Department of Paediatric Orthopaedic Surgery, Turku University Hospital. The study was started after the permission of the Department of Children and Adolescents of Turku University Hospital. No additional patient contacts are needed for the purposes of this study. Therefore, according to the ethical committee of the Hospital District for Southwest Finland no formal ethical committee evaluation is requested.

The hypothesis of this study is that posterior spinal fusion with pedicle screw instrumentation (PSI) for both juvenile idiopathic scoliosis and adolescent idiopathic scoliosis would significantly improve spinal deformity and health related quality of life. However, it was also hypothesized that patients with juvenile idiopathic scoliosis would demonstrate more adding on due to continued anterior growth and higher risk of revisions.

2 BACKGROUND

2.1 Definition of idiopathic scoliosis

Scoliosis is the most common deformity of the spine and it is defined as a lateral curvature of the spine that is 10 degrees or greater according to the Cobb method on a coronal radiographic image while the patient is in a standing position (James 1954, 37; Hresko 2013, 834). Scoliosis is typically categorized according to cause. Congenital scoliosis is an anatomical anomaly due to failure of formation or segmentation of the vertebral column which, with growth, may lead to progressive spinal deformity. Neuromuscular scoliosis is deformity caused by dysfunction of the central nervous system, dysfunction of the peripheral neuromuscular unit or combined sensory and motor dysfunction. Scoliosis is also common in patients with neurofibromatosis and in patients with certain connective tissue diseases such as Marfan's syndrome. (Hresko 2013, 834.) In most patients with scoliosis, the cause is unrecognized. Idiopathic scoliosis is subclassified as infantile (in children from birth up to 3 years of age), juvenile (in children 3 to 10 years of age) or adolescent (in children older than 10 years of age). (James 1954, 37; Hresko 2013, 834.)

Adolescent idiopathic scoliosis is a structural, lateral, rotated curvature of the spine that arises in otherwise healthy children and adolescents at or around puberty (Weinstein et al, 2008, 1527). On examination of scoliosis classic findings are shoulder and scapular asymmetry, rib prominence on forward flexion on the Adams test and also asymmetry of the waist and trunk (Hresko 2013, 835). Patients are generally screened with Adams` forward bending test using a scoliometer. A definitive diagnosis cannot be made without measuring the Cobb angle on a standing coronal radiograph. (Weinstein et al. 2008, 1527.) The decision to perform surgery for correction of idiopathic scoliosis is always based on objective radiographic measures (Mielke, Lonstein, Denis, Vandenbrink & Winter 1989, 1171).

Juvenile idiopathic scoliosis is defined as a form of idiopathic scoliosis diagnosed between the ages of three and nine years and eleven months (James 1954; Lenke & Dobbs 2007). Untreated juvenile idiopathic scoliosis is associated with increased mortality due to cardiopulmonary compromise while untreated adolescent idiopathic scoliosis is not (Pehrsson, Larsson, Oden & Nachemson 1992). Neural element

anomalies (Chiari, syrinx, tethered cord) are more common in the JIS as compared with AIS (Gupta, Lenke & Bridwell 1998; Dobbs et al. 2002). Early spinal fusion may result in short trunk and restrictive lung disease and therefore growth friendly instrumentation has been recommended in immature patients with JIS (Hefti & McMaster 1983; Lenke & Dobbs 2007; Karol, Johnston, Mladenov, Schochet, Walters & Browne 2008). On the other hand, it has been reported that a progressive JIS between the age of 9 and 11 years can be treated already using a definitive spinal fusion with better curve correction, less surgeries, and minimal loss of spinal height as compared with traditional growing rods (Pawelek, Yaszay, Nguyen, Newton, Mundis & Akbarnia 2016).

Progression of the spinal deformity due to continued growth of the unfused anterior part of the spine - known as the crankshaft phenomenon or adding on - may complicate definitive spinal fusion at an early age (Dubousset, Herring & Shufflebarger 1989; Sanders, Herring & Browne 1995; Sponseller et al. 2009). To prevent crankshaft a combined anteroposterior approach has been recommended in patients with significant growth left (Risser 0, open triradiate cartilage) (Dubousset et al. 1989; Sanders et al. 1995; Sponseller et al. 2009; Sponseller et al. 2016). Despite the differences between JIS and AIS, studies reporting the outcomes of definitive spinal fusion using bilateral, segmental pedicle screw instrumentation on radiographic parameters and especially health related quality life are few in the juvenile subgroup. The effect of direct vertebral column derotation on rib hump and crankshaft or adding on in this patient cohort is not known. (Sarlak, Atmaca, Buluç, Tosun & Musaoğlu 2009; Sponseller et al. 2016.)

2.2 Conservative treatment of idiopathic scoliosis

Treatment with a brace is used to arrest the progression of scoliosis below the level requiring surgical treatment (Hresko 2013, 837). Studies show, that results from bracing appear to be most positive when the average daytime brace wear is at least 12 hours. A typical brace prescription is for 18 to 20 hours per day, though full adherence is rarely achieved. (Morton, Riddle, Buchanan, Katz & Birch 2008, 338.)

Several studies have reported that conservative treatment does not impact the quality of life of adolescents with scoliosis (Parent, Hill, Mahood, Moreau, Raso & Lou 2009, 345; Danielsson et al. 2010, 203). Lee, Choi, Hwang & Park (2016) however showed that adolescents under observation or brace therapy showed higher HRQoL than adolescents receiving physiotherapy and who continued exercising at home (Lee, Choi,

Hwang & Park 2016, 3). Danielsson, Hasserius, Ohlin & Nachemson (2012) reported that regardless of bracing, adolescents with less body asymmetry and similar curve size had higher quality of life. It seems that adolescents perceive their body appearance being more important than the bracing itself. (Danielsson, Hasserius, Ohlin & Nachemson 2012, 760.)

2.3 Operative treatment of idiopathic scoliosis

The goals of operative treatment for adolescent idiopathic scoliosis are to prevent progression of the curve by means of fusion, correct the curve and cosmetic improvement (Helenius et al. 2008). The generally agreed indication for surgery in adolescents is a primary curve greater than a Cobb angle of 45 degrees. Posterior instrumentation remains the mainstay of treatment for most idiopathic curves. (Weinstein et al. 2008, 1531.) The current treatment of pediatric spinal deformity commonly involves the use of pedicle screw instrumentation to maximize spinal deformity correction (Suk, Lee, Kim, Chung & Park 1995, 1401).

It has been reported that use of pedicle screw instrumentation decreases the number of fusion levels and results in improved postoperative appearance (Ledonio, Polly, Vitale, Wang & Richards 2011, 1232). The treatment of idiopathic scoliosis follows standardized protocols. The guidelines for operative treatment are very well established and follow the principles of the prevention of further progression of the curve and the correction of the deformity. (Parsch, Gaertner, Brocai & Carstens 2001, 1133.)

Bilateral pedicle screw instrumentation, which traverses all three spinal columns, may lower the risk of crankshaft and adding on as compared with hybrid instrumentation (Burton, Asher & Lai 2014; Sponseller et al. 2016). Recently, Sponseller et al. (2016) reported distal adding on more than 10 degrees in seven out of 20 children with open triradiate cartilage even when using pedicle screws in a prospective, multicenter database study. However, majority of patients with distal adding on were fused one level short of stable vertebra and bilateral, segmental pedicle screw instrumentation was not used in all patients. In patients undergoing combined approach the risk of adding on was lower. (Sponseller et al. 2016.) Thus, it remains unclear whether bilateral segmental PSI up to stable vertebra can provide long term stable fusion also in patients with JIS, without a formal anterior spinal fusion. Direct vertebral column derotation might also reduce the risk of adding on, but its effect has not been evaluated.

2.4 Untreated Idiopathic Scoliosis

Although the physical deformity of adolescent idiopathic scoliosis is often obvious, the effect on HRQoL is less apparent. Long term retrospective reviews of untreated patients are contradictory but suggest that adults with untreated AIS may experience worse physical function, such as increased back pain and more psychosocial issues including lower self-image and increased depression than unaffected peers. No correlation between the severity or type of the curve and back pain had founded, a Cobb angle greater than 50° at skeletal maturity tend to be a significant predictor of decreased pulmonary function. (Freidel, Petermann, Reichel, Steiner, Warschburger & Weiss 2002, 87; Weinstein, Dolan, Spratt, Peterson, Spoonamore & Ponseti 2003; Haefeli, Elfering, Kilian, Min & Boos 2006.)

Statistically, untreated adolescents with AIS have worse pain and self-image than those unaffected (Rushton & Grevitt 2013, 784). On the other hand, Danielsson et al. (2010) presented, that the quality of life of untreated adult patients with moderate curves of AIS is as good as that of the normal population (Danielsson et al. 2010, 203). The literature suggests that only self-image tends to be worse clinically and this should be considered when considering the possible benefit of surgery (Rushton & Grevitt 2013, 784).

2.5 Pulmonary function

Several studies has suggested a correlation between pulmonary impairment and thoracic spinal deformity. The curve magnitude, curve location, number of involved vertebrae and decrease in thoracic kyphosis independently contribute to pulmonary impairment. The strength of these associations has been variable. There are patients with adolescent idiopathic scoliosis who may have clinically relevant pulmonary impairment that is out of proportion with the severity of the scoliosis, and this might alter the decision-making process regarding which fusion technique will produce an acceptable clinical result with the least additional effect on pulmonary function. (Newton, Faro, Gollogly, Betz, Lenke & Lowe 2005.)

It has been shown that patients with untreated scoliosis have an increased risk of developing respiratory failure and also dying prematurely (Nachemson 1968; Bergofsky 1979; Pehrsson, Larsson, Oden & Nachemson 1992). Though, respiratory

failure was seen in untreated patients with idiopathic scoliosis who had a large scoliotic angle and low vital capacity, especially if the onset of their scoliosis was at a younger age (Pehrsson, Bake, Larsson & Nachemson 1991).

Pehrsson, Danielsson & Nachemson (2001) showed in their study that pulmonary function has increased in patients with adolescent idiopathic scoliosis 25 years after posterior spinal surgery or after start of brace treatment when compared with measurements before intervention. For surgically treated patients the pulmonary function also improved from completion of surgical treatment. (Pehrsson, Danielsson, & Nachemson 2001, 391.)

2.6 Health related quality of life

In health care research, quality of life is commonly conceptualised as health-related quality of life, which is a multidimensional construct encompassing domains such as physiological, psychological, social and spiritual areas of life. This is in line with the World Health Organization's definition of health as the state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. (Helseth & Misvaer 2009, 1457.) Health related quality of life includes the subjectively perceived impact of a disease and its treatment on physical, psychological and social well-being (Edgar & Mehta 1988). The last decade has evidenced a dramatic increase in the development and utilization of health-related quality of life measures in an effort to improve patient health and determine the value of healthcare services (Fayers & Machin 2000).

Health related quality of life can be evaluated using a general (i.e. Short Form, SF-36) or disease specific questionnaires (Oswestry Disability Index). The Oswestry Disability Index (ODI) has been developed to assess pain-related disability in people with low back pain. Since it was first published in 1980, several different versions have been developed (Modified ODI and ODI Chiropractic Version). (Merola et al. 2002, 2046.)

The Pediatric Quality of Life Inventory (PedsQL) measurement model is a brief, standardized, generic assessment instrument that systematically assesses patients' and parents' perceptions of health-related quality of life in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL is considered one of the most frequently used generic HRQoL instruments for children and adolecents and

also has the option of adding disease-specific modules to the generic score scales. (Varni, Seid & Rode 1999, 127.)

The Scoliosis Research Society (SRS) has developed a patient-oriented outcome questionnaire to assess the impact of surgical treatment on patients with adolescent idiopathic scoliosis (Merola et al. 2002, 2046). The SRS- questionnaire provides information on back pain, patient satisfaction, cosmetic aspects and level of activity (Helenius et al. 2008, 1232). The goal of the SRS 24- questionnaire is to provide a high-quality, validated, standardized and broadly accepted questionnaire that can be adopted for use across many clinical investigations (Merola et al. 2002, 2046). Haher et al. (1999) designed the questionnaire based on previously validated questionnaires and added questions to address several prior insufficiencies, especially patients` concerns about self-image (Haher et al. 1999, 1438).

The SRS 24- questionnaire (Appendix 1) includes 24 questions designed to assess several aspects of outcome as perceived by the patient. Each question contains an odd number of responses, comprising a Likert-type scale, except for three yes-or-no type questions, which represent an all-or-none response. The 24 questions represent seven domains: Pain, General Self-Image, Postoperative Self-Image, Postoperative Function, Function from Back Condition, General Level of Activity and Satisfaction. Each domain score ranges from 1-5, with 5 being the optimal response. (Merola et al. 2002, 2046-2047.) Unlike other available quality-of-life questionnaires, SRS- 24 instrument contains only 24 questions, allowing minimal time for completion and evaluation. This information can be used in the clinical practice to improve the quality of patient care and offers individual assessment of patient status. (Haher et al. 1999, 1438.)

Adolescent idiopathic scoliosis has been associated with body image, impaired functioning and health-related quality of life, but the goal of surgical treatment is to prevent curve progression and achieve curve correction, not to improve the possible impairment in HRQoL. A few studies have reported significant improvement in HRQoL domain scores when preoperative and postoperative data are compared. However, there are no prospective studies that confirms this improvement in a long-term follow-up. (Mariconda, Andolfi, Cerbasi & Servodidio 2015, 4510.)

Although pain is typically not the primary factor for the patient with AIS to seek treatment, it is a critical factor to analyze in understanding the efficacy and outcomes of surgical intervention (Bastrom, Marks, Yaszay & Newton 2013, 1848). Several studies have

shown that surgical correction in AIS significantly improves overall average pain domain scores at two years postoperatively compared with preoperative scores. There was a significant improvement in all preoperative domains of the SRS questionnaire two years after surgical treatment. (Merola et al. 2002; Upasani et al. 2008; Carreon, Sanders, Diab, Sturm & Sucato 2011, 966.)

One recent study demonstrates that patients with painful adolescent idiopathic scoliosis can expect significant improvement in pain level with surgical treatment and will also experience significant improvement in health-related quality of life (Djurasovic, Glassman, Sucato, Lenke, Crawford & Carreon 2016). Bastrom et al. (2013) noticed also that patients with postoperative pain scored significantly lower on the pain domain of the SRS-22 questionnaire and their scores in all other domains except for function were lower than patients who did not experience postoperative pain (Bastrom et al. 2013, 1851).

Studies also show that parents typically score higher than their children in the operative treatment of idiopathic scoliosis in total score, self-image and overall satisfaction based on SRS-24 questionnaire data. Parents showed greater concern about the disease than the patients. (Bridwell, Shufflebarger, Lenke, Lowe, Betz & Bassett 2000, 2397-2398; Rinella, Lenke, Peelle, Edwards, Bridwell and Sides 2004, 303,309.) Studies show, that families have many different fears regarding the scoliosis surgery, and they feel that the factual counseling and support offered do not always correspond to their needs. Pain was the greatest concern for both patients and parents. (Chan et al. 2001, 1247.) Time of counseling is always a challenge. Developing and evaluating preoperative preparation strategies that focus on these problems is an opportunity to optimize the patient and parental surgical experience.

3 AIMS OF THE STUDY

Aim of this study is to compare the clinical, radiographic, and health related quality of life outcomes of posterior spinal fusion using bilateral pedicle screw instrumentation and direct vertebral column derotation in patients with juvenile idiopathic scoliosis and adolescent idiopathic scoliosis with a minimum of two-year follow-up.

Aim is also to assess which factors predict the quality of life in these patients (gender, age, back pain before surgery, curve correction, surgical technique, complications etc.) and to produce information that can be used to promote patient`s change in health. The aim of this study is also to obtain new knowledge to enable developing the nursing of scoliosis surgery patients.

Research problems are as follows:

1. How the health-related quality of life has changed in patients operated for juvenile and adolescent idiopathic scoliosis?

2. To compare the quality of life between patients with juvenile and adolescent idiopathic scoliosis.

3. To describe the possible changes of health-related quality of life.

4 MATERIALS AND METHODS

4.1 Study design

The study was a prospective comparative cohort study on the clinical, radiographic, and health related quality of life using the Scoliosis Research Society 24- questionnaire in patients with JIS (Risser 0) and AIS (≥Risser 2) undergoing posterior spinal fusion with bilateral segmental pedicle screw instrumentation using the direct vertebral column derotation technique in a single center (Haher et al. 1999; Merola et al. 2002). The patients were enrolled between 2009 and 2015. Twenty-one children fulfilled the inclusion criteria (diagnosis of JIS without associated spinal cord anomalies or syndromes, Risser 0, fifteen patients with open triradiate cartilage). The AIS cases (diagnosis of AIS, aged 13-18 years, bilateral segmental PSI with DVR, N=84, Risser ≥2) were enrolled consecutively under the same time period resulting in 1:4 comparison (21 juvenile vs. 84 adolescent).

The study subjects were followed using standardized protocol including preoperative and immediate postoperative assessment, and two visits at the outpatient clinic at six months and at two years after surgery (Table 1). All the patients had JIS or AIS as an indication for instrumented posterior spinal fusion (Cobb angle of major curve 45° or more) (Kim, Lenke, Bridwell, Cho & Riew 2004; Mattila, Jalanko & Helenius 2013). All the operations were performed at the Turku University Hospital by the same two experienced orthopaedic spine surgeons. Physical examination included measurement of thoracic rib hump on forward bending test using scoliometer, neurologic examination of the lower extremities, and evaluation of walking capability on toes and heals.

4.2 Scoliosis Research Society 24 outcome questionnaire

All patients filled out the SRS-24 questionnaire preoperatively, at six months, and at two-year follow-up visit. The SRS- 24 questionnaire has been translated but not validated into Finnish. Patients filled out the SRS-24 questionnaire either Finnish or Swedish. The SRS-24 is a disease-specific health-related quality of life questionnaire used to assess the current state of patients with idiopathic scoliosis and the effects of scoliosis surgery, consisting of twenty-four questions with a maximum score of 120, indicating a highly

satisfied and asymptomatic patient. The questionnaire has seven domains: pain, general self-image, function from back condition, activity level, postoperative self-image, postoperative function, and satisfaction (Appendix 1). (Haher et al. 1999; Merola et al. 2002.)

4.3 Surgical technique

All patients were operated using posterior only approach. Bilateral segmental pedicle screw instrumentation with en bloc direct vertebral column derotation (6.35 CD Legacy or Solera 6.0, Medtronics Spinal and Biologics, Memphis, TN, USA) was used to correct spinal deformity as described previously. (Mattila et al. 2013; Helenius et al. 2016.) Pedicle screws were inserted with free hand technique (Kim et al. 2004). Posterior Ponte osteotomies were performed as needed (Geck, Macagno, Ponte & Shufflebarger 2007). All structural curves according to the Lenke classification for JIS (curves crossing midline) were instrumented and the fusion was extended to stable vertebra in all juvenile patients (Central sacral vertical line (CSVL) between the pedicles of lowest instrumented vertebra) **(**Figure 1). For the AIS cases the lowest instrumented vertebra was selected for A and B curves as the lowest touched vertebra and for C curves as the lowest vertebra bisected by the CSVL (Murphy et al. 2017). None of the patients underwent thoracoplasty. Spinal cord monitoring was performed in all patients.

4.4 Radiographic measurements

Standard standing posteroanterior and lateral radiographs were taken of the entire spine preoperatively, at six-months and at two-year follow-up. Bending radiographs were obtained to evaluate flexibility of the curves preoperatively. The proximal thoracic, main thoracic, and thoracolumbar / lumbar curves were measured from the posteroanterior radiographs. Thoracic kyphosis (T5-T12), lumbar lordosis (T12-S1) and segmental kyphosis (T2-T5; T10-L2) or lordosis were measured from the lateral radiographs by the Cobb technique by independent observer (Cobb 1948). Lenke classification was used for JIS and AIS (Lenke et al. 2001; Lenke & Dobbs 2007). Coronal balance was determined as the horizontal distance of the spinous process of C7 from the CSVL measured in millimeters. Sagittal balance was measured from the lateral projection with a similar method by dropping a vertical line from the middle of C7 vertebral body and

measuring the horizontal distance of the uppermost portion of S1 vertebral body from this vertical line. Adding on was defined as an increase in the coronal Cobb of ten degrees or more during follow-up. (Sanders, Herring & Browne 1995; Sponseller et al. 2016.)

4.5 Statistical Methods

Data analysis is the process of evaluating data using analytical and logical reasoning to examine each component of the provided data. Data analysis is just one of the many steps that must be completed when conducting a research experiment. Data from various sources is gathered, reviewed, and analyzed to form some sort of finding or conclusion. There are a variety of specific data analysis methods, some of which include data mining, data visualizations and text analytics. (Clarke 2005, 253-254.)

Statistical significance is a measure of the probability of the null hypothesis being true compared to the acceptable level of uncertainty regarding the true answer. To perform a hypothesis test in statistics, a p-value helps to determine the significance of the study results. There are several methods in research for obtaining a p-value. (Tenny & Abdelgawad 2017.)

The p-value can be described as the probability that the null hypothesis is true given the researcher's current set of data. Result of a study is stated to be statistically significant if the p-value of the data analysis is less than the prespecified alpha (significance level). A small p-value (typically ≤ 0.05) indicates strong evidence against the null hypothesis, large p-value (> 0.05) indicates weak evidence against the null hypothesis while P-values very close to the cutoff (0.05) are considered to be marginal. (Tenny & Abdelgawad 2017.)

Mann-Whitney U test is a non-parametric test that is used to compare two sample means that come from the same population, and also used to test whether two sample means are equal or not. The Mann-Whitney U test is usually used when the data is ordinal or when the assumptions of the t-test are not met. (Porkess 2005, 148-149.)

The Chi-Square test is commonly used for testing relationships between categorical variables. The null hypothesis of the Chi-Square test is that no relationship exists on the categorical variables in the population. The Chi-Square test is a test that involves the use of parameters to test the statistical significance of the observations under study. Chi-

Square Test is defined as the square of the standard normal variable. (Porkess 2005, 37-44.)

The Wilcoxon Sign test is the non-parametric alternative of the dependent samples t-test. The Wilcoxon Sign test is mathematically similar to conducting a Mann-Whitney U-test (which is sometimes also called Wilcoxon 2-sample t-test). (Porkess 2005, 262-267.)

In this study, values are given as mean (SD). Since the distribution of all continuous variables did not follow normal distribution, non-parametric testing using the Mann-Whitney U test was applied for between group and Wilcoxon signed rank sum test for within group comparisons. The statistical significances of the unadjusted differences between frequency distributions were tested with Pearson's chi square test. P-values of 0.05 or less were considered as significant. All the data analysis in this study was done by the author and the mentor of this study.

4.6 Ethical aspects

The Ethics Committee of Turku University Hospital granted approval for the study. No additional patient contact was needed for this study, and therefore written informed consent was not requested by the Ethics committee.

5 RESULTS

5.1 Clinical characteristics

Clinical and radiographic follow-up rate was 100% at two years. Patients with juvenile idiopathic scoliosis were operated at an earlier age ($p<0.001$) and the juvenile cohort had significantly more girls than boys than adolescent idiopathic scoliosis cohort ($p=0.027$). Juvenile patients had also more fused levels ($p=0.012$) and more posterior column osteotomies ($p=0.014$), but operative time and intraoperative blood loss were similar in both groups (Table 1).

Thoracic rib hump averaged 14 degrees in both groups. It was corrected to six degrees at six months, and to eight degrees in the juvenile group ($p=0.016$) and seven degrees in adolescent group at two-year follow-up ($p<0.001$, preoperative vs 2-year follow-up) (Table 1). This represented a 56% correction at six months and 39% at two-years for the juvenile group (vs. 54% at six months [$p=0.67$] and 49% for the AIS group at two-year follow-up [$p=0.81$]).

5.2 Radiographic Outcomes

Fifteen (71%) of the juvenile patients had an open triradiate cartilage preoperatively. Patients with JIS had a significantly larger main curve than the adolescent group (58 vs. 53 degrees, $p=0.0032$) (Table 2). The main curves were corrected to a mean of 13 degrees in the juvenile and 12 degrees in the adolescent group at two-year follow-up. This represented 78% correction of the main coronal curve in the juvenile and 77% in the adolescent group, respectively ($p=0.90$). Thoracic kyphosis averaged preoperatively 20° and 24° in the juvenile and adolescent groups and was 17° and 20° at two-year FU without any significant differences between the study groups. Distal adding on (>10 degrees) was observed in one (4.8%) juvenile and three (3.6%) patients with AIS ($p=0.80$). None of the patients has been operated for distal adding-on and there were no signs of non-union at follow-up.

5.3 Complications

There were two (9.5%) complications in the juvenile and four (4.8%) in the adolescent group (p=0.80). To address these a re-operation was required in one (4.8%) juvenile and in two (2.4%) adolescent patients (p=0.56). Complications recorded in the juvenile group included one intraoperative dural lesion and one deep wound infection treated with irrigation and debridement while all complications in the adolescent group were screw related. These included one asymptomatic rod slippage from pedicle screw, while two adolescent patients suffered from transient right sided motor deficits. The first due to malpositioned T9 screw inside the spinal canal requiring screw removal at a separate session and the other due to a spinal cord contusion caused by a pedicle probe entering spinal canal via fractured pedicle channel (treated with staged surgery). The first patient recovered immediately while the latter recovered fully from motor deficit within six weeks and sensory deficit within the two-year follow-up. One patient developed a L4 root injury due to fractured pedicle. He had a sensory deficit but no motor deficit at 2-year follow-up and has not been re-operated.

5.4 The SRS-24 outcome questionnaire

SRS-24 questionnaire was available preoperatively in 95 patients (17 JIS, 78 AIS), in 98 patients (18 JIS, 80 AIS) at six months, and in 97 patients (18 JIS, 79 AIS) at the two-year follow-up (Table 3). Patients with JIS showed significantly better SRS-24 score for back pain (p=0.040), function from back condition (p=0.040), and satisfaction (p=0.049) at two-year follow-up as compared with the adolescent group. The total score of SRS-24 at two-years averaged 101 (4.2) points in the juvenile and 97 (4.0) in the adolescent group (p=0.040). Both groups showed a statistically significant improvement in the back pain score from preoperative to six months ($p<0.001$ in both groups) and from preoperative to two-year follow-up (p=0.0039 for JIS and $p<0.001$ for AIS).

6 COMPARISON WITH PREVIOUS DATA

Pawelek et al. (2016) reported that JIS patients between nine and eleven years of age benefited from definitive spinal fusion instead of traditional growing rods in terms of better correction of spinal deformity and less surgeries than patients undergoing growth friendly instrumentation (Pawelek et al. 2016). In this study it has been chosen to perform definitive spinal fusion for the juvenile patients when the estimated length of thoracic spine will reach at least 22 centimeters after spinal deformity correction. These criteria are mainly based on findings of pulmonary function testing after thoracic spine fusion for early onset scoliosis (Karol, Johnston, Mladenov, Schochet, Walters & Browne 2008).

In the study by Sponseller et al. (2016) a relatively large proportion of juvenile patients had adding on after pedicle screw instrumentation (45%, 9/20), while patients undergoing a combined approach had a low risk. In their series fusing short of stable vertebra and posterior only approach were risk factors for adding on (Sponseller et al. 2016). In this series one of the juvenile patients showed distal adding-on, but none has required a revision surgery. In this study, all juvenile patients were systematically fused to the stable vertebra and en bloc DVR was performed on all patients.

The hypothesis of this study is that by bringing the rotated thoracic and/or lumbar spine fully to the midline aiming at maximum correction in all three planes using en bloc DVR may actually decrease the risk of adding on in immature patients with JIS. This hypothesis is in line with the historical recommendation of an anterior arthrodesis for immature scoliosis patients who have more than two years growth left, residual deformity of more than 30 degrees, and rotation of more than 20 degrees postoperatively (Dubousset, Herring & Shufflebarger 1989). Thoracic kyphosis was reduced in both groups postoperatively, but no further progression of thoracic flattening occurred during follow-up suggesting that a three column fixation using maximum length thoracic pedicle screws can control the continued anterior growth of the spine in an effective manner.

There are no previous studies on the use of DVR and its effectiveness for rib hump correction in patients with JIS. In a previous study, Mattila et al. (2013) were able to demonstrate better spinal derotation using en bloc DVR, but this was not reflected as improved rib hump correction as compared with the no DVR group in patients with AIS (Mattila et al. 2013). In the present study, a similar correction of rib hump obtained in the juvenile and adolescent study groups at six months, but the recurrence of thoracic rib

hump during follow-up was slightly more enhanced in the juvenile group (56% correction at six months and 39% at two-years). The recurrence of thoracic rib hump seems to be related to the larger growth potential of the thoracic cage in the juvenile group.

Prospective studies evaluating the effects of spinal fusion on health related quality of life are few in patients with JIS. Sponseller et al. (2016) showed a similar improvement of SRS-22 scores in patients undergoing spinal fusion for JIS and AIS (Sponseller et al. 2016). In the present study, patients with JIS showed significantly better SRS-24 score for back pain, function from back condition, satisfaction, and total score at two-year follow-up as compared with the adolescent group. However, any correlation was not found between the SRS-24 scores and the radiographic correction of scoliosis, which averaged over 75% for both study groups being a relatively high level as compared with a previous systematic literature review (Ledonio et al. 2011).

7 DISCUSSION

Patients with JIS had similar radiographic outcomes of segmental pedicle screw instrumentation and direct vertebral column derotation than AIS patients without increased risk of crankshaft or adding on. Juvenile patients had less rib hump correction, but reported a significantly better SRS-24 total score, back pain, function from back condition, and satisfaction than AIS patients at two-year follow-up.

Preoperative preparation and counseling present a challenge to healthcare providers due to the wide diversity in physical, cognitive, and psychological maturation in adolescence (Busen 2001). During this period of rapid maturity, surgery may pose a direct challenge to the adolescent's struggle to develop independence. In addition, for patients with scoliosis, surgery may induce further stress due to concerns about body image and the resulting cosmetic effects of the procedure. (Chan et al. 2017, 1245-1246.)

Providing preoperative counseling and preparation tailored to the needs of idiopathic scoliosis patients from diverse families and populations presents a challenge. However, preoperative preparation addressing patients´ concerns may help minimize preoperative anxiety and improve patient outcomes. (Chan et al. 2017, 1247-1249.)

The results of this study can be utilized for nursing practice and its developing for example in education of patients and their families, postoperative pain care and enabling better recovery for scoliosis patients. In addition, results can be utilized in planning preoperative counseling and written guidance material for idiopathic scoliosis patients and their families. Patients and their families often need a great deal of counseling in connection with scoliosis surgery. The findings could be used to make family counseling correspond better to the patients' and families' needs. Training and education would also make the personnel involved better equipped to respond to the families' counseling needs. Developing and evaluating preoperative preparation strategies that focus on these problems is an opportunity to optimize the patient and parental scoliosis surgery experience.

Patient reported outcome measures (PROM) are regarded as one of the most important outcomes of surgery. This study supports the hypothesis of improved HRQoL for both

juveniles and adolescents undergoing scoliosis surgery. As such, this strongly supports the role of pediatric scoliosis surgery as a documented value based health care concept.

A novel finding of this study was the difference in the improvement of HRQoL between the juvenile and adolescent study groups. Therefore, juvenile idiopathic scoliosis can be regarded as predictor of major improvement in HRQoL after scoliosis surgery.

The hypothesis of this study is that by using direct vertebral column derotation and maximal deformity correction by bringing the spine entirely to the midline may decrease the risk of crankshaft and adding on in children with juvenile idiopathic scoliosis and immature spine.

8 VALIDITY OF THE DATA

The term validity refers to the strength of the conclusions that are drawn from the results. In other words, how accurate are the results and do the results actually measure what was intended to be measured? Validity of research can be explained as an extent at which requirements of scientific research method have been followed during the process of generating research findings. (Cohen, Manion, Morrison & Morrison 2007.) Oliver (2010) considers validity to be a compulsory requirement for all types of studies. There are different forms of research validity and main ones are specified by as content validity, criterion-related validity, construct validity, internal validity, external validity, concurrent validity and face validity. (Oliver 2010.)

Reliability is defined as the consistency of the measurements. To what level will the instrument produce the same results under the same conditions every time it is used? Reliability adds to the trustworthiness of the results because it is a testament to the methodology if the results are reproducible. The reliability is often examined by using a test and retest method where the measurement are taken twice at two different times. The reliability is critical for being able to reproduce the results, nevertheless the validity must be confirmed first to ensure that the measurements are accurate. Consistent measurements are useful only if they are accurate and valid. (Neuman & Neuman 2006.)

Reliability is a concern every time a single observer is the source of data, because there is no certain guard against the impact of that observer's subjectivity (Babbie 2010, 158). According to Wilson (2010) reliability issues are most of the time closely associated with subjectivity and once a researcher adopts a subjective approach towards the study, then the level of reliability of the work is going to be compromised (Wilson 2010).

The strengths of the study include the prospective data collection and standard surgical technique using segmental bilateral pedicle screw instrumentation with direct vertebral column derotation to stable vertebra in patients with JIS. Two orthopedic spine surgeons performed all the operations, and the postoperative follow-up was standardized. The study population included all consecutive juvenile patients operated for idiopathic scoliosis between 2009 and 2015 in a single center providing complete clinical and radiographic data collection. Consecutive AIS patients (at least Risser 2) operated using

similar surgical technique formed a control group resulting into 1:4 patients to control ratio. Independent observer measured all radiographs.

Due to the prospective data collection, the SRS-24 questionnaire was not changed to a more modern version in order to increase the validity of the preoperative vs postoperative as well as between groups comparisons. The SRS-24 total score has been reported to fulfill the properties of internal construct validity (Rothenfluh, Neubauer, Klasen & Min 2012). The limitations of this study include the relatively small number of juvenile patients mainly due to the selection of definitive spinal fusion instead of growth friendly instrumentation in patients with immature spine (Risser 0).

The ethical aspects of this study were carefully evaluated by the ethical committee of the Turku university hospital. Studies documenting patient reported outcome measures have been regarded as even more important than pure clinical parametres such as complications, radiographic parametres etc.

9 CONCLUSION

This study shows significant improvement in clinical, radiographic, and health related quality of life outcomes in both the juvenile and adolescent idiopathic scoliosis operated using bilateral, segmental pedicle screw instrumentation. Both groups showed over 75% stable radiographic coronal curve correction during two-year follow-up. The correction of thoracic rib hump decreased from over 50% at six months to 39% at two-years, but the risk of radiographic adding on was low and no patient required revision for adding on in the juvenile group during the follow-up.

Health related quality of life as measured using the SRS-24 questionnaire was significantly better for the juvenile than in the adolescent idiopathic scoliosis group at two-year follow-up. Both groups showed a statistically significant improvement in the back pain score from preoperative to six months and from preoperative to two-year follow-up.

Future studies should aim at evaluation and documentation of health related quality life in children with other spinal disorders undergoing spinal surgery. These include e.g. Scheuermann kyphosis, neuromuscular scoliosis, and early onset scoliosis. In addition, future treatment options should be carefully compared with the solid findings in this study. For juvenile idiopathic scoliosis endoscopic anterior vertebral body tethering will be started at the Department of Paediatric Orthopaedic Surgery, Turku University Hospital in the beginning of 2018. Whether this non-fusion technique can provide a similar and sustainable clinical, radiographic and health related quality of life outcomes in juvenile idiopathic scoliosis than pedicle screw technique should be evaluated in the near future.

These novel findings on the improvement of health related quality of life especially in the juvenile idiopathic scoliosis have a great impact on the counselling families before a major surgical procedure and produce re-assurance of the positive outcomes related to spinal deformity surgery.

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Appendix 1. Scoliosis Research Society 24-Questionnaire

Scoliosis Research Society's Scoliosis Patient Questionnaire

Patient Name: _____ Age: _____ Date: _____

Medical Record #: _____ SS#: _____

Surgery date: _____ Follow-up: _____

We are carefully evaluating the condition of your back. Please circle the best answer to each question unless otherwise indicated.

1. On a scale of 1 to 9, with 1 meaning "no pain" and 9 meaning "severe pain", Indicate the degree of pain you experience regularly

1 2 3 4 5 6 7 8 9

2. Using the same scale, indicate the most severe degree of pain you have experienced over the last month.

1 2 3 4 5 6 7 8 9

3. If you had to spend the rest of your life with your back as it is right now, how would you feel about it?

Very happy Somewhat happy Neither happy nor unhappy
Somewhat unhappy Very unhapppy

4. What is your current level of activity?

Bedridden/Wheelchair Primarily no activity
Light labor, such as household chores Moderate manual labor and moderate sports, such as walking and biking Full activities without restriction

5. How do you look in clothes?

Very good Good Fair Bad Very bad

6. Do you experience back pain when at rest?

Very often Often Sometimes Rarely Never

7. What is your current level of work/school activity?

100% normal 75% normal 50% normal 25% normal 0% normal

8. What medications, if any, are you currently taking for your back? (circle all that apply)

None Non-steroidals (i.e. Motrin) Steroids (cortisone)

Muscle Relaxants (Valium) Narcotics (Morphine)

9. Does your back limit your ability to do things around the house?

Yes No

10. Have you taken any sick days from work/school due to back pain?

Yes No

11. Do you feel your condition affects your personal relationships?

Yes No

12. Are you and/or your family experiencing financial difficulties because of your back?

None Some A lot

13. Do you go out more or less than your friends?

More Same Less

14. Do you feel attractive?

Yes, very Yes, somewhat Neither attractive nor unattractive

No, not very much No, not at all

15. On a scale of 1 to 9, with one being very low and 9 being extremely high how would you rate your self-image?

1 2 3 4 5 6 7 8 9

16. Has your back treatment changed your function or daily activity?

Increased Not changed Decreased

17. Has your back treatment changed your ability to enjoy sports/hobbies?

Increased Not changed Decreased

18. Has your treatment _____ your back pain?

Increased Not changed Decreased

19. Has your treatment changed your confidence in personal relationships with others?

Increased Not changed Decreased

20. Has your treatment changed the way others view you?

Much better Better Same Worse Much worse

21. Has your treatment changed your self-image?

Increased Not changed Decreased

22. Are you satisfied with the results of your back treatment?

Extremely satisfied Somewhat satisfied Neither satisfied nor dissatisfied Somewhat dissatisfied Extremely dissatisfied

23. Compared to before your treatment, how do you feel you now look?

Much better Better Same Worse Much worse

24. Would you have the same treatment again if you had the same condition?

Definitely yes Probably yes Not sure Probably not Definitely not

Thank you for completing this questionnaire.

Appendix 2. SRS-24 Questionnaire in Finnish

SRS-kyselylomake

Nimi: _____ Syntymäaika _____

Päiväys _____

Ohjeet: Selkänne tilan arvioimiseksi tarkasti **on tärkeää, että vastaatte jokaiseen kysymykseen itse. Ympyröikää paras vastaus kuhunkin kysymykseen**. Merkitkää lopuksi, kuinka monta minuuttia teiltä kului tämän kyselykaavakkeen täyttöön.

1. Asteikolla 1 – 9, jossa 1 tarkoittaa ”ei kipua” ja 9 ”vaikea kipu”, ilmoittakaa kipunne aste viimeisten *kuuden kuukauden* aikana.

   1 2 3 4 5 6 7 8 9

2. Osoittakaa samalla asteikolla pahin mahdollinen kivun aste viimeksi kuluneen kuukaudenaikana.

   1 2 3 4 5 6 7 8 9

3. Miltä teistä tuntuisi jos selkänne olisi loppuelämänne sellainen kuin se on nyt?
   5 Oikein hyvältä
   4 Melko hyvältä
   3 Ei hyvältä eikä pahalta
   2 Melko pahalta
   1 Oikein pahalta

4. Mikä on tämänhetkisen aktiivisuutenne taso?
   1 Vuoteessa / pyörätuolissa
   2 Ei juuri mitään aktiivisuutta
   3 Kevyttä työtä, esim. kotityötä
   4 Keskiraskasta ruumiillista työtä ja liikuntaa kuten kävelyä ja pyöräilyä
   5 Täysin aktiivinen ilman rajoituksia

5. Millainen on ulkonäkönne vaatteet päällä?
   5 Oikein hyvä
   4 Hyvä
   3 Kohtalainen
   2 Huono
   1 Oikein huono

6. Onko teillä selkäkipua levossa?
   1 Hyvin usein
   2 Usein
   3 Joskus
   4 Harvoin
   5 Ei koskaan

7. Mikä on tämähetkinen aktiivisuustasonne työssä/koulussa?
   5 100 % normaalista
   4 75 % normaalista
   3 50 % normaalista
   2 25 % normaalista
   1 0 % normaalista

8. Mikä seuraavista kuvaa parhaiten selän vuoksi käyttämiänne lääkkeitä?
   5 Ei lääkitystä
   4 Tavallisia kipulääkkeitä (esim. aspiriini, Burana) viikottain tai harvemmin
   3 Tavallisia kipulääkkeitä päivittäin
   2 Huumaavia kipulääkkeitä (esim. Panacod, OxyContin) viikottain tai harvemmin.
   1 Huumaavia kipulääkkeitä päivittäin
   Muuta: _____

9. Rajoittaako selkä kotiaskareitanne?
   1 Kyllä
   5 Ei

10. Oletteko viimeisten kolmen kuukauden aikana ollut poissa työstä/koulusta selkäkivun vuoksi?
    1 Kyllä
    5 Ei

11. Vaikuttaako vaivanne mielestänne ihmissuhteisiinne?
    1 Kyllä
    5 Ei

12. Onko teillä ja/tai perheellänne taloudellisia vaikeuksia *selkänne* vuoksi?
    5 Ei lainkaan
    3 Jossain määrin
    1 Paljon

13. Käyttekö ulkona enemmän vai vähemmän kuin ystävänne?
    5 Paljon vähemmän
    3 Yhtä paljon
    1 Paljon vähemmän

14. Tunnetteko olevanne viehättävä?
    5 Erittäin
    4 Melko
    3 En viehättävä enkä päinvastoin
    2 En kovin
    1 En ollenkaan

15. Asteikolla 1 – 9, jossa 1 on hyvin pieni ja 9 erittäin suuri, millaiseksi luokittelisitte omanarvontunteenne?

    1 2 3 4 5 6 7 8 9

16. Onko selkäsairautesi hoito muuttanut toimintaasi tai päivittäisiä aktiviteettejäsi?
    5 Lisännyt
    3 Ei ole muuttanut
    1 Vähentänyt

17. Onko selkäsairautesi hoito muuttanut sinun mahdollisuuksiasi nauttia harrastuksista tai liikunnasta?
    5 Lisännyt
    3 Ei ole muuttanut
    1 Vähentänyt

18. Onko selkäsairautesi hoito _____ selkäkipujasi?
    1 Lisännyt
    3 Ei ole muuttanut
    5 Vähentänyt

19. Onko selkäsairautesi hoito muuttanut luottamustasi henkilökohtaisissa suhteissasi?
    - 5 Lisännyt
    - 3 Ei ole muuttanut
    - 1 Vähentänyt

20. Onko selkäsairautesi hoito muuttanut muiden näkemystä sinusta?
    - 5 Parantanut paljon
    - 4 Parantanut
    - 3 Ei ole muuttanut
    - 2 Huonontanut
    - 1 Huonontanut paljon

21. Onko selkäsairautesi hoito muuttanut omakuvaasi?
    - 5 Parantanut
    - 3 Ei ole muuttanut
    - 1 Huonontanut

22. Oletteko tyytyväinen selkänne hoitotuloksiin?
    - 5 Erittäin tyytyväinen
    - 4 Melko tyytyväinen
    - 3 En ole tyytyväinen enkä ole tyytymätön
    - 2 Melko tyytymätön
    - 1 Erittäin tyytymätön

23. Verrattuna ennen hoitoa, miltä näytätte nyt?
    - 5 Paljon paremmalta
    - 4 Paremmalta
    - 3 Samalta
    - 2 Huonommalta
    - 1 Paljon huonommalta

24. Haluaisitteko saman hoidon uudelleen jos teilä olisi sama vaiva?
    - 5 Ehdottomasti kyllä
    - 4 Luultavasti kyllä
    - 3 En tiedä
    - 2 Luultavasti en
    - 1 Ehdottomasti en

Aikaa täyttämiseen kului _____ min.

Appendix 3. SRS-24 Questionnaire in Swedish

SRS-frågeformulär

Namn: _____ Födelsetid _____

Datum: _____

Anvisningar: För att kunna noggrannt utreda era ryggproblem är det ytterst viktigt, **att ni svarar på alla frågor helt själv. Omringa det svar som bäst motsvarar er situation vid varje fråga.** Ange till sist hur många minuter det tog er att fylla i formuläret.

1. På en skala av 1 till 9, där 1 betyder “ingen smärta” och 9 betyder “svår smärta”, ange vilken grad av smärta ni erfarit under de senaste 6 månaderna.

   1 2 3 4 5 6 7 8 9

2. Genom att använda samma skala, ange den kraftigaste smärta ni erfarit under den senaste månaden

   1 2 3 4 5 6 7 8 9

3. Om du var tvungen att tillbringa resten av ditt liv med ryggen, som den är nu, hur skulle känna dig då?
   5 Mycket nöjd
   4 Ganska nöjd
   3 Varken nöjd eller missnöjd
   2 Ganska missnöjd
   1 Mycket missnöjd

4. Vilken är er grad av aktivitet för tillfället
   5 Sängliggande/ rullstolsbunden
   4 Just ingen aktivitet
   3 Lätt arbete/ såsom hushållsarbete
   2 Medeltungt fysiskt arbete och motion, såsom promenader och cycling
   1 Fullt aktiv utan begränsningar

5. Hurudant är ert utseende med kläderna på?
   5 Mycket bra
   4 Bra
   3 Nöja

2 Dålig
1 Mycket dålig

6. Erfar ni smärta i vila?
   1 Mycket ofta
   2 Ofta
   3 Ibland
   4 Sällan
   5 Aldrig

7. Vilken är er aktivitetsgrad i arbetet/skolan för tillfället?
   5 100 % av det normala
   4 75 % av det normala
   3 50 % av det normala
   2 25 % av det normala
   1 0 % av det normala

8. Vilken medicinering använder ni för tillfället pga ryggproblemet?
   5 Ingen
   4 Vanliga smärtmediciner
   (tex Burana, aspirin) några gånger per vecka eller mera sällan
   3 Vanliga smärtmediciner dagligen
   2 Starka smärtmediciner (Panacod, Oxycontin) några gånger i veckan
   eller mera sällan
   1 Starka mediciner dagligen

9. Begränsar ryggen er förmåga att göra hushållssysslor??
   1 Ja
   5 Nej

10. Har ni under de senaste 3 månaderna varit borta från jobbet/skolan pga ryggvärk?
    1 Ja
    5 Nej

11. Har ni och/eller er familj finansiella svårigheter pga er rygg?
    1 Ja
    5 NeHar ni och/eller er familj finansiella svårigheter pga er rygg?
    5 Inte alls
    3 I någon mån
    1 Mycket

12. Går ni ut mer eller mindre än era vänner?
    5 Mycket mera

3 Lika mycket
1 Mycket mindre

13. Känner ni er attraktiv?
    5 Ja, mycket
    4 Ja, i någon mån
    3 Varken attraktiv eller oattraktiv
    2 Nej, inte just
    1 Nej, inte alls

14. På en skala från 1 till 9, där 1 är mycket dåligt och 9 mycket bra, hur skulle ni bedöma er självkänsla?

    1 2 3 4 5 6 7 8 9

15. Har behandlingen av er rygg förändrat er function och dagliga aktivitet?
    5 Ökat
    3 Ingen förändring
    1 Minskat

16. Har behandlingen av er rygg förändrat er förmåga att njuta av hobbyer och motion?
    5 Ökat
    3 Ingen förändring
    1 Minskat

17. Har behandlingen av er rygg _____ er ryggvärk?
    1 Ökat
    3 Inte förändrat
    5 Minskat

18. Har er behandling ökat ert självförtroende när det gäller personliga relationer?suhteissasi?
    5 Ökat
    3 Ingen förändring
    1 Minskat
19. Har behandlingen förändrat den bild andra har av dig?
    5 Mycket batter
    4 Bättre
    3 Samma
    2 Försämrat
    1 Mycket sämre

20. Har behandlingen förändrat din självkänsla??
    - 5 Förbättrat
    - 3 Ingen förändring
    - 1 Försämrat

21. Är du nöjd med resultatet av din behandling?
    - 5 Mycket nöjd
    - 4 Ganska nöjd
    - 3 Varken nöjd eller missnöjd
    - 2 Ganska missnöjd
    - 1 Mycket missnöjd

22. Jämfört med situationen före behandlingen, hurudant är ert utseende?
    - 5 Mycket batter
    - 4 Bättre
    - 3 Samma
    - 2 Sämre
    - 1 Mycket sämre

23. Skulle ni genomgå samma behandling på nytt om ni hade samma besvär?
    - 5 Absolut ja
    - 4 Troligen ja
    - 3 Vet inte
    - 2 Troligen inte
    - 1 Absolut inte

24. Skulle ni genomgå samma behandling på nytt om ni hade samma besvär?
    - 5 Absolut ja
    - 4 Troligen ja
    - 3 Vet inte
    - 2 Troligen inte
    - 1 Absolut inte

Table 1. Clinical Characteristics of the Study Groups

	Juvenile (n=21)	Adolescent (n=84)	P value
Age at surgery, years	12.0 ± 1.3	15.8 ± 1.5	<0.001
Gender (M/F)	1/20	23/61	0.027
Mean follow-up, years	2.2 ± 0.3	2.1 ±0.3	0.81
Open triradiate cartilage (n)	15	0	<0.001
Lenke classification (n)*			
1	3	30	N.S.
2	5	28	
3	8	6	
4	3	4	
6	2	16	
Number of levels fused (n)	10.9 ± 1.4	10.0 ± 1.4	0.012
Posterior column osteotomies, (n, %)	12 (57.1%)	24 (28.6%)	0.014
Operative time, hours	3.7 ± 0.9	3.4 ± 1.1	0.11
Intraoperative blood loss(mL)	737 ± 405	561 ± 316	0.076
Intraoperative blood loss per body weight (mL/kg)	11.5 ± 6.4	9.5 ± 5.1	0.37
Thoracic rib hump (°)			
Preoperative	14.4 ± 4.6	14.1 ± 4.6	0.59
At 6 months	6.0 ± 3.1	6.5 ± 3.3	0.87
Correction (%)	57.2 ± 22.5	52.5 ± 24.7	0.67
At two-year	7.9 ± 4.3	7.2 ± 3.3	0.66
Correction (%)	38.6 ± 41.0	48.8 ± 19.4	0.81

Values indicate mean ± SD unless otherwise specified. *Lenke classification for juvenile idiopathic scoliosis and for adolescent idiopathic scoliosis.

Table 2. Radiographic Outcomes

	Juvenile (n=21)	Adolescent (n=84)	P value
Major curve (°)			
Preoperative	58.0 ± 8.1	53.0 ± 7.1	0.0032
On bending	40.9 ± 15.8	34.9 ± 11.9	0.20
At six months	14.0 ± 4.8	12.1 ± 5.9	0.16
Correction (%)	75.4 ± 9.8	77.3 ± 11.2	0.58
At two-year	12.7 ± 4.5	12.3 ± 6.3	0.45
Correction (%)	78.2 ± 7.7	76.9 ± 10.8	0.90
Th kyphosis (T5-T12, °)			
Preoperative	20.9 ± 14.6	21.0 ± 14.2	0.84
At six months	18.5 ± 13.0	18.8 ± 8.7	0.91
At two-year	16.6 ± 8.1	19.4 ± 8.8	0.54
Lordosis (T12-S1, °)			
Preoperative	53.5 ± 10.6	51.1 ± 12.1	0.67
At six months	48.5 ± 11.4	47.8 ± 10.4	0.88
At two-year	46.3 ± 18.1	47.3 ± 12.1	0.95
Coronal balance (mm)			
Preoperative	7.6 ± 14.6	2.7 ± 17.5	0.016
At two-year	2.7 ± 13.4	1.5 ± 10.9	0.15
Sagittal balance (mm)			
Preoperative	14.6 ± 23.2	13.4 ± 22.0	0.78
At two-year	4.6 ± 27.4	5.5 ± 19.9	0.17

Values indicate mean ± standard deviation

Table 3. Outcomes of the Scoliosis Research Society (SRS) 24- Questionnaire

SRS Score	Juvenile (n=21)	Adolescent (n=84)	P value
Pain			
Preoperative	3.5 ± 0.5	3.5 ± 0.5	0.84
At six months	4.5 ± 0.4*	4.3 ± 0.6*	0.11
At two-year	4.6 ± 0.4**	4.3 ± 0.5*	0.040
General self-image			
Preoperative	3.8 ± 0.7	3.7 ± 0.6	0.82
At six months	4.2 ± 0.6	4.0 ± 0.7	0.64
At two-year	4.4 ± 0.7	3.9 ± 1.0	0.063
Function from back condition			
Preoperative	4.2 ± 0.2	3.9 ± 0.5	0.084
At six months	4.0 ± 0.5	4.0 ± 0.5	0.96
At two-year	4.4 ± 0.7	4.0 ± 0.9	0.040
General activity			
Preoperative	4.8 ±0.5	4.6 ± 0.7	0.22
At six months	4.1 ± 1.0	4.1 ± 0.9	0.96
At two-year	4.8 ± 0.5	4.8 ± 0.4	0.37
Postoperative self-image			
At six months	3.3 ± 0.6	3.2 ± 0.5	0.64
At two-year	3.5 ± 0.6	3.1 ± 0.8	0.075
Postoperative function			
At six months	2.2 ± 0.9	2.0 ± 0.9	0.47
At two-year	3.1 ± 0.3	2.5 ± 1.0	0.072
Satisfaction			
At six months	4.4 ± 0.5	4.1 ± 0.8	0.25
At two-year	4.5 ± 0.5	3.9 ± 1.1	0.049
Total SRS-24 score			
At six months	95.6 ± 9.6	92.5 ± 9.8	0.26
At two-year	101.4 ± 6.1	96.7 ± 9.3	0.040

Values indicate mean ± SD. *Preoperative vs. follow-up p≤0.001; **p=0.0039.

Figure 1. Posterior spinal fusion

Figs. 1-A to 1-C. 12-year-old girl with juvenile idiopathic scoliosis (Risser 0, open triradiate cartilage). Preoperative standing radiographs (A) demonstrate 52 degree thoracic scoliosis. Standing radiograph at two-year FU (B, C) demonstrate bilateral segmental pedicle screw instrumentation without distal adding-on, proximal junctional kyphosis or flattening of the thoracic kyphosis.

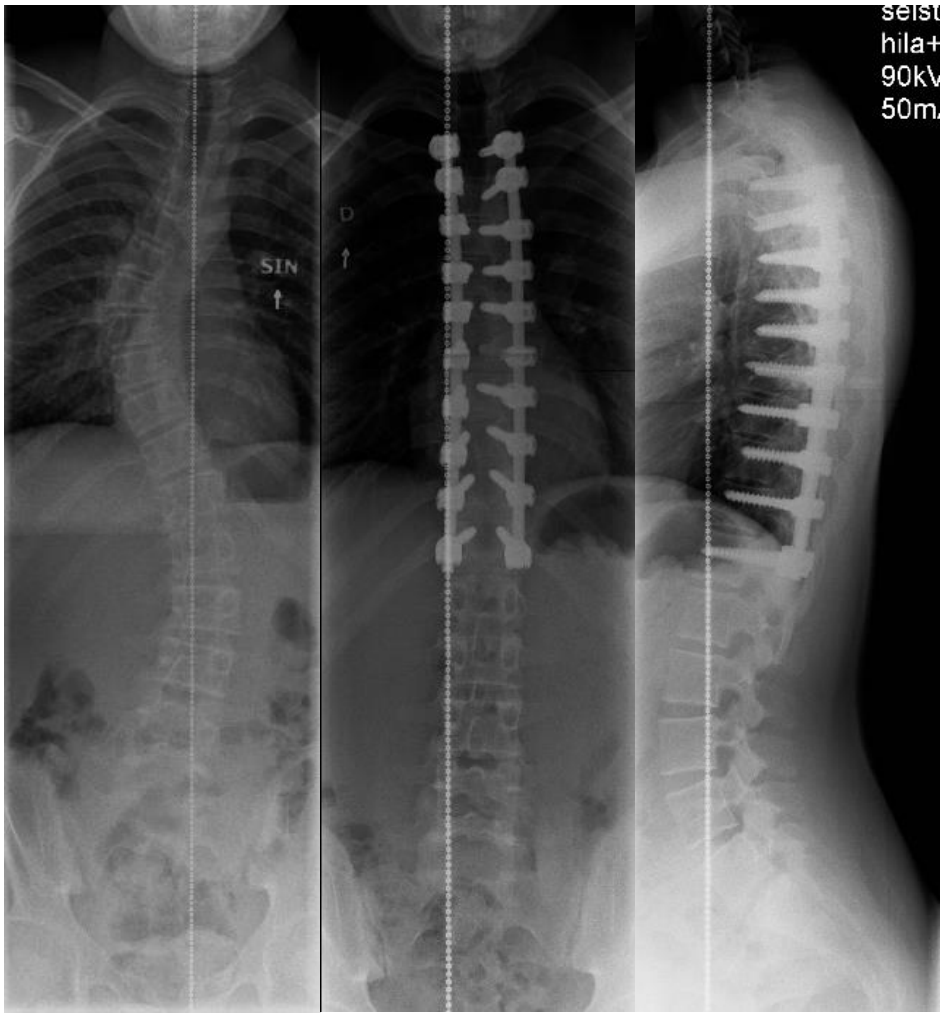

Fig.1-A Fig. 1-B Fig. 1-C