Pre- and postoperative evaluation of function and activity in patients with paralytic scoliosis

Eva-Lena Larsson
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ABSTRACT

This thesis evaluates surgical correction in patients with paralytic scoliosis with emphasis on function and activity. The thesis includes four studies of 100 consecutive patients preoperatively evaluated and surgically corrected between 1992 and 1996 at Linköping University Hospital. Eighteen different diagnoses were represented. The postoperative follow-ups were at one year and in average seven years. Six patients dropped out during the first year and twelve during the long-term follow-up period. The assessments included general information, lung function, and measurements of radiographs, function and activity - seating posture, ADL, pain, care and need for rest. The patients or relatives view on the effects of surgery were evaluated in follow-up questionnaires.

The preoperative results of the 100 patients described a heterogeneous group in terms of function and activity. Even when the patients were grouped into subgroups according to the Scoliosis Research Society classification, they remained heterogeneous. In patients who could understand verbal instructions assessments that needed co-operation could be used and in those who could not understand verbal instructions, assessments relied more heavily on measures of function and level of dependence. Preoperative results of weight distribution on the seating surface were explained by thoracolumbar/lumbar spinal imbalance and pelvic obliquity $R^2=0.45$ (n=45).

The one-year follow-up of 94 patients showed improvements in angle of scoliosis, sitting balance, weight distribution to the seating surface, seating supports in the wheelchair, time needed for rest. The results in subgroups were almost the same as in the whole group. The subjective results for patients or relatives in the follow-up questionnaire showed a positive outcome of surgery. In the comparison between the one-year follow-up and the long-term follow-up there were further improvements in sitting balance, ADL, and care given, but the angle of scoliosis was increased. These results were in line with patients’ and relatives’ assessments in the follow-up questionnaire and in the open-ended questions.

Due to the heterogeneity of patients with paralytic scoliosis, irrespective of disorder, it is important to focus on different subgroups with regards to the patients’ total situation. The surgically corrected and stabilised spine resulted in the strength to keep the body upright with improvements in function, activity and possibilities to belong in social activities. Further improvements were shown between the one-year follow-up and the long-term follow-up. It is recommended that patients who have been surgically corrected for paralytic scoliosis are followed for more than one year.
“To see a world in a grain of sand,
and a heaven in a wild flower,
hold infinity in the palm of your hand,
and eternity in an hour”

William Blake 1757-1827

To my family
Göran,
and
Niklas and Sara
and their families
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>COPM</td>
<td>Canadian Occupational Performance Measure</td>
</tr>
<tr>
<td>(D)</td>
<td>Disabilities</td>
</tr>
<tr>
<td>DMD</td>
<td>Duchenne Muscular Dystrophy</td>
</tr>
<tr>
<td>GAS</td>
<td>Goal Attainment Scale</td>
</tr>
<tr>
<td>(H)</td>
<td>Handicaps</td>
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<tr>
<td>ICC</td>
<td>Intraclass Correlation Coefficient</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities, and Handicaps</td>
</tr>
<tr>
<td>(I)</td>
<td>Impairments</td>
</tr>
<tr>
<td>LOCF</td>
<td>Last Observation Carried Forward</td>
</tr>
<tr>
<td>MMC</td>
<td>Myelomeningocele</td>
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<tr>
<td>S1</td>
<td>First sacral vertebra</td>
</tr>
<tr>
<td>SF-36</td>
<td>Short form of Health Survey</td>
</tr>
<tr>
<td>SMA</td>
<td>Spinal Muscular Atrophy</td>
</tr>
<tr>
<td>SRS</td>
<td>Scoliosis Research Society</td>
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<tr>
<td>T1</td>
<td>First thoracic vertebra</td>
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<tr>
<td>VAS</td>
<td>Visual Analogue Scale</td>
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<td>WHO</td>
<td>World Health Organization</td>
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</table>
LIST OF PAPERS

The thesis is based on following papers, which will be referred to in the text by their Roman numerals I-IV


IV. E-L. Larsson, S. Aaro, H. Normelli, B. Öberg. Long-term follow-up of functioning after spinal surgery in patients with paralytic scoliosis,

(in manuscript)
INTRODUCTION
This thesis deals with evaluation of the effect of spinal surgery in patients with paralytic scoliosis in relation to activities and function. Describing paralytic scoliosis patients pre- and postoperatively from a perspective other than solely bio-medical is uncommon. The conviction that it is important to know and respect the unique perspective of the patient, even in the presence of all kinds of impairments, is closely related to a humanistic perspective.
Kielhofner (1997) maintained that disability is a personal matter and emphasised the value of the right of individuals to choose their own activities, even if this requires the support of care professionals. Understanding how paralytic scoliosis, pre- and postoperatively, affects the individuals’ functions, activities of daily living, and possibility to participate in activities are of vital importance here.

BACKGROUND
Neuromuscular diseases and paralytic scoliosis
Paralytic scoliosis is frequently encountered in neuromuscular diseases, which constitute a diverse group of disorders with primary abnormalities at different sites in the brain, spinal cord, peripheral nerves, or muscles (Shook and Lubicky, 1991). Many of the neuromuscular disorders exist at birth and are hereditary (e.g. spinal muscular atrophy) or acquired (e.g. cerebral palsy) abnormalities. Disorders that appear later are acquired (e.g. spinal cord injury) or genetic defects that manifest themselves during childhood (e.g. Duchenne muscular dystrophy).
Winter (1990) describes a classification, endorsed by the Scoliosis Research Society, that comprises upper and lower motor neuron lesions, myopathic, and congenitals. Examples of upper motor neuron lesions are cerebral palsy, spinocerebellar degeneration (Friedreich's ataxia, Charcot-Marie-Tooth and Roussy-Lévy), syringomyelia, spinal cord trauma, and tumors. Examples of lower motor neuron lesions are poliomyelitis, spinal muscular atrophy (Werding-Hoffman and Kugelberg-Welander) and myelomeningocele. Paralytic scoliosis also affects patients with myopathies such as arthrogryposis, muscular dystrophy (Duchenne’s and Becker’s diseases), and myotonica dystrophica, as well as congenital malformation syndrome. Prior to the advent of poliomyelitis vaccines, the most common cause of paralytic scoliosis was poliomyelitis. Today cerebral palsy and Spinal Muscular Atrophy (SMA) are the leading causes of paralytic deformity.
According to the definition of scoliosis in the Scoliosis Research Society classification, the deformity has to be at least 10° as measured according to Cobb (Cobb, 1948).
In an attempt to prolong the upright position for sitting independence, early spinal instrumentation and fusion is advocated in patients with Duchenne Muscular Dystrophy (DMD) if scoliosis curve is >20°, and if the vital capacity is >40%. If the patient’s pelvic obliquity is >10° instrumentation is recommended to the sacro-pelvis (Mubarak et al. 1993).

In scoliosis that exceeds 40° as measured by Cobb, progression cannot be prevented with brace treatment in children with myelomeningocele (Berned-Müller and Nordwall, 1994). The characteristics of paralytic scoliosis include early onset, rapid progression, progression after skeletal maturity, compromised functional abilities, long spinal curves which include the sacrum, resulting in pelvic obliquity. The scoliosis and pelvic obliquity have been reported to be causes of high-pressure concentrations under the tuber ischi (Osebold et al. 1982, Drummond et al. 1985, Tredwell and Roxborough 1991, Smith and Emans 1992).

Patients with spinal deformity can be spastic and need modular seating systems that provide control of the pelvis and trunk in order to attain an optimal sitting position. They can also be flaccid and have a tendency to slip down in the wheelchair (Shook and Lubicky, 1991). The patients are commonly placed in a backward or reclined posture because of the risk of falling forward, but in this position their visual line is upward rather than horizontal, which results in difficulty in communicating and in looking at the surroundings. In relation to the reclined position, Guymer (1986) noted that it is difficult to eat and drink and the risk of choking is increased, because swallowing is a neurological flexor activity. There is also a risk of pressure sores developing in the sacral area when sitting in a reclined position (Mulcahy et al., 1988).

According to Dubousset (1997) the three main goals of surgical treatment for paralytic spinal deformities are:
1. "To improve cardio-respiratory function or prevent worsening of it by correction of the spinal deformity.
2. To provide trunk realignment and balance to enhance ambulation or sitting ability through adequate correction of the curve.
3. To ensure permanent improvement by achieving a solid fusion” (p. 933).
Function and activity

Individuals with neuromuscular diseases are usually wheelchair users with an impaired sitting position because of the collapsing spine and instability in postural adjustments (Shook and Lubicky, 1991). Therefore, one can assume that performance in activities is often limited, with restriction to take part in a social context as a consequence. The results of surgery for patients with paralytic scoliosis are usually presented as the angular correction of deformity. Therefore, even if the patients suffer from the loss of function and daily life activities, it is often described in terms of disease. Kielhofner (1997) points out that dysfunction in activities are not synonymous with disease, because dysfunction in activities occurs whenever occupational behaviour is disrupted and he pointed out as an example, when children cannot participate in normal play activities they may fail to develop necessary language, cognitive, and motor skills. In relation to surgical correction, it is therefore important to evaluate the limitations in activities as well as functions from a perspective representing a non-medical viewpoint. In order to evaluate scoliosis in relation to functions and activities, there is a need to clarify the concepts of function and activities.

Function comes from the Latin word “fungi” which means, “to perform”. Function can be derived from an organ or system of the body, such as muscle function, arm function, breathing function, and so on (Fisher, 1992). The same author noted that according to the Classification of Impairment, Disability and Handicap (WHO, 1980), an analysis of function means to identify functional possibilities for activity. The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) had moved away from being a consequences of disease classification (1980 version) to became a components of health classification” (ICF, 2001, p.4).

ICF describes two parts, each with two components: The first part comprises Functioning and Disability, including body functions that “are the physiological functions of body systems” (p. 47), and body structures defined as “anatomical parts of the body such as organs, limbs and their components” (p. 105).

Wilcock (1998) states that the integrative functions of the central nervous system, activated by involvement in occupation, are central to survival, and facilitate health and well-being. Mosey (1986) pointed out that motor function, sensory integration, visual perception, cognitive function, psychological function, and social interaction are involved together in performance components. Keilhofner (1997) mean that the neurological and musculoskeletal components refer to the nervous and musculoskeletal systems, which are used in the interpretation of sensory information of motor actions.
Bradford (1987) points out that for patients with paralytic scoliosis, it is of great importance to maintain their functional levels, and even improve function by means of spinal surgery.

Törnquist (1995, p. 155) described, according to WHO classification system (WHO, 1980), that the concept of activity is differentiated from the concept of function in the following way:
- activity has a goal or intention, in contrast to function
- activity occurs at the individual level while function is confined to the organ level
- activity is complex and depends on different functions of organs
- activity is related to the environment to a greater extent than function
- dysfunction of different organs or systems of organs may lead to reduction in the ability to perform activities or vice versa

Activities of daily living (ADL) are recurrent activities such as personal care, living- and communication activities, since they often constitute a basis for other activities (Törnquist, 1995).

Activity, according to ICF (WHO, 2001), is defined, as “activity is the execution of a task or an action by an individual” and described in the domains of Activities and Participation, where “participation is involvement in a life situation” or “the lived experience”. Performance qualifier describes what an individual does in her/his environment in an actual context where they live, while the capacity qualifier describes an individual’s ability to perform a task (WHO, 2001, p. 123). Activity comes from the Latin word “agree”, to do (Wilcock, p. 24, 1998). The same author defined activity as “the state of being active” and argues that without the possibility to engage in activities, time appears to pass extremely slowly, both in adult life and in childhood Wilcock (1998).

The second part of ICF (WHO, 2001) represents Contextual Factors including Environmental Factors that is defined as “factors make up the physical, social and attitudinal environment in which people live and conduct their lives” (p. 171). Children and/or teenagers with paralytic scoliosis are often in environments where others set the standards, because they have great need for care given by others. This can lead to uncertainty about whether and how the child should be involved in the determination of his or her needs or goals. Coster (1998) maintains that it is commonly believed that children have difficulties to assess their own performance, and the ability to identify and express their personal meanings and values may be limited. Personal Factors is according
Accordingly, to consider an individual using a holistic approach is to understand the physiology of a disease process, and to understand what a disease or trauma means in terms of an individual’s functions, ability to perform activities, and possibility to engage and belong in activities.

**Previous evaluations of patients with paralytic scoliosis**

Patients with paralytic scoliosis are heterogeneous regarding impairments and limitations in performing activities, which is individual-specific and focuses on person’s everyday life situation, rather than disease- or symptom-specific.

Bradford (1987) pointed out in a textbook on patients with paralytic scoliosis that surgical treatment might prevent progressive deformity and back pain, and improve sitting balance, and free the upper extremities for activities of daily living. Those were only speculations, however, because he did not refer to any prospective studies. In a postoperative study Osebold et al. (1982) reported unchanged daily activities and ambulation, but improved sitting balance in 40 patients with myelomeningocele, but did not report any preoperative measurements. Retrospective studies have also been conducted by other authors. Hibbs (1924) reported on 59 patients with infantile paralysis and scoliosis who were treated with spinal fusion, and he found that the patients seemed to experience relief from fatigue and an improvement in general physical well being. Brown et al. (1989) reported that patients with Spinal Muscular Atrophy (SMA) and paralytic scoliosis demonstrated slightly improved sitting balance postoperatively, but no preoperative measurements were performed. Cassidy et al. (1994) reported in a retrospective study that surgically corrected and fused patients with cerebral palsy were more comfortable and generally better off after surgery than non-fused patients. Those results were reported by the care staff. Improvement in ability to sit was also confirmed described by Dias et al. (1996) in a telephone interview with 22 caregivers of children with cerebral palsy who had undergone surgical correction. Bridwell et al. (1999) reported a study, where mail questionnaires with 20 questions regarding factors including function, pain, cosmetics, care, and satisfaction were sent to 33 patients with Duchenne Muscular Dystrophy (DMD) and 21 patients with Spinal Muscular Atrophy (SMA),
surgically treated from 1985 to 1995. They summarised their results by saying that all patients had benefited from the surgery.

Aprin et al. (1982) found, postoperatively in 22 patients with Spinal Muscular Atrophy (SMA), no change in the ability to perform daily hygiene, dressing and eating, but sitting balance was improved for most of the patients, compared with the preoperative results and the self-rated reports were mostly positive. Berned-Müller el al. (1994) evaluated 14 patients, with myelomeningocele, one year postoperatively, regarding motor skills, activities of daily living, and ambulation, in a prospective study. They reported poor results in motor skills and unchanged daily activities, and decreased ambulatory ability due to hip contractures, worsened by straightening out of the lumbar lordosis. In a prospective study, Askin el al. (1997) reported poor results in functional assessment including physical ability one year after surgical correction. Their results showed unchanged daily activities, locomotion, and sitting balance postoperatively in a group of 20 patients. The caregivers or the patients stated that there was an improvement in cosmetic appearance. The study included results from patients with different diagnoses and different intellectual function. The authors evaluated all the patients as a group, and did not explain how ADL was assessed in the mentally disabled patients. It is obvious that patients with paralytic scoliosis always represent different diagnoses and different intellectual function, which limits the possibility of analysing them as one group.

Rice et al. (1998) found in a long-term follow-up study of patients with Duchenne Muscular Dystrophy (DMD) that the patients had a well-balanced sitting position postoperatively as assessed by observation compared with preoperative findings.

Galasko et al. (1992) conducted in a prospective study with a long-term follow-up of 5 years. They compared individuals with Duchenne Muscular Dystrophy (DMD) and paralytic scoliosis who refused surgery (n=26) with another group of patients with DMD and paralytic scoliosis who had undergone surgical correction (n=31). The groups did not differ with respect to initial spinal curves. They found significant differences in vital capacity and progression of scoliosis with the worsened values in the group who refused surgery.

The attempts in retrospective studies, seems to support that apart from effects on the curve and lung function the seating position is better. In prospective studies with outcome on more than angle of deformity, vital capacity, and post surgical complications are few. The available literature is lacking the descriptions concerning results of evaluations including function and activities i.e. how they can sit, if they can reach, how to ambulate, if they can dress themselves, manage personal hygiene, etc
AIMS

The general purpose of this thesis was to evaluate the effect of surgical correction in patients with paralytic scoliosis with emphasis on function and activities.

The aims of the thesis were:

- to implement a set of instruments to describe paralytic scoliosis patients according to function and activities

- to investigate what factors explain weight distribution on the seating surface in patients with paralytic scoliosis who are wheelchair users and with independent ability to sit

- to evaluate the effect of surgical correction in relation to function and activities in patients with paralytic scoliosis, who were preoperatively evaluated and surgically corrected between 1992 and 1996, with emphasis on subgroups

- to evaluate the patients’ and relatives’ experience of how surgery had affected them postoperatively
PATIENTS AND METHODS

Patients

Study population
One hundred consecutive patients with paralytic scoliosis were included in the study. The patients who were preoperatively evaluated and surgically corrected at the University Hospital in Linköping between 1992 and 1996. Studies II-IV include the patients who were preoperatively evaluated in study I (fig. 1).

Fig. 1. The study population through the four studies.
**Study 1:** One hundred consecutive patients were included in the preoperative evaluation. Eighteen different diagnoses were represented. The patients were classified in accordance with the Scoliosis Research Society (SRS) as follows: upper motor neuron lesions (n=45), lower motor neuron lesions (n=39), myopathies (n=10), and congenital abnormalities (n=6) (table 1). The patients were also classified according to whether they understood verbal instructions (n=67) or did not understand verbal instructions (n=33).

Table 1. Number of patients and their diagnoses according to the Scoliosis Research Society classification n=100

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Upper motor neuron lesion</strong></td>
<td></td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>26</td>
</tr>
<tr>
<td>Rett’s syndrome</td>
<td>11</td>
</tr>
<tr>
<td>Injury of spinal cord</td>
<td>4</td>
</tr>
<tr>
<td>Aicardis syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Charcot-Marie-Tooth</td>
<td>1</td>
</tr>
<tr>
<td>Encephalopathy</td>
<td>1</td>
</tr>
<tr>
<td>Microcephaly</td>
<td>1</td>
</tr>
<tr>
<td><strong>Lower motor neuron lesion</strong></td>
<td></td>
</tr>
<tr>
<td>Myelomeningocele</td>
<td>23</td>
</tr>
<tr>
<td>Spinal muscular atrophy</td>
<td>10</td>
</tr>
<tr>
<td>Poliomyelitis</td>
<td>4</td>
</tr>
<tr>
<td>Central core disease</td>
<td>1</td>
</tr>
<tr>
<td>Guillian Barré syndrome</td>
<td>1</td>
</tr>
<tr>
<td><strong>Myopathies</strong></td>
<td></td>
</tr>
<tr>
<td>Myopathies</td>
<td>5</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>4</td>
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<tr>
<td>Duchenne and Becker</td>
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<tr>
<td>Arthrogryposis</td>
<td>1</td>
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<tr>
<td><strong>Congenital abnormalities</strong></td>
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<tr>
<td>Malformation, multiple</td>
<td>3</td>
</tr>
<tr>
<td>Chromosomal abnormalities</td>
<td>2</td>
</tr>
<tr>
<td>Prader Willi’s syndrome</td>
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</table>
**Study II:** One year after surgical treatment, 94 patients remained. The six dropout patients included 2 patients who had died, 2 patients who refused to participate in the postoperative investigation, and 2 patients who did not participate due to long travel distance. In the classification of those individuals who understood verbal instructions 64 patients remained and in the group who did not understand verbal instructions 30 patients remained.

The patients were also classified in accordance with the Scoliosis Research Society. There were 41 with upper motor neuron lesions that remained, and of those 41 there were 15 individuals who understood verbal instructions and 26 who did not. In the group of lower motor neuron lesions 37 patients remained, and in myopathy and congenital abnormality groups there were 10 and 6 patients, respectively who remained.

**Study III:** Forty-five of the 69 patients who were in study I preoperatively evaluated with a pressure plate system for weight distribution on a seating surface were included. The inclusion criteria were ability to sit during evaluation of pelvic obliquity and weight distribution, and being a wheelchair user. The patients were surgically corrected between 1993 and 1996. In the postoperative evaluation 43 patients remained. This study also included a reference material of 16 girls and 11 boys with a mean age of 14 years in order to get a reference value for weight distribution on a seating surface. The reference material was selected in a traditional way, i.e. we received assistance from the school nurses at three elementary schools.

**Study IV:** This study was a long-term follow-up with a mean of 84.5 months (range 60-116). Of the 100 patients who underwent preoperative evaluation between 1992 and 1996, 82 remained. Six patients dropped out during the first year. Of the other 12 dropouts five patients had died, four patients refused to participate in the postoperative investigation, one patient did not participate due to long travel distance, and two patients were surgically corrected a second time after two and three years, respectively, because of progression below the fusion. Theses patients had too short time for follow-up since the last surgery. The patients were classified according to whether they understood (n=55) or did not understand verbal instructions (n=27). They were also classified according to whether they had a progressive disease (n=14) or a non-progressive disease (n=68). In addition, they were classified into two age groups done by using the mean age of 22 years in the total group. The two groups were 13 to 21 years and 22 to 51 years. The characteristics of the patients in the four studies are presented in table 2.
Table 2. Characteristics of patients in the studies

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Study I Pre-operative n=100</th>
<th>Study II one-year follow-up n=94</th>
<th>Study III Pre-operative n=45</th>
<th>Study III one-year follow-up n=43</th>
<th>Study IV long-term follow-up n=82</th>
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<tr>
<td>Age (years)</td>
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<tr>
<td>mean</td>
<td>15 (4-52)</td>
<td>15 (5-44)</td>
<td>15 (8-43)</td>
<td>16 (9-44)</td>
<td>22 (13-51)</td>
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<td>median</td>
<td>14 (11-17)</td>
<td>15 (12-18)</td>
<td>14 (11-16)</td>
<td>15 (12-17)</td>
<td>21 (19-24)</td>
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<tr>
<td>Females (n)</td>
<td>60</td>
<td>55</td>
<td>33</td>
<td>31</td>
<td>49</td>
</tr>
<tr>
<td>Males (n)</td>
<td>40</td>
<td>39</td>
<td>12</td>
<td>12</td>
<td>33</td>
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<tr>
<td>Use of a wheelchair (n)</td>
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<td></td>
<td>85 (85%)</td>
<td>80 (85%)</td>
<td>45 (100%)</td>
<td>43 (100%)</td>
<td>72 (87%)</td>
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<td>Subgroups</td>
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<td>disease</td>
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<td>- age</td>
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</tbody>
</table>

1. Diagnoses according to the Scoliosis Research Society classification
**Instruments**

A set of instruments was used pre- and postoperatively to evaluate function and activities in patients with paralytic scoliosis. The assessments were performed one or two days before spinal surgery, at one year postoperatively, and after between 5 and 9 years postoperatively at the Orthopaedic department, University Hospital in Linköping. The set of instruments was composed of well-reputed instruments combined with new ones developed by an occupational therapist (Samuelsson, K) in order to evaluate patients with paralytic scoliosis pre- and postoperatively.

The instruments used in the four studies are presented in table 3 and include:
Table 3. The set of instrument through the four studies.

<table>
<thead>
<tr>
<th>VARIABLES</th>
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<th>II</th>
<th>III</th>
<th>IV</th>
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<tr>
<td><strong>GENERAL INFORMATION</strong></td>
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<td>Personal data</td>
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<td></td>
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<tr>
<td>Mental status</td>
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<td>Persistent skin discolouration</td>
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<tr>
<td>Ambulating/wheelchair use</td>
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<td>Occupation</td>
<td>X</td>
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<tr>
<td>Understands/does not understand</td>
<td>X</td>
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<td>verbal instructions</td>
<td></td>
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<tr>
<td>Brace</td>
<td>X</td>
<td>X</td>
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<tr>
<td><strong>FUNCTION AND ACTIVITY</strong></td>
<td></td>
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<td></td>
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<tr>
<td>Lung function (VC)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Angle of scoliosis (Cobb)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
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<tr>
<td>Mediolateral transl T1</td>
<td>X</td>
<td></td>
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<tr>
<td>Mediolat transl thoracolumbar/lumbar curve</td>
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<td>Pelvic obliquity</td>
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<tr>
<td>Sitting balance</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Seating supports in wheelchair</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Weight distribution on the seating surface</td>
<td>X</td>
<td>X</td>
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<td>X</td>
</tr>
<tr>
<td>Reaching</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Pain estimation</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Barthel ADL index</td>
<td>X</td>
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<td>Klein-Bell ADL scale</td>
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<td>X</td>
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<td></td>
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<tr>
<td>Care given (physical effort)</td>
<td>X</td>
<td>X</td>
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<td>Care given (time consumption)</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Time used for resting</td>
<td>X</td>
<td>X</td>
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<tr>
<td><strong>FOLLOW-UP QUESTIONNAIRE</strong></td>
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<td>X</td>
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<tr>
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<td>X</td>
<td>X</td>
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<td>X</td>
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<td>Daily activities</td>
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<td>X</td>
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<tr>
<td>Care given</td>
<td>X</td>
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<tr>
<td>Need for rest</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Cosmetic appearance</td>
<td>X</td>
<td>X</td>
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<tr>
<td><strong>TWO OPEN-ENDED QUESTIONS</strong></td>
<td></td>
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<tr>
<td>What do you think has become improved</td>
<td>X</td>
<td></td>
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<tr>
<td>since the surgery?</td>
<td></td>
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<tr>
<td>What do you think has become worse</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>since the surgery?</td>
<td></td>
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</tbody>
</table>
General information:
- personal data
- diagnoses (from the "case record" of the Regional Pediatric Rehabilitation Centre).
- the patient’s or relative’s motive for surgery with the following answer alternatives: respiration, pain, seating position, and cosmetics, with yes/no alternatives. An open-ended question was also included to allow for other answers.
- mental status (from the "case record" of the Regional Pediatric Rehabilitation Centre)
- persistent skin discolouration ("erythema that does not blanch on pressure and persists for at least 24 hours", Witkowski, 1991). The patient or relative was asked if there was any persistent discolouration and if so, in what part of the body it was located. If there was any uncertainty about the discolouration, the area was inspected.
- ambulating or wheelchair use, totally or partially.
- occupation (school, work, other)
- understands/does not understand verbal instructions
- brace use
**Function and Activity**

- **Lung function** was measured as vital capacity
- **Angle of scoliosis** was measured on X-ray in coronal plane according to Cobb (1948) (figure 2).

![Image](image.png)

**Figure 2.** The Cobb method, used for measurements of curve size on radiographs
- **Mediolateral translation of the first thoracic vertebra** (study III) was measured in millimetres as the orthogonal distance from T1 to a perpendicular line drawn upwards from the spinal process of S1 in direction of T1, according to the Scoliosis Research Society classification (figure 3).

- **Mediolateral translation of the thoracolumbar/lumbar curve** (study III) was measured in millimetres as the orthogonal distance from the spinal process of the apex vertebra to a perpendicular line drawn upwards from the spinal process of S1, according to the Scoliosis Research Society classification (figure 3).

Figure 3. Measurements on radiographs of the mediolateral translation of the first thoracic vertebra and of the thoracolumbar/lumbar curve.
- **Pelvic obliquity** (study III) was measured according to Osebold et al. (1982) as an angle between a line connecting the most proximal points on the iliac crests and a line, intersecting this line, drawn parallel to the lower end of the roentgenogram (figure 4).

![Figure 4](image)

Figure 4. Measurements on radiographs of pelvic obliquity.

- Sitting ability was defined as **sitting balance** on a 7-point scale, and was rated from no ability (1 point) to full ability to sit with ability to attain the position (7 points), with the patient sitting on a box with the feet supported (Mulcahy et al., 1988). Position of the hands and arms, as well as if support was provided by relatives (at level 1), were noted in the protocol.

- **Seating supports** in the wheelchair was rated as from 0 to 7 supports. The number of supports needed to maintain the patient in sitting a position and all other supports were counted and noted in the protocol (Samuelsson et al., 1996).
- **Weight distribution** on the seating surface. A computerised EMED system (figure 5), which produces an image of the pressure patterns and force distribution was used. The system calculates maximum pressure (N/cm$^2$), centre of gravity, total force (N), and area (cm$^2$), and the balance between the right and left sides for pressure, force and area (Novel, Munich, Germany) (Samuelsson et al., 1996). Weight distribution was measured in a sitting position with the feet supported, the knees at a 90° angle, and a 90° angle between the tights and trunk. All positions including how the hands were held, and how the patient needed to be supported were noted in the protocol. In the following measurements, we tried to have the same position as previous by noted in the protocol.

![Figure 5. The measurements of weight distribution on seating surface, the EMED system have been used. This is a commercially available system used mainly in analysis of footprints.](image)

- **Pain estimation** (1-15 points). The patients were asked about the intensity of their pain, the frequency of pain, and the use of medicine. There were three questions with five possible ratings for each, and the points from the three questions were summarised (Samuelsson et al., 1996).

- **Reaching** (0-60 points), which means functional motions of the upper extremity with the patient in a sitting position with the feet supported. The reaching measurements were obtained in 5 different areas of the body with 4 levels for each: reaching the mouth, top of the head, the processus spinousus C7, the columna at level of angulus inferior of scapula, and the toes. The reaching levels were recorded weather the patient could reach with one
hand or with both, because the patient might have needed to support himself/herself with one hand due to the scoliosis.

To exemplify the 4 levels in different areas: "reach toes": 3 points if both hands can reach between the resting position and the middle of the tibia, 6 points if both hands can also reach the front aspect of the middle of the tibia, 9 points if both hands can also reach the lateral malleol, 12 points if both hands can reach the toes (Samuelsson et al., 1996).

- **Barthel ADL Index** (0-100 points; zero is no ability). Ability to perform skills in activities of daily living was assessed (Mahoney and Barthel, 1965). Patients receiving 30 points or less were considered to be in need of a great deal of help and are supposed to be dependent in most activities (Samuelsson et al., 1996). The ADL Barthel assessment was performed as interview.

- **Klein-Bell ADL Scale** (0-303 points; zero is no ability). Ability to perform skills in activities of daily living was assessed (Klein and Bell, 1982). Was used in those patients with Barthel ADL Index >30 points (Samuelsson et al., 1996). The Klein-Bell assessment was performed as interview.

- **Care given** in physical effort (0-30 points) for hygiene, dressing, transfer, eating, bathing/shower, and going to the toilet. Physical effort was assessed as being from one point (very easy) to five points (very heavy).

For each activity, the care given was also assessed in terms of estimated time consumption (minutes/day). Both physical effort and time consumption were documented by relatives (Samuelsson et al., 1996).

- **Time used** for resting and sleeping (hours/week) was assessed. The patients or relatives filled in a form for a period of one week (Samuelsson et al., 1996).

- **Follow-up questionnaire** comprised subjective assessments, where the patients and relatives, or only the relatives if the patient could not take part, evaluated the results of surgery. The assessment included questions about how surgery affected 12 different areas: seating posture, reaching, pain, respiration, gastrointestinal function, daily activities, ambulating, school, work, care given, need for rest, and cosmetic appearance. The response alternatives were: very positive, positive, unchanged, negative, very negative (Samuelsson et al., 1996).

- **Two open-ended questions** were mailed to the patients or parents six months before the subjective and objective assessments were performed. The questions were:

  "What do you think has become improved since the surgery?"

  "What do you think has become worse since the surgery?"

Those two questions were classified and reported according to different dimensions.
Reliability

- **Sitting balance:**
The inter-rater reliability was performed in testing sitting balance. Nine patients were observed by two occupational therapists at the Orthopaedic clinic, Linköping, and the results were noted separately. The Spearman rank correlation coefficient was $r_s=0.95$ ($p=0.0071$). This analysis is unpublished.

In an early version of classification of physical ability, including sitting ability, performed by Hallet et al. (1987), for children and adolescents with multiple handicaps complicated by scoliosis, the reliability and repeatability of measuring physical ability, including sitting balance, were performed and described as good (no figures were reported). However, the authors stated that the results were best when testing was done by the same therapist.

- **Weight distribution on the seating surface:**
The test-retest reliability of the computerised EMED system for measurement of weight distribution on the seating surface in N/cm$^2$ and in area (cm$^2$) was performed in 14 individuals with a mean age of 19.6 years (range 9-34) by the therapist at the Orthopaedic clinic, Linköping. Ten patients with spinal deformities and four normal subjects had measurements performed twice during the same day by the same therapist. The intra class correlation coefficient (ICC) for weight distribution (N/cm$^2$) was 0.99, with a mean difference of −0.2 (range from -4 to 6), and the ICC for area (cm$^2$) was 0.97, with a mean difference of −0.7 (range from −10 to 5).

- **Reaching:**
The test for inter-rater reliability was performed for testing reaching. Two therapists at the Orthopaedic clinic, Linköping observed ten patients during the reaching test to five areas of the body. The observation was performed by the two therapists of the same patients at the same time. The Spearman rank correlation test was used: $r_s=0.99$ ($p=0.0028$). This analysis is unpublished

- **Barthel ADL index**
According to Hsueh et al. (2001), the ADL Barthel index has high inter-rater reliability for individual items (kappa value range, 0.53-0.94) and total score (ICC=0.94).
- Klein-Bell ADL scale

For inter-rater reliability for all items for all patients, there was 92% agreement between raters according to Klein and Bell (1982).

**Statistical methods**

Descriptive analyses have been performed, mostly with nonparametric methods, as the variables are not on an interval or ratio scale level (studies I, II, and IV). In study III, however, both parametric and nonparametric methods were used with respect to scale levels.

Comparison between groups due to nonparametric data, Mann Whitney-U test was used (studies I, II, IV), to detect differences between two groups. The Kruskal Wallis test was used to test for differences between several groups (study I) in order to avoid Type I errors (Altman, 1997). In study III unpaired the \( t \)-test was used for comparison of means.

Change over time with comparison within groups, in the three follow-up studies (studies II, III, IV), Wilcoxon’s rank sum test was used to detect any differences between the pre- and postoperative results in non-parametric data. For parametric data paired \( t \)-test was used (study III).

Proportion of the frequency of assessed results was used for the answers in the follow-up questionnaire (studies II and IV).

The answers to the open-ended questions (study IV) were classified as dimensions, positive as well as negative. To visualise and exemplify the results, quotations from the responses was used.

The 12 dropouts in study IV were kept in the trial using an intention to treat analysis and were performed as the last observation were carried forward (LOCF) from the one-year follow-up results (Gillings and Koch, 1991).

To study relationships a variety of correlation analyses, both parametric as well as nonparametric, have been performed. Spearman’s rank correlation test for nonparametric data was used to test for correlation between the Barthel ADL index and other variables (study I). In study IV, Spearman’s rank correlation test was also used to evaluate if ADL results was related to age. In study III, which aimed to evaluate what factors could explain weight distribution on a seating surface, a multiple stepwise regression analysis
was used to test all possible combinations to determine the highest $R^2$ value and which predictors that were added into the regression equation (Polit and Hungler, 1991). A test-retest reliability analysis was used in study III, with the intra class correlation (ICC) analysis (Steiner and Norman, 1995).

**Surgical methods**
All patients had posterior segmental spinal instrumentation with sublaminar wires, hooks and screws applied from the upper thoracic vertebra (T2). The instrumentation and fusion extended to the pelvis for those individuals who were wheelchair users and had pelvic obliquity. In patients with myelomeningocele or those with severe spasticity, an anterior instrumentation with Zielke apparatus was combined with the posterior segmental instrumentation.

The patients were directly mobilised without brace treatment and hospitalisation was between ten and 14 days.

**Radiographic procedure**
Routine radiographs of the whole spine in the anterior-posterior plane were performed in the sitting position on a chair with the feet supported. Radiographs from the skull to the coccyx were taken and measured preoperatively, one year postoperatively and at the long-term follow-up. All measurements on the radiographs were performed by an independent orthopaedic surgeon.

**Ethical considerations**
Before surgery for paralytic scoliosis, patients, either with or without relatives were asked to participate in the evaluation of surgery. The purpose of the study was explained, and it was stressed that participation was voluntary. In the one-year and the long-term follow-ups the patients and/or relatives were asked to continue participating in the evaluation of the effect of surgery.

The author has been involved only in the routine clinical work i.e. postoperative information to the patients, the relatives and the Regional Pediatric Rehabilitation Centres, and there was therefore no dependency relationship between the author and the included patients that could have influenced either whether or not the patients chose to participate, or their subjective assessments of the effect of the surgery.

Studies I, II and IV were approved by the Research Ethics Committee of the Faculty of Health Sciences, Linköping University.
RESULTS

Study I:
”Preoperative evaluation of activity and function in patients with paralytic scoliosis”

Most patients with paralytic scoliosis are wheelchair users, and in this preoperative study of 100 patients with paralytic scoliosis, 85% used wheelchairs. Thirty-six individuals used a brace to obtain an upright sitting position in the wheelchair because of their collapsing spine, and some of them used a brace in an attempt to prevent progression of the scoliosis. The brace was used despite large curves (the median Cobb angle was 83° with a minimum value of 53° and a maximum of 158°). Persistent discoloration of the back on the convex side of the ribs as well as persistent discoloration of the tuber ischi were found (n=41).

The 100 patients with paralytic scoliosis constituted a heterogeneous group with 18 different diagnoses.

The patients’ diagnoses were classified according to the Scoliosis Research Society into upper motor neuron lesions (n=45), lower motor neuron lesions (n=39), myopathies (n=10), and congenital abnormalities (n=6). There were significant differences among the groups in mental function (p<0.001), sitting balance (p<0.05), and angle of scoliosis (p<0.05) as well as in Barthel ADL (p<0.0001), and in understanding/not understanding of verbal instructions (p<0.0001). There were also differences among the groups in use of a wheelchair (p<0.001), care given in physical effort (p<0.05) and time consumption (p<0.05), time used for resting (p<0.0001), and seating supports in the wheelchair (p<0.01). Cerebral palsy and myelomeningocele were the most common diagnosis in this study. The patients with cerebral palsy (n=26) were classified as having upper motor neuron lesions consisting of spastic quadriplegia and diplegia, as well as those with athetoid and ataxic symptoms. Patients with cerebral palsy differ from one another in terms of their ability to understand verbal instructions. Patients with myelomeningocele (n=23) were classified as having lower motor neuron lesions, and all of them could understand verbal instructions.

Since the patients were given verbal instructions in the evaluation situation regarding reaching toward defined body parts, ADL, and pain assessments, only 67 patients could be evaluated. In the evaluation of the whole group (n=100), there were consequently many missing values (table 4).
Table 4. Preoperative data on 100 patients with paralytic scoliosis.

<table>
<thead>
<tr>
<th>Variables</th>
<th>No. evaluated</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental level normal or deficient</td>
<td>100</td>
<td>46 are deficient</td>
</tr>
<tr>
<td>Persistent discoloration of skin</td>
<td>100</td>
<td>41 have skin discoloration</td>
</tr>
<tr>
<td>Understand verbal instructions</td>
<td>100</td>
<td>67 understand</td>
</tr>
<tr>
<td>Use of a wheelchair</td>
<td>100</td>
<td>85 use a wheelchair</td>
</tr>
<tr>
<td>Use of brace</td>
<td>100</td>
<td>36 use brace</td>
</tr>
<tr>
<td>Median (range: q3-q1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting balance (1-7p.)</td>
<td>100</td>
<td>4 (6-2)</td>
</tr>
<tr>
<td>Weight distribution when sitting on one seating surface (%)</td>
<td>69</td>
<td>94 (100-75)</td>
</tr>
<tr>
<td>Angle of scoliosis (Cobb)</td>
<td>94</td>
<td>84 (100-60)</td>
</tr>
<tr>
<td>Lung function (VC)</td>
<td>61</td>
<td>2.0 (2.4-0.8)</td>
</tr>
<tr>
<td>Reaching (0-60p.)</td>
<td>67</td>
<td>54 (60-42)</td>
</tr>
<tr>
<td>Pain estimation (1-15p.)</td>
<td>62</td>
<td>1 (7-1)</td>
</tr>
<tr>
<td>Barthel ADL index (0-100p.)</td>
<td>100</td>
<td>25 (70-5)</td>
</tr>
<tr>
<td>Klein-Bell ADL scale(0-303p.)</td>
<td>41</td>
<td>240 (276-209)</td>
</tr>
<tr>
<td>Care given (physical effort 0-30p.)</td>
<td>85</td>
<td>16 (19-7)</td>
</tr>
<tr>
<td>Care given (time consumption in min)</td>
<td>85</td>
<td>170 (336-60)</td>
</tr>
<tr>
<td>Time used for resting (h/week)</td>
<td>100</td>
<td>1 (7-0)</td>
</tr>
<tr>
<td>Seating supports in wheelchair (0-7 supports)</td>
<td>100</td>
<td>2 (5-0)</td>
</tr>
</tbody>
</table>

The patients were further classified into the following subgroups: one group who understood verbal instructions (n=67) and who took active part in daily activities, and those who did not understand verbal instructions (n=33). The two groups differed significantly in the Barthel ADL index (p<0.001), care given in physical effort (p<0.001), and in time consumption for care given (p<0.001), time used for resting (p<0.001), and in seating supports in the wheelchair (p<0.01). All instruments, including ADL, reaching and pain estimation, could be used in the group who understood verbal instructions, while for the group who did not understand verbal instructions it was necessary to use reduced version of the set of instruments.

Study II:
"Activities and functional assessment 1 year after spinal fusion for paralytic scoliosis"

Ninety-four patients remained one year after surgical correction for paralytic scoliosis. All patients who were ambulatory before surgery, continued to be ambulatory. There were fewer patients with persistent skin discolouration (p<0.001), and less need to use of a brace (p<0.001).
The patients in this one-year follow-up study were classified in accord to the previous study as to whether or not they could understand verbal instructions. In this postoperative study, the group who understood verbal instructions (n=64) showed improvements in comparison to preoperative results in weight distribution to one seating surface (p<0.001), Cobb angle (p<0.0001), less time used for resting (p<0.05), and fewer seating supports in the wheelchair (p<0.01). Reaching, pain, ADL, and care given in physical effort and time consumption were unchanged. In the other group who did not understand verbal instructions (n=30) there were improvements in sitting balance (p<0.01), weight distribution to one seating surface (p<0.05), Cobb angle (p<0.0001), time used for resting (p<0.05), and number of seating supports in wheelchair (p<0.01). There were no worsened values.

In the group with upper motor neuron lesions and those who understood verbal instructions (n=15), there were improvements in weight distribution to one seating surface (p<0.05), Cobb angle (p<0.001), and reaching (p<0.05). Those who did not understand verbal instructions (n=26) showed improvements in sitting balance (p<0.01), Cobb angle (p<0.0001), time used for resting (p<0.01), and seating supports in wheelchair (p<0.01).

The group with lower motor neuron lesions (n=37) improved in weight distribution (p<0.05), Cobb angle (p<0.0001), and number of seating supports in the wheelchair (p<0.01).

In the analysis of the myopathies (n=10) including Duchenne muscular dystrophy (n=4), ability to reach the mouth was decreased because of the straight fused spine, along with weak upper extremities. The group with congenital abnormalities (n=6) showed improvement in ADL and in the ability to perform bathing/hygiene activities (p<0.05).

In a follow-up questionnaire patients or relatives assessed how surgery had affected 12 different areas. Positive ratings were given regarding respiration, sitting posture, school, work, and cosmetic appearance. Negative ratings were given in relation to reaching, ambulation, and care given (figure 7). The results for the subgroups reflected the results for the whole group.

The patients’ or relatives’ motives for surgery were assessed. The answers showed that patients or relatives wanted improved respiration, less pain, and better sitting posture after surgical correction. In general, the ratings in the other areas on the questionnaire were higher if the area corresponded to the motive for surgery indicated preoperatively.
Figure 7. Assessed results from the follow-up questionnaire by patients or relatives at one-year follow-up.

Study III:
"Weight distribution in the sitting position in patients with paralytic scoliosis: pre- and postoperative evaluation”

The preoperative results (n=45) in the stepwise regression analysis showed that the variables pelvic obliquity and thoracolumbar/lumbar spinal imbalance explained weight distribution on the seating surface (the adjusted R² was 0.45). For pelvic obliquity and thoracolumbar/lumbar medial translation the Beta value were 0.42 and 0.41, respectively. In the analysis of patients with unilateral hip dislocation (n=9) we found an inverse correlation to the side of the hip dislocation for the following variables: side of weight distribution, side of thoracolumbar/lumbar medial translation, and side of pelvic obliquity.

In the reference group of 16 girls and 11 boys (without spinal deformities), the mean percentage of weight distribution to one side of the seating surface was 59%, with a minimum value of 50% and a maximum value of 86%.

When the patients were grouped postoperatively according to even weight distribution (50-59%) (n=12), and uneven weight distribution (60-100%) (n=31), there were no significant differences in any of the variables. However, in the group with even weight
distribution, mean pelvic obliquity was 6°, and in the other group mean pelvic obliquity was 12° (p=0.0619). Of those patients who had more than 60% of their weight distributed on one side, one patient had persistent skin discoloration below the pelvic obliquity.

In the comparison between the preoperative and one-year follow-up results there were significant improvements in the angle of scoliosis (p<0.0001), in mediolateral translation of the thoracic curve (p<0.0001), in mediolateral translation of the thoracolumbar/lumbar curve (p<0.001), in pelvic obliquity (p<0.0001), in weight distribution (p<0.001), in area distribution (p<0.01), and in number of seating supports in the wheelchair (p<0.01). The mediolateral translation of the first thoracic vertebra and sitting balance were unchanged one-year postoperatively.

**Study IV:**

**Long-term follow-up of functioning after spinal surgery in patients with paralytic scoliosis**

This long-term follow-up study, with a mean of 84.5 months, included 82 of the 100 patients who were preoperatively evaluated between 1992 and 1996. Seventy-two of the 82 patients used a wheelchair, none of the patients had persistent skin discoloration, and none used a brace at the time of follow-up.

The analyses included pre- and long-term follow-up results of the whole group (n=82) and showed an improved sitting balance (p<0.001), more even weight distribution to the seating surface (p<0.01), a straighter spine according to Cobb (p<0.0001), better lung function in terms of vital capacity (p<0.001), better ability in ADL (p<0.01), less time used for resting during the day (p<0.01), and fewer seating supports in the wheelchair (p<0.0001). In the analyses comparing measurements at the one-year follow-up and the long-term follow-up, further improvements at long-term follow-up were seen in terms of better sitting balance (p<0.05), more independence in ADL (p<0.001), and less physical effort in care given in physical effort (p<0.01). However, the Cobb angle had increased (p<0.01) (table 5).
Table 5. The patients who fulfilled the follow-ups (n=82). Comparison of the preoperative and the long-term follow-up results, and one-year postoperative results with the long-term follow-up results

<table>
<thead>
<tr>
<th>Variables</th>
<th>Preoperative</th>
<th>Postoperative one-year</th>
<th>Postoperative long-term</th>
<th>Preoperative Long-term</th>
<th>One-year Long-term</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>median</td>
<td>median</td>
<td>median</td>
<td>P-value</td>
<td>P-value</td>
</tr>
<tr>
<td></td>
<td>(range: q3-q1)</td>
<td>(range: q3-q1)</td>
<td>(range: q3-q1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting balance (1-7p.)</td>
<td>4 (6-2)</td>
<td>5 (6-3)</td>
<td>5 (7-2)</td>
<td>0.0003***</td>
<td>0.0294*</td>
</tr>
<tr>
<td>Weight distribution on one seating surface (%)</td>
<td>91 (100-73)</td>
<td>70 (89-58)</td>
<td>74 (86-60)</td>
<td>0.0027**</td>
<td>0.9484</td>
</tr>
<tr>
<td>Angle of scoliosis (Cobb)</td>
<td>81 (100-57)</td>
<td>32 (56-17)</td>
<td>39 (60-22)</td>
<td>0.0001***</td>
<td>0.0073**</td>
</tr>
<tr>
<td>Lung function (VC)</td>
<td>2.0 (2.4-0.8)</td>
<td>---------------</td>
<td>2.4 (3.4-1.2)</td>
<td>0.001***</td>
<td></td>
</tr>
<tr>
<td>Reaching (0-60p.)</td>
<td>54 (60-42)</td>
<td>56 (59-42)</td>
<td>54 (60-35)</td>
<td>0.1151</td>
<td>0.3638</td>
</tr>
<tr>
<td>Pain estimation (1-15p.)</td>
<td>1 (7-1)</td>
<td>1 (2-1)</td>
<td>1 (6-1)</td>
<td>0.1221</td>
<td>0.6131</td>
</tr>
<tr>
<td>ADL Klein&amp;Bell (0-303p.)</td>
<td>240 (269-203)</td>
<td>232 (265-188)</td>
<td>262 (283-214)</td>
<td>0.0016**</td>
<td>0.0002***</td>
</tr>
<tr>
<td>Care given (physical effort 0-30p.)</td>
<td>16 (19-8)</td>
<td>16 (20-9)</td>
<td>14 (20-3)</td>
<td>0.1054</td>
<td>0.0055**</td>
</tr>
<tr>
<td>Care given (time consumption in min)</td>
<td>170 (339-61)</td>
<td>190 (313-55)</td>
<td>140 (325-14)</td>
<td>0.0735</td>
<td>0.382</td>
</tr>
<tr>
<td>Time used for resting (h/week)</td>
<td>1 (7-0)</td>
<td>0 (5-0)</td>
<td>0 (4-0)</td>
<td>0.0042**</td>
<td>0.891</td>
</tr>
<tr>
<td>Seating supports in wheelchair</td>
<td>2 (4-1)</td>
<td>1 (3-0)</td>
<td>2 (3-0)</td>
<td>0.0001***</td>
<td>0.7974</td>
</tr>
</tbody>
</table>

The patients had been classified into subgroups in the preoperative and one-year follow-up studies regarding whether they understood (n=55) or did not understand verbal instructions (n=27), and most of the results were in line with those for the whole group. However, individuals who understood verbal instructions had less physical effort (p<0.05) and time consumption in care given (p<0.05) in the comparison of preoperative results and long-term follow-up results. Comparison of the one-year follow-up and long-term follow-up the results for those individuals who could understand verbal instructions was in accord with results for the whole group.

For those individuals who did not understand verbal instructions, all variables were unchanged between the one-year follow-up and the long-term follow-up.

We had classified the patient material into those with progressive disease (n=14) and those without progressive disease (n=68). In the analysis of those with progressive disease (n=14) there was a decreased Cobb angle (p<0.001), and for those in this group who understand verbal instructions (n=13) there was also less care given in time consumption (p<0.05) between the preoperative and the long-term follow-up results. Between the one-year follow-up and the long-term follow-up the results were unchanged.
for the 14 individuals, except for the Cobb angle (p<0.01), less care given and time consumption (p<0.05) for those who understood verbal instructions (n=13).

In the group with non-progressive disease (n=68) there were improvements in sitting balance (p<0.0001), weight distribution on the seating surface (p<0.05), Cobb angle (p<0.0001), lung function (p<0.0001), ADL (p<0.01), time used for resting (p<0.05), and seating supports in the wheelchair (p<0.0001) in the comparison between the preoperative and long-term follow-up results. In the comparison between the one-year and long-term follow-up there were further improvements in sitting balance (p<0.01), ADL (p<0.001), and care given in physical effort (p<0.05) for the 68 patients with non-progressive disease, but with a worsened Cobb angle (p<0.01).

For those who understood verbal instructions (n=42) in the non-progressive disease group there were improvements in sitting balance (p<0.01), Cobb angle (p<0.0001), ADL (p<0.01), and seating supports in the wheelchair (p<0.01) in the comparison of preoperative and long-term follow-up results. Between the one-year and the long-term follow-up there were further improvements in sitting balance (p<0.01), ADL (p<0.001), and in care given in physical effort (p<0.01), but an increased Cobb angle (p<0.01).

In the age-related groups, with 51 individuals aged 13-21 years and 31 individuals aged 22-51 years, the results showed improvements in ADL (p<0.01), but a worsened Cobb angle (p<0.05) in the 13-21 years age group. In the other group (22-51 years) there were improvements in care given in physical effort (p<0.01), and in pain (p<0.05).

An inverse correlation was found between one-year follow-up and the long-term follow-up in Klein-Bell ADL Scale due to age ($r_s = -0.36$, p<0.05), which means the higher change in ADL score, the younger patient.

In the analysis of “intention to treat” including the 12 drops out, the results did not change from the first analysis.

Results of the follow-up questionnaire showed no significant differences between the one-year follow-up and the long-term-follow-up in any variables, but most ratings were rated in a positive direction.

The two open-ended questions, mostly positive ratings, although, some of the assessments were negative. The dimensions were as follow: sitting position with examples as “better sitting balance” or “difficult sitting on the floor now”, lung function: “better and easier breathing”, mobility: “she can pick up things from the floor” or “can’t turn over in bed any longer”, posture: “stable and safe” or “it’s more difficult to bend her body when putting her into the car”, daily activities: “can manage ADL better now”, and
other which represented related health; “better general health” and quality of life; “her quality of life is undoubtedly much better after the scoliosis surgery”.

**GENERAL DISCUSSION**

In this discussion focus will be placed on the results concerning the patients function and ability to perform in activities and belong in social life after surgical correction of paralytic scoliosis.

**Methodological considerations**

Methodological considerations will be addressed concerning the patients in the study, and the subjective and objective assessments that have been performed in the four studies using the different instruments.

- **Design:**
  One hundred consecutive patients were preoperatively evaluated and surgically corrected between 1992 and 1996. The patients were followed for more than five years. A randomised clinical trial would have constituted a stronger design, but for ethical reasons this was not possible. Therefore, a consecutive prospective series was chosen.

- **Patients with paralytic scoliosis:**
  Patients with neuromuscular disorders and paralytic scoliosis comprise a heterogeneous group of individuals with different body structures and functions including mental deficiency, but with scoliosis as a common impairment.
  This study of 100 preoperatively evaluated patients with paralytic scoliosis included 18 different diagnoses preoperatively (study I) and 16 at the long-term follow-up (study IV). The patients presented a mixed clinical picture, not only of weakness and spasticity but also of mental deficiency, with difficulties in understanding information and instruction situations. A broad range of diagnoses constitutes a weakness. To attain homogeneity, we tried sub-grouping using the Scoliosis Research Society classification into upper and lower motor neuron lesions, myopathies, and congenital abnormalities (Winter, 1990). With this approach, heterogeneity was still present, even within the subgroups, especially in understanding verbal instructions (study I). Nevertheless, the 100 patients with numerous diagnoses can be considered as representative for paralytic scoliosis despite different ages, functional problems and difficulty in understanding verbal instructions,
progressive, or non-progressive disease. Thus, to attain homogeneity it is more useful to have subgroups, not necessarily based on medical diagnosis.

There was a wide age range from 4-52 years, with a mean of 15 years (study I), and at the long-term follow-up the range was 13-51 years with a mean of 22 years (study IV). According to Dubousset et al. (1989), the more immature patient at the time of surgery, the greater the postoperative progression. It is useful to evaluate patients with paralytic scoliosis according to age on one hand due to the growing child/youth, on the other hand due to the development of learning activities in daily life. Wilcock (1993) states that children learn practical skills and how activities are organized while growing.

Patients with progressive disease are homogeneous with respect to weak muscle function and risk of progression of the disease over long periods, and consideration should be given to evaluating these patients as a subgroup.

- **Dropouts:**
  In the one-year follow-up study (study II) six patients dropped out; two patients had died during the first year, two patients refused the follow-up measurements, and two patients did not participate due to long travel distance. Since the dropouts was equally distributed between understanding and not understanding verbal instructions, and in function and activities, one can assume that this did not affect the results.
  In the long-term follow-up study (study IV), there were an additional 12 patients who dropped out; five patients had died, four refused to participate, one did not participate due to long travel distance. Further, two patients had been surgically corrected a second time after two and three years, respectively, and were therefore excluded. Because of the 12 dropouts in the long-term follow-up study, an intention to treat analysis was performed to keep all patients in the trial to prove that the dropouts did not bias the analysis. This was done by replacing the missing values by the last observation by carried forward (LOCF) (Gillings and Koch, 1991). This analysis showed that the dropouts did not affect the results. The small number of dropouts is a strength of these studies.

- **Exclusion criteria:**
  In study III we evaluated what factors that explained weight distribution across the seating surface. We excluded those patients who had no ability to sit. This in relation to the radiographic measurements of pelvic obliquity and the measurements of weight distribution. This was to avoid bias as a result of relatives supporting the patient when sitting. Patients who were ambulatory and did not use a wheelchair were also excluded.
Evaluating weight distribution and pelvic obliquity in those without risk for long-term periods of pressure would not be important.

In study IV, two patients were excluded because of the crankshaft phenomenon, and they were surgically corrected a second time after two and three years, respectively. Because of the short time period since their last surgery, they could not be included in a long-term follow-up study.

- **Reference material:**

  The youth from the three elementary schools (n=27) were examined by an orthopaedic surgeon to exclude anyone with spinal deformity. The result of the measurements of weight distribution on seating surface showed that a mean of 59% of weight was supported on one side, and there was a tendency to put more weight on the left side. These results were in line with Smith and Emans (1992). One of the girls had 86% of her weight distributed on one side, and for that reason we repeated the measures two times with the same results. It may be that this girl always placed her weight to one side as a matter of a habit (study III).

- **Instruments**

  In the encounter with the patient with paralytic scoliosis before surgical correction of the spine, information was given about routines involved with this surgery, and activities and function were evaluated pre- and postoperatively.

  The strength of this procedure is that all measurements were performed by the same therapist (E-L Larsson), after the orthopaedic surgeon had determined what kind of surgery to perform. On the other hand, a weakness is the lack of blinding, which cannot be done in a study like this. Another alternative could have been to use a therapist not involved in the study performing the measurements, but there is an advantage to use a therapist with knowledge of paralytic scoliosis.

  Lung function was measured preoperatively and at the long-term follow-up. In the measurement procedure only the individuals who were able to understand verbal instructions could take part. Not performing lung function tests in all individuals is a weakness. There should be an alternative measurement for individuals who do not understand verbal instructions as well as for those with decreased ability to perform the procedure due to weak muscle function or spasticity. Several authors have stated that the lung function test has proved to be useful in patients with paralytic scoliosis (Aprin 1982, Hsu 1983, Bradford 1987, Shook and Lubicky 1991, Galasko, 1995, Robinson et al. 1995).
The measurements on the radiographs are well-established methods described of the Scoliosis Research Society (SRS) and have been used at the Orthopaedic clinic, University hospital in Linköping routinely.

Sitting balance The scale for sitting ability from Mulcahy et al. (1988) was difficult to apply in a few patients because of their spasticity, and in some patients with mental retardation. The measurement procedure therefore had to be interrupted, and repeated later. If there was uncertainty about the values, the procedure was repeated two or three times, and if different values were obtained, the lowest value was noted. The values from patients with spasticity and from those with mental retardation were few and could therefore not have affected the results. Hallet and Hare (1987) stated that the results were more reliable if the same therapist carried out all measurements. In further studies it might be better to combine this method with photos and vertical lines as references to make the measurements even more reliable.

Seating supports in the wheelchair were needed preoperatively (study I) for support of the collapsing spine. An additional method could have been to rank the supports, but a trunk support for one patient can have the same effect as a table for another patient depending on different diseases. Ranking the supports is also too complex in clinical situations and is not useful for follow-ups on a group level. It is important to evaluate seating supports, however, the most important issue to discuss is that an seating adaptation should function as a support to the collapsing spine and not, as mentioned by Trefler and Taylor (1991), as an obstacle when the individual is carrying out activities.

Weight distribution on the seating surface. If the patients were unable to sit for even a short while, positions and personal support were noted in the protocol. Based on the analyses performed, those who were unable to sit and those who were ambulatory did not affect the results. This was demonstrated in the comparison between the preoperative results from study III (m=86% and median=93%), where wheelchair users and ambulatory patients were excluded, and study I (m=86% and median=94%), where those patients were remained in the trial with no significant differences as a result.

In retrospect, using photographs and vertical lines as reference to secure the measurements could have made the test more reliable. However, the test-retest reliability for 14 individuals showed a high correlation (ICC value of 0.99).

Pain estimation was limited to those patients who could understand verbal instructions. The assessments of pain showed quite low values preoperatively, although with great variation. Consequently, with this low initial pain level, the postoperative results could only demonstrate worsening values. In this study we asked about the dimensions of intensity, frequency, and use of medication. Rating scales with few steps might not be as
useful as graphic rating or VAS. On the other hand it is sometimes better to use words in rating scales especially for individuals who are not used to graphic assessments. An improvement of the measurements might be to use pain estimation in relation to performing different activities and duration of pain periods. Reaching could only be evaluated in those who could understand verbal instructions. Reaching with only one hand because the other is needed for support, or using both hands for support can be one reason for needing help in ADL situations. Wheelchair users usually need to carry out ADL while seated (Zimmerman, 1969). The patients were asked to reach with both hands, but if they could not do that they were asked to reach first with the right hand and then with the left hand. The four-level reaching test is done in the five areas, but more levels are needed in the above-mentioned areas to minimise the relative distance and make the scale more sensitive. Reaching is evaluated on the level of function, but it is useful to do the reaching test both on a level of function as well as on a level of activity by asking the patient to perform a specific activity in relation to reaching as a goal setting formulation.

Barthel ADL index as well as Klein-Bell ADL scale assessments were performed by interviews. The interview or report by patients, parents, or proxies is defined according to Young and Wright (1995) as indirect measurement in contrast to direct measures. According to the authors, direct methods are considered to be more valid because of the biases of the reporter are eliminated, but these methods may be sensitive to environmental differences. Rogers et al. (1996) stated that the social context affects performance of activities, which is in accord with Mahoney and Barthel, (1965) who maintained that in clinical situations it is difficult to attain the environmental circumstances present in the home. An interview has enhanced feasibility and a great consistency in terms of administration, and of the two above-mentioned ADL indexes are quite easy to administer.

The authors of the Klein-Bell ADL scale (Klein and Bell, 1982) pointed out that the index is sensitive to small changes in functioning at several levels within the same ADL area (dressing, eating, etc). The Klein-Bell ADL scale has been used in many clinical studies (Bolding and Llorens 1991, Shillam et al. 1983, Chen-Sea 1993 and 2001, Titus et al. 1999, Nelson et al. 2002, Wressle et al. 2002) most of them involving stroke patients. In the preoperative study about 40% of the patients could be evaluated with the Klein-Bell ADL scale, but since some of them had quite high level of ability to perform ADL, we could only measure worsened values for those patients. Therefore, it could be useful to use the Klein-Bell ADL scale in combination with a goal setting formulation where patients preoperatively identify one or more problems on a
scale in relation to activities they consider most important, using for example the Goal Attainments Scale (GAS) (Streiner and Norman, 1995) or the Canadian Occupational Performance Measure (COPM) (Law et al. 1998). Chan and Lee (1997) stated that it is logical to use an ADL index before using a goal setting formulation in order to give patients the opportunity to be aware of the problems in daily activities. Using a goal setting formulation such as the GAS or the COPM gives patients a greater opportunity to set their own priorities, in contrast to instruments developed by professionals.

Care given, with the two dimensions of physical effort and time consumption, was assessed at home and a formulary was filled by the relatives. The relatives had no problems completing the physical effort part and could easily assess the strain in relation to a specific situation. Assessing time consumption was found to be more difficult by some relatives, with explanations such as, "I care for him all day" or "it is difficult to assess the time - I just do it..." so the dimension of time consumption may therefore be underestimated due to some missing values. However, at the long-term follow-up the care given in physical effort as well as in time consumption had decreased (study IV). Since it can be difficult to assess time in hours, the experienced time used for care may be stable. The importance of discussing the care given is obvious, as it is not always experienced as negative and as a strain by caregivers. Therefore, caregivers should also be asked how the time consumption affects their own daily activities. The quality of care is one of the factors that affect work satisfaction and that can affect the care process.

Crowe et al. (1997) reported in a study on the role of mothers with disabled children that the role of caregiver differs depending on age, level of dependence, and need for care. They pointed out that the complexity of competing demands in care giving versus the satisfaction from those tasks combined with support from others were very important when the role became time consuming.

The patients or relatives filled in a form concerning time needed for rest during the day due to scoliosis. The need for rest was explained in terms of the risk for pressure sores and the need to unload in the prone position, back pain, or other explanations that seemed to be more closely related to more general tiredness because of the collapsing spine, etc. The amount of time varied, and some individuals needed to rest only one hour per day, while others needed long periods of rest. For those who did not understand verbal instructions we had only the relatives’ interpretation of how much the patient needed to rest. However, relatives are usually familiar with such needs, and could clearly explain why the patient needed to rest and when in relation to activities, and the duration of time. Irrespective of the reason for the need this is a good measure to follow and it was also sensitive to change.
The two open-ended questions and the follow-up questionnaire are self-administered, subjective assessments of the results of surgery. Young and Wright (1995) maintained that the difficulties with self-report measures include uncertain understanding of the questions and response bias. The two open-ended questions that were sent by mail to patients or parents (study IV) were returned in stamped envelopes to the Orthopaedic clinic, but the time for follow-up took place about 6 months later. In spite of that, the open-ended answers reflected the later follow-up questionnaire, which can be seen as a strength. The fact that the results from the follow-up questionnaire were similar to those in the one-year follow-up (study II) and long-term follow-up (study IV) could be influenced by a “ceiling effect” probably due to the directly positive changed situation for the whole family at the one-year follow-up. Other authors (Dias et al. 1996, Bridwell et al. 1999, Whitaker et al. 2000) have also reported positive results in follow-up questionnaires after spinal surgery for paralytic scoliosis. However, although the answers from the follow-up questionnaire were in accordance with the open-ended responses, the patients or relatives also reported other dimensions in the open-ended responses such as health and quality of life, even if they were influenced by the traditional questions in a questionnaire.

**Outcome considerations, pre- and postoperatively**

The measurements and postoperative evaluation were mostly performed at a level of function while the patients or relatives expressed and related the effect of surgery in relation to activities.

**Lung function**

One of the main reasons for spinal surgery in paralytic scoliosis is to improve or maintain lung function. Robinson et al. (1995) pointed out that respiratory failure, usually due to pulmonary infection, is a common problem in patients with paralytic scoliosis and especially in Spinal Muscular Atrophy (SMA). The authors state that there is an inverse linear relationship between the severity of scoliosis and vital capacity. In the long-term follow-up (study IV), lung function (vital capacity) was improved compared to preoperative results. This was also confirmed by patients and/or relatives in their responses to the open-ended questions, where they reported that it was easier to breathe, there were fewer episodes of pulmonary infections, and there was less tiredness during the day.
Spine and pelvis
As expected, individuals with paralytic scoliosis had great deformities due to scoliosis and pelvic obliquity (studies I and III). The Cobb angle had decreased significantly at the one-year follow-up, but at the long-term follow-up the spinal curve had increased (study IV). A long-term increase can be related to the fact that some patients were still growing at the time of surgery. Dubousset (1989) stated that the more immature the patient the greater the risk for postoperative regression, due to the crankshaft phenomenon. In the subgroup analysis, patients who did not understand verbal instructions and patients with progressive disease showed no regression at long-term follow-up. These groups have insufficient capability in their movements and in self-care activities, so the question is whether if it is age and immaturity that explain long-term increase. In their answers to the open-ended questions, some of the patients pointed out that their spine had become “twisted”, but that was nothing they suffered from because they felt safe with a straighter spine.

Dubousset (1997) stated that most spinal deformities could cause pelvic obliquity, and defined pelvic obliquity as regular when the pelvis and spine are going in the same direction. Most of the patients with paralytic scoliosis had regular pelvic obliquity, i.e., with a C-curved scoliosis (study III). Shook and Lubicky (1991) pointed out that the goal of spinal surgery is to have a spine that is as straight as possible over a pelvis that is as level as possible. Nevertheless, the patients improved postoperatively in pelvic obliquity, but still had an oblique pelvis with a range of 0-36° (mean 10°). A tilted pelvis not only influences the spine, but can also constitute a risk for pressure sores for individuals without sensibility in their lower extremities (Osebold et al. 1982). The effect of a fused spine diminishes the possibility of compensating the sitting position by active trunk movements. Taking these factors into considerations there might be a need to adjust the sitting posture into an aligned position and to use a cushion to compensate for the uneven weight distribution in order to avoid pressure sores if the surgeon cannot get the pelvis level.

Sitting posture
To understand what constitutes an abnormal sitting position, it was of importance to have a concept of reference values. In study III, normal subjects without spinal deformity were included to get reference values for weight distribution on the seating surface. These results of static measurements showed that 59% of the weight was supported by the side of the seating surface carrying the larger load. This result was in line with Smith and Emans (1992). The results of weight distribution on the seating surface preoperatively
(studies I and III) demonstrated an uneven distribution as compared to the reference group. Due to an unbalanced trunk and pelvic obliquity, there was a shift in the centre of gravity that led to an uneven distribution of pressures when sitting, and the results of the stepwise regression showed a rather low explanatory factor of $R^2 = 0.45$. There are obviously factors other than pelvic obliquity and thoracolumbar and lumbar imbalance that explain weight distribution on a seating surface (study III). According to Drummond (1985) and Smith and Emans (1992), uneven weight distribution can constitute a risk for pressure sores, especially in patients without sensation in the buttocks and sacral area. Tredwell and Roxborough (1991) report that normal seating is usually asymmetrical, meaning that most subjects tend to show a right or left dominance. Those authors also state that sitting is a static posture, although the act of sitting is not static, and with dynamic tests they found a constant side-to-side oscillation of weight occurring several times per minute.

The problems involved in attaining dynamic sitting for patients with paralytic scoliosis must be taken into consideration. Related factors are the supporting pads in the wheelchair and the common use of a reclined position. The seating supports in the wheelchair are needed because of the collapsing spine, but these supports can be regarded as an obstacle when performing activities while seated.

Difficulties being dynamic in a sitting position were pointed out by Myhr and von Wendt (1990) when children with cerebral palsy were placed in a backward tilted seat and their position against the backrest maintained by trunk support. They could not use their hands because their arms were held in a “high gard” position, their head was in hyperextension, and their feet were fixed to the foot support of the wheelchair. This probably diminished their possibility for motor learning. Nwaobi (1987) pointed out that when individuals are in an upright sitting position with their orientation of the body in space, it is possible to use the arms and hands for activities as well as to get horizontal eye contact with surroundings. A better position influences motor learning in a positive direction. Myhr (1994) defined a functional sitting position in which postural control is such “that the child can obtain the maximum degree of independent function when performing arm and hand movements for purposeful tasks” when discussing the sitting position of children with cerebral palsy.

Improved sitting posture was an overall motive for surgery according to the assessment of the patients or relatives. Those expectations were fulfilled as confirmed by patients’ and relatives’ assessments of postoperative results (studies II and IV). In their responses to the open-ended questions, the patients or relatives reported that the consequences of a better
sitting position were due to a body that no longer collapsed, and they also mentioned very specific improvements such as a better position when riding a horse.

The overall results, irrespective of disease, from the one-year follow-up questionnaire reflected sitting posture and cosmetic considerations as the most positive factors assessed by patients or relatives. This result was in line with other self-reported assessments by patients and caregivers (Aprin 1982, Dias 1996, Askin 1997).

O’Brian et al. (1975) reported an improved sitting position following spinal surgery for post-polio myelitic scoliosis due to not needing the hands for support during activities. These results are similar to the postoperative assessed results from the follow-up questionnaire and the open-ended responses showing (studies II and IV) that the possibility of letting go of the armrests on the wheelchair was experienced as positive. In one case this led to being able to drive a tractor on the family farm and to drive a car. The adaptations of cars and the tractor, respectively, were successful and made independence possible (reported by two patients with Spinal Muscular Atrophy and one patient with Duchenne Muscular Dystrophy).

Despite these positively assessed results, the group with progressive disease did not improve in objectively evaluated sitting balance. This could be due to the fact that some of the individuals with progressive disease had become worse during the long-term follow-up period. In any case, the sitting position of those patients did not become worse during this long period, which must be looked upon as a good result. Although no improvement was demonstrated in the objective evaluation, the assessment by the patients showed that the sitting position was better. It is obvious that an objective assessment differs from subjective assessments, and it seems that the patients and relatives reported improvements of situations from the daily life activities, instead of strictly describing sitting position.

For the patients with non-progressive disease, the objective evaluation of sitting balance showed improvements in the long-term follow-up, and in the comparison between the one-year follow-up and the long-term follow-up those patients continued to improve their sitting position, with the exception of those who did not understand verbal instructions. In the open-ended responses most of the patients and relatives reported sitting posture as positive with respect to better sitting balance, with less need for seating supports.

Sitting posture is of significance, because it was one of the most important motives for surgery reported by patients and relatives, and it was also shown to be an overall positively assessed result. The objectively evaluated results regarding sitting posture were also improved. This indicates the importance of continuing to evaluate sitting position in individuals with paralytic scoliosis both objectively and subjectively.
Pain

Pain is a subjective evaluation and pain estimation was limited to those who understood verbal instructions. We do not know the intensity or duration of pain from individuals who did not understand verbal instructions. One mother said that her daughter cried every evening before surgery, which she interpreted as meaning that her daughter had pain. This crying behaviour disappeared after surgery, and she felt that this was related to less pain. There were a few patients who estimated their pain preoperatively as very severe because sitting was painful due to pelvic obliquity. Those patients had learnt to handle this situation by lying down and unloading several times during the day to relieve the pain. This decreased their possibilities of involving in other activities.

Pain estimations were low throughout the study, indicating that pain is not a major problem for this group. Perhaps the unchanged results are dependent on the scale used, with less sensitivity due to categorical levels. If so, pain intensity and current pain could be estimated on a horizontal VAS, which has been used in many studies (Scott and Huskisson, 1976). Another way to handle questions of pain might be to do assessments in relation to activity and also to include frequencies and duration of the pain periods.

Using a questionnaire, Danielsson et al. (2001) asked individuals surgically corrected for idiopathic scoliosis about strain in mainly sedentary activities, and only 8% reported strain. On the other hand, 72% felt strain while doing light exercises 4 h/week, but when compared with normal subjects, no significances were found.

Reaching

Reaching was evaluated in those who could understand verbal instructions. The results were unchanged postoperatively, probably due to a ceiling effect and the lack of sensitivity of the ratings with low sensitivity for minor changes. The patients with full ability to reach preoperatively were those with myelomeningocele (MMC), paraplegia, and poliomyelites, and for them it was therefore not possible to measure any further improvement. Some of the patients who improved in reaching postoperatively (study IV) were those with cerebral palsy (diplegia and athetosis), and they had better ability to reach their feet. The patients who became worse were those with progressive disease, but three patients with MMC (studies II and IV), also became worse. The decreased reaching was due to a decreased ability to reach their mouth.

In the open-ended responses the patients and relatives had differing opinions. For example, some felt it was easier to pick things up from the floor, while others felt it was difficult to reach their mouth (study IV).
It seems reasonable to suggest that evaluation of reaching should be performed in patients with a deficit preoperatively and in those with progressive disease. The score would be more sensitive if additional steps in the scoring system were added.

**Activities of daily living (ADL)**
ADL (Klein-Bell ADL scale) assessments were performed by means of interviews because of the difficulties involved in constructing a standardised setting for the clinical procedure, and also because observations of ADL are too time consuming. Some of the patients who could not understand verbal instructions performed a few basic activities for self-maintenance – personal ADL.

The authors of the Klein-Bell ADL scale (1982) stated that in the clinical procedure there may be a person with good motor skills enabling the performance of personal care, but who lacks the cognitive or perceptual skills to manage his/her entire day’s activities, and this requires judgement on the part of the therapist. Yerxa et al. (1990) point out that activities of daily living are pursuits that are purposeful, self-initiated, and goal-directed. Without co-operation during the instruction procedure, ADL assessments would seem to be difficult. Therefore, in a clinical evaluation situation it can be more important to evaluate function and the level of dependence for those individuals who do not understand verbal instructions. At the one-year follow-up (study II), there were no changes in ADL in the patients surgically corrected for paralytic scoliosis. Similar results have previously been presented in other prospective short-term follow-up studies (Berned-Müller 1992, Askin 1997).

There was a slight improvement at the one-year follow-up in bathing and hygiene evaluated using the Klein-Bell ADL scale. Those results were in line with Shillam et al. (1983), who evaluated disabled persons after bathing training with the Klein-Bell ADL scale. The results showed improvements in their ability to bathe independently. Bathing and hygiene activities require good balance, indicating that one possible way of attaining improvements could be individualised training in bathing situations.

With a stabilized spine as achieved in individuals surgically corrected for paralytic scoliosis, sitting balance was improved and these persons could therefore manage hygiene situations more easily.

Dressing, elimination, and mobility improved according to the Klein-Bell ADL scale between the one-year follow-up and the long-term follow-up, and in the open-ended responses the patients reported being less dependent in their activities after surgery. This indicates that patients need more than one year to learn to handle their new body and new
techniques, such as using leverage because of their stiff spine. Another interpretation of
the long-term effect is to think about the effects of activity performance and learning of
how daily activities occur within a context. Wilcock (1993) pointed out that children learn
to practice skills to enable them to interact with others, to choose future roles, which
means developing in accordance with their environment and cultural values. The patients
in the long-term follow-up became more independent in their daily activities, which gave
them the possibility of expanding their range of activities. Age also seems to have an
influence on the results, as was demonstrated in study IV, probably due to the fact that
ADL skills was developed and changed over a long period for still growing children.
Eating is a basic self-care task, and eating is also the third most representative item after
dressing and ambulation (Törnquist, 1995). For those individuals with Duchenne
Muscular Dystrophy (DMD) eating is one of the few basic self-care activities they could
perform preoperatively. Postoperative (studies II and IV) patients with DMD could no
longer reach their mouth, as the spinal fusion had made the collapsing spine straighter and
longer with an erect position. These negative results can be balanced by environmental
factors, such as adaptations to help the individual become independent in eating
situations. For individuals with weak upper extremities eating needs to be measured either
as reaching from a perspective of function, or as subjectively expressed by the patient as
consequences regarding an activity level. The effect on eating, with a risk for a decreased
capacity, is very important and patients and relatives should be informed before the spinal
surgery.
Patients or relatives did not mention ADL preoperatively as a motive for surgery, perhaps
because the orthopaedic surgeon often discussed the effect of surgery on the level of body
function. On the other hand, patients and relatives did express thoughts in the open-ended
responses about activities, such as for example: "ADL situations are easier" and "it’s
easier for her to take a shower now" (study IV).
Early in our encounters with the patient and relative we need to make it clear that the effect
of surgical correction even is on the level of activity, due to the stabilised spine.

**Care given**

Care given in time consumption was affected preoperatively, because the care is quite
strictly scheduled according to times for eating, medication, etc. As a consequence, the
family need to organize their activities in relation to when he/she needs care. Care is
needed in different dimensions and in our evaluation of physical effort it was shown that
dressing, and urination and bowel situations, especially when a brace was needed were
assessed as strained. In ambulation situations, the efforts were assessed as strained
because it was necessary to hold and support or to lift him/her. Although, feeding seems to be an easy activity, the relatives assessed feeding as a strain because of the need to support the child’s upper extremity. Patients were sometimes placed in a reclined position to reduce the physical effort (study I), and this constitutes a risk for choking in a feeding situation, as reported by Guymer (1986).

Care given both in time consumption as well as physical effort were unchanged one year postoperatively (study II), but at the long-term follow-up (study IV) time consumption and physical effort were reduced for those who understood verbal instructions, and for individuals with non-progressive disease there was a reduction in physical effort. This is probably due to an effect from being more active in every day activities, with less need for care as a result. Klein and Bell (1982) stated that the lower the score on the Klein-Bell ADL scale, the greater the amount of assistance required ($r = -0.86$).

For those with progressive disease and those who did not understand verbal instructions care given was unchanged even at the long-term follow-up, and perhaps changes in care could not be expected for those individuals, as the need for care is governed by other aspects than the spinal deformity. Nevertheless, even though these patients needed a great deal of care, care given did not increase during this long period.

The open-ended responses showed that the change in need for care differed in different activities. This can be illustrated by comments about “stand and walk better” and “have the strength to keep herself upright” with less need for help as a result, that “feeding for her and caring for her is easier”, while more help was needed in mobility expressed as “more difficult to get up from floor” or “can’t turn over in bed any more” (study IV).

**Health and well-being**

In the long term follow-up (study IV), the patients or relatives reported quality of life and health related views that also included the whole family. Examples are “the whole family feels better after the scoliosis surgery”, “her quality of life is undoubtedly much better” and “less mobility because of an increase in weight”.

Introducing measurements of health and quality of life involves introducing a more generic perspective regarding the patient and/or the family’s situation. This allows for a broader perspective concerning evaluation of the consequences that go beyond the levels of the ICF (WHO, 2001), and also provides the opportunity for comparisons with other groups of patients. However, in future work ICF will broaden the concepts to also include quality of life concepts and measurements of subjective well-being. The EuroQol (1990) and the SF-36 (Sullivan, 1995) are examples of instruments that are commonly used in health assessments and an idea might be to use them both for patients and
relatives in evaluation of paralytic scoliosis. Another problem in measurement of health is that it is a general problem to relate changes to the effect of interventions in progressive diseases since a change might be explained by the disease itself, or health can be influenced by external factors such as changes in the family situations, work, etc.

**Time needed for resting**

In the subjective assessments of time needed for rest during the day most of the patients reported, preoperatively, that they discontinued activities because of tiredness in their collapsing spine and increased the length of time they rested (study I). Clark (1997) pointed out that "daily life has a rhythm; it has a tempo’ and that activities occur in a stream of time. As a speculation, tension in the tempo between the need to rest and the desire to participate in activities can result in risk factors, and according to Wilcock (1998), risk factors can result in bored, depressed, and sometimes destructive moods when there is imbalance in one’s activities.

Time needed for rest can probably be expected in the group who did not understand verbal instructions, according to the results from study I, as well as for those individuals for whom sitting was painful (SMA) and those without sensibility in their lower extremities who had a pressure sore (paraplegia and MMC). It was obvious that the time periods differed, and need for longer rest periods can be expected to influence the possibility of a flow in activities (study I).

All patients reduced their resting time postoperatively (studies II and IV), except for those with progressive disease. However, most of the patients with progressive disease did not need to rest during the day either preoperatively, or postoperatively. In the follow-up questionnaire about 50% of patients or relatives had assessed less time needed for rest during the day, and this was also expressed in the open-ended responses as a better capacity to sit for longer periods and a feeling that sitting was less tiresome (study IV). These results lead to a better possibility of involving in social activities, as there is no need to organise the day around rest periods.

**Results according to the International Classification of Functioning, Disability and Health (ICF)**

Patients with paralytic scoliosis, because of neuromuscular disorders, can be impaired as well as limited in activity and restricted in social activities due to the collapsing spine. Surgical correction of paralytic scoliosis have usually been described according to impairments, but the results of surgery had in this thesis been demonstrated and expressed as Body function and Body structure, Activities and Participation, as well as
Environmental factors according to ICF (WHO, 2001). These terms replace Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980). In 1993, WHO published a new preliminary version of ICIDH, that was helpful in study I and II in categorising the items in the instruments and for describing the effects of surgery according the three levels: Impairments, Disabilities and Handicaps. ICF have a broader spectrum of different applications than the earlier versions, but the variables categorised at the level of Impairments according to ICIDH (1993), can be categorised at Body structure and Body function according to ICF (2001). The variables categorised at the Disability and Handicap level according to ICIDH was further been categorised to Activities and Participation with partial overlap of the domains to only be involved in a life situation or/and belong in activities (ICF), while other variables, previously categorised at Handicap level could be categorised to Environmental factors according to ICF (WHO, 2001).

To summarise the results according to ICF (2001):
The individuals who could understand verbal instructions improved in Body structures and Body function (less deformity and sitting position), and in Participation according to belong and/or be involved in life situations (less time needed for rest), while Activity in self-care was unchanged. There was less need for Environmental factors such as assistive products (seating supports in a wheelchair) according to the one-year follow-up. In the long-term follow-up (study IV) those individuals who understood verbal instructions had improved at Body function and in Activity (self-care) as well as within the domain of Participation to be involved in a life situation or belong in activities (less time needed for rest). The improvements according to Environmental factors were: less need of seating supports and less need of caring, which probably, in combination with personal factors have had an impact on the individuals improved activity over a long period, as a result of age and coping styles in relation to learning activities in a context (study IV). In the follow-up questionnaire and open-ended responses the reports were positive and in direction to the domains of Activity and Participation (studies II and IV).

Between the one-year follow-up and the long-term follow-up, Body structure had worsened (increased Cobb angle) but nevertheless it did not affect any of the domains within Activity and Participation (study IV).

For those who did not understand verbal instructions there were improvements of Body structure due to less spinal curve with less need for seating supports in the wheelchair as a result (environmental factor: fewer assistive products). In this group there were improvements at the Body function including a better sitting balance. Self-care in the
Activity and Participation was not possible to evaluate, however reduced time needed for resting based on the sense of belonging in social activities at the one-year follow-up as well as at the long-term follow-up were shown. These results reflect the reports from relatives, which contained comments about less strain in providing care (Support and Relationships at the Environmental factors) (studies II and IV).

The individuals with progressive disease had improvements only at the Body structure according to the Cobb angle. Postoperatively, eating (Activity) had decreased because of a longer and straighter body and weak upper extremities, but those patients had found new activities related to community and social life such as “have taking my driving test and driver’s licence”, “I’m now studying on a folk high school” (Activity and Participation), as compared to what they had had preoperatively, as assessed in the follow-up questionnaire and the open-ended responses (study IV).
CONCLUSIONS

- The stabilised spine resulted in sufficient strength to keep the body upright with the possibility of looking around at the surroundings more easily. Better sitting position with less need for seating adaptations in the wheelchair and with reduced time needed for resting during the day. Those improvements maintained the ability to be dynamic in a sitting position and minimised the risk for pressure sores. The upright posture also led to easier breathing and fewer episodes of pneumonia. The stabilised spine also freed the arms and hands and enabled independence in daily activities, with less care needed as a result.

- A stiff and erect spine with long leverage can be experienced as a hindrance, resulting in less possibility for self-care activities for patients with progressive disease due to difficulty reaching the mouth because of weak upper extremities. Assistive adaptations can be applied to facilitate self-care situations.

- The time for learning and using a new technique was considerable, with handling of the “new body” using leverage because of the stiff spine. An early individual training programme could be helpful in shortening the time for attaining independence in activities.

- With pelvic obliquity that is still present postoperatively, additional attention should be focused on the seating surface and adjustment of sitting position due to the stiff spine.

- Due to the heterogeneity of patients with paralytic scoliosis it is important to focus on different subgroups so that their respective outcomes can be attained taking into account their total situation. Patients with progressive disease constitute one subgroup, and those with non-progressive disease who understand verbal instructions, constitute another subgroup. The third subgroup comprises patients who do not understand verbal instructions. Age should be related to subgroups.

- Based on the continued improvements that occur between one year and more than five years after surgery, we recommend that patients surgically corrected for paralytic scoliosis should be followed for more than one year.

- ICF can be used as a framework to define the different dimensions of measurements that should be used in evaluation of paralytic scoliosis.
- We recommend that measurements of paralytic scoliosis comprise the sitting balance and weight distribution on the seating surface due to long periods of sitting in a wheelchair, and also because the patients or relatives reported that improved sitting posture was an overall motive for surgery. To use an ADL scale together with a goal setting formulation, in relation to ADL as well as in relation to reaching is needed. The relationship between activities and reaching should be further explored. It is recommended that time needed for rest should be followed since the patients’ or relatives’ clearly expressed reasons for resting.

- It is of great importance to introduce measurements of patients’ and relatives’ well-being and quality of life before and after interventions in patients with paralytic scoliosis.
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REFERENCES


UNIVERSITETSJUKHUSET
I LINKÖPING
Ortopedkliniken
Ryggsektionen, arbetsterapi

ARBETSTERAPEUTENS UNDERLAG

FÖR BEDÖMNING AV PATIENTER MED

PARALYTISK SCOLIOS

Preop bedömning
Postop 6 mån
Postop 1 år
Postop 2 år

Förslag utarbetat av
Kerst. Samuelsson -92
PATIENTDATA

Datum: 
Ansvarig arb.ter: 

Personnr: Namn: 

Adress: 

Telefon hem: arbete: 

Närmast anhörig: 

Diagnos: 

INDIKATION FÖR OPERATION: 

- Andningsfunktion □
- Smärta □
- Sittställning □
- Kosmetik □
- Annat * □

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COBBVINKEL 

Preop □ 
Postop □ 

DATUM FÖR OPERATION: 


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- Delvis □

C. INTELLEKTUELL NIVÅ

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- Nedsatt □
- Svårt att bedöma □

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- Svårt att bedöma □

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- Föreg □

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KLEIN-BELL
ADL SCALE
SCORE SHEET
© 1979
SITTFUNKTION

A. ANVÄNDER KORSETT?
Ja ☐ Nej ☐

Nedanstående uppgifter gäller för rullstolsbarna patienter

B. HAR BENÄGENHET FÖR TRYCKSÄR?
Ja ☐ Nej ☐

C. RULLSTOL

D. NUVARANDE ANPASNING AV SITTFÄLLNING

- Formgjuten sits ☐
- Nackstöd ☐
- Bälstöd ☐
- Sidostöd ☐
- Knästopp ☐
- Bord ☐
- Ingen ☐
- Annat ☐

E. VINKEL MELLAN RYGG OCH SITS

(K Samuelsson)
DOKUMENTATION AV SITTSTÄLLNING

FRONTAL BILD

BILD FRÅN HÖ SIDA

BILD FRÅN VÄ SIDA

Personnr: ........................................

Namn: ..........................................

Datum: ...................... Sign: ...........
SITTFUNKTIONSNIVÅ

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<tr>
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<td>Kan bibehålla position och röra sig inom understödsytan</td>
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<td>Kan bibehålla position och röra sig utanför understödsytan</td>
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<td>Kan röra sig utanför position</td>
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(C M Mulcahy; T E Postney R L Nelham; E M Green; G D Billington)
RÖRELSEOMFÅNG I SITTANDE

Går ej att bedöma ☐

A

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<th>Båda händer samtidigt</th>
<th>Vänster hand</th>
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<td>Nä mellan viloläge och acromion</td>
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C

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SMÄRTA

Före och efter operation grupp A och B

Går ej att bedöma ☐

A. HUR OFTA FÖREKOMMER SMÄRTA?
   Alltid, dag och natt ☐
   Dagligen ☐
   Flera gånger/vecka ☐
   Vid enstaka tillfällen ☐
   Aldrig ☐

B. SMÄRTORNA UPLEVS SOM
   Mycket svåra ☐
   Svåra ☐
   Varken svåra eller lätt ☐
   Lätta ☐
   Mycket lätt ☐

C. HUR OFTA TAR DU SMÄRT-
   STILLANDE MEDICINER?
   Flera gånger/dag ☐
   Dagligen ☐
   Flera gånger/vecka ☐
   Vid enstaka tillfällen ☐
   Aldrig ☐

(P. Fritzell)
VÅRDTYNGD

Före och efter operation grupp A

<table>
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<th>Uppgiftslämnare:</th>
<th>Tid i min per dygn</th>
<th>Mycket lätt</th>
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SUMMA

(K Samuelsson)
**UNIVERSITETSSJUKHUSET**  
I LINKÖPING  
Ortopedkliniken  
Ryggsektionen  
Arbetsterapi

**SKATTNING AV OPERATIONSRESULTATET**  
Efter operation grupp A och B

| Uppgiftslänare: __________________________ |

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Annat som påverkats positivt/negativt av operationen:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(K Samuelsson)
UNIVERSITETSSJUKHUSET  
I LINKÖPING  
Orthopedikliniken  
Ryggskolheten  
Arbetstherapin  

ANVÄNDNING AV TID  

Före och efter operation grupp A och B  

Upplagslämnare:  

INSTRUKTION  

Varje rad motsvarar ett dygn, varje ruta 1 timma.  
Markera aktuella tider på dygnet då patienten sover respektive vilar på följande sätt:  

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<th>Vilar</th>
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Datum  Tid på dygnet  

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(K. Meguro, M. Ueda, T. Yamaguchi et al)
UNIVERSITETSSJUKHUSET
I LINKÖPING
Ortopedkliniken
Ryggsektionen
Arbetseterapien

ANDNINGSFUNKTION

Går ej att bedöma

Ingen indikation för operation

SPIROMETRIVÄRDE (FVC)

SYREUPPTAG (VO2) Vila Arbete
UNIVERSITETSSJUKHUSET
I LINKÖPING
Ortopedkliniken
Ryggsjukhusen
Arbetstherapin

Personnr: ..................-......
Namn: ........................
Datum: ................. Sign: .......

BALANS OCH TRYCKFÖRDELNING I SITTANDE

Före och efter operation grup A och B