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Preoperative evaluation of activity and function in patients with paralytic scoliosis

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Abstract Preoperative evaluation of patients with paralytic scoliosis should take into account the consequences of surgery on the every day life of the patient. However, the parameters that are customarily used in these operations relate only to very narrow measures such as the angle of scoliosis or kyphosis. The aim of this study was to introduce a set of instruments appropriate for measuring both function and activities in paralytic scoliosis patients. The study took as its starting point the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH), in which an activity is described at the level of the individual and function at the level of the organ. A consecutive series of 100 paralytic scoliosis patients with 18 different diagnoses were evaluated preoperatively with a set of instruments that had been specially developed at Linköping hospital, in which the variables are classified according to the system used in the ICIDH. The set of instruments included general information and evaluation of activities and function – sitting, balance, weight distribution to sitting surface, angle of scoliosis, reaching, pain estimation, activities of daily

living (ADL) Barthel and ADL Klein and Bell, care given, time spent resting, and seating supports). The results showed that patients with paralytic scoliosis constitute a heterogeneous group in activities and function. Even when the patients were grouped into four subgroups according to the Scoliosis Research Society Classification, they remained very heterogeneous. However, reaching, Klein and Bell Activities of Daily Living and pain could only evaluate patients who could understand verbal instructions. In those who could not, assessment relied more heavily on measures of function and level of dependence. It was concluded that the choice of assessment must be guided by the patient's ability to understand verbal instructions irrespective of his/her disorder. It is important to use the three levels – impairments, disabilities and handicaps – in order to focus on the different outcomes in the two groups with respect to the patient's total situation.

Key words Paralytic scoliosis · Neuromuscular disorders · Activity · Function · International Classification of Impairments, Disabilities, and Handicaps (ICIDH)

Introduction

A belief in each person's essential humanity, despite all kinds of impairments, is a central tenet in meeting a patient. Closely tied to this perspective is the conviction that it is important to understand and respect the unique perspective of the patient [16], including their right to pursue their own goals. We aimed to test a set of instruments that would allow for evaluation of function and ability to perform activities within each individual patient's own context in order to identify what constitutes an impairment, a disability, or a handicap. The study took as its starting point the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH), in which an activity is described at the level of the individual and function at the level of the organ.

Paralytic scoliosis

Neuromuscular diseases constitute a diverse group of disorders with primary abnormalities at different sites in the brain, spinal cord, peripheral nerves, neuromuscular junctions, or muscles. In this study we used the Scoliosis Research Society's classification of paralytic scoliosis into upper and lower motor lesions, myopathies and congenital defects and malformations [15].

Patient evaluation

Within the traditional field of surgery for the correction of spinal deformities, evaluating activity and function pre- and postoperatively has been uncommon. The results of surgery are usually presented as the correction of different angles of the deformity. Such an approach assesses the in-

dividual only at an organ level, according to the International Classification of Impairments, Disabilities and Handicaps (ICIDH) [14].

In order to understand the consequences of surgery for the patient and his/her family, a broader approach is needed. This study aimed to test a set of instruments to describe paralytic scoliosis patients using measurements that cover impairment, disability and handicap, in accordance with the ICIDH classification system.

Materials and methods

Patients

21 patients with paralytic scoliosis (or parents if the patient could not communicate verbally) who had received surgical treatment between 1990 and 1992 at the University Hospital in Linköping were asked to participate in the first stage of this study. This stage consisted of interviews with the patient/parent to assist in obtaining relevant items for the instrument. Based on the results of the interview, some existing assessments were chosen and some new instruments were developed [10].

In the second stage, 100 consecutive patients with paralytic scoliosis were evaluated preoperatively between March 1992 and September 1996 using this set of instruments. The mean age was 15.1 years (range 4–52 years) and the median was 14 years. There were 60 females and 40 males. In this material of 100 patients with neuromuscular scoliosis, there were 18 different diagnoses (Table 1).

Set of instruments

The set of instruments consists of general information and activities and function. It is made up of existing instruments (e.g. sitting balance, activities of daily living, time spent resting) combined with new ones (e.g. weight distribution, reaching, pain estimation, seating supports, and care given, which were developed in the first stage of the study by Samuelsson et al. [10]. This set of instru-

Table 1 Number of patients and their diagnoses, according to the International Classification of Diseases and Related Health Problems (ICD-10) [13]

N	Diagnosis	ICD-10
26	Cerebral palsy	G80.1, G80.3, G80.4, G82.0, G82.4, F70–79
23	Myelomeningocele	Q05.1, Q05.2, Q05.7
11	Rett's syndrome	F84.2, F70–79
10	Spinal muscular atrophy	G12.0, G12.1
5	Myopathies	G72.9, F70–79
4	Injury of spinal cord	T09.3
4	Muscle dystrophy Duchenne and Becker	Q71.0
4	Poliomyelitis	A80.9
3	Malformation, multiple	Q10–18, Q35–37, Q68.8, Q85.9, F70–79
2	Chromosomal abnormalities	Q90–99, Q96.9, F70–79
1	Aicardis syndrome	Q04.0
1	Arthrogryposis	Q74.3
1	Central core disease	G71.2
1	Charcot-Marie-Tooth	G60.0
1	Encephalopathy	G93.4, F70–79
1	Guillain-Barré syndrome	G61.0
1	Microcephaly	Q02, F70–79
1	Prader Willi's syndrome	Q87.1, F70–79

Table 2 The set of instruments, existing and new, developed by Samuelsson et al. [10] for use with paralytic scoliosis patients, including general information and variables about activities and function

General information	Activities and function
Personal data	Sitting balance 0–7 points [9]
Diagnosis	Weight distribution – EMED system: force (N), pressure (N/cm ²), area (cm ²) [10]
Patients motive for surgery	Angle of scoliosis (Cobb)
Mental status	Reaching to defined body parts in sitting position 0–60 points [10]
Persistent skin discoloration	Pain estimation [10]
Ambulation/wheelchair use	ADL Barthel 0–100 points [7]
Occupation	ADL Klein & Bell 0–303 points (was done in those with ADL Barthel > 30 points) [6]
Understands/does not understand verbal instructions	Care given to the patient in terms of physical effort and time consumption [10]
Brace	Time use for resting in h/week [8]
	Seating supports in wheelchair [12]

Table 3 The variables in the set of instruments

	Functional level (WHO concepts)		
	Organ (Impairment)	Individual (Disability)	Social (Handicap)
Definitions	Reduction in or influence on organ/organ system using Törnqvist's [12] definition	Reduction in performance of different human activities	Influence on fulfillment of social roles
Variables in the set of instruments	Sitting balance Weight distribution Angle of scoliosis Reaching Pain Mental level Persistent skin discoloration	ADL Barthel ADL Klein & Bell Understanding verbal instructions	Care given in terms of physical effort and time consumption Time use for rest Use of seating supports Use of wheelchair Use of brace

ments has been consistently used in clinical work at the Linköping Spine Center since 1992 (Table 2). The patients are evaluated before surgical correction of the spinal deformity, and 12 months postoperatively.

Using Törnqvist's [12] discussion of activities of daily living (ADL) taxonomy as a basis, the variables in the set of instruments were classified into measures of Impairment, Disability and Handicap, as used in the WHO ICIDH classification [14].

Statistical methods

To detect any significant differences between groups, the Mann Whitney-U test, Kruskal-Wallis test and Chi-Square test were used. In bivariate analysis of correlation we used the Spearman rank correlation test.

Results

Patients with paralytic scoliosis ($n = 100$)

Paralytic scoliosis patients constitute a heterogeneous group in terms of activities and function, irrespective of other diagnoses (Table 4). The group as a whole included many wheelchair users and had a generally low level of

ADL. Of the 100 patients, only 67 could understand verbal instructions. For those who could not understand verbal instructions, ADL could be evaluated only by observation of a few basic activities for physical self-maintenance – personal ADL – and parental interviews. The Klein and Bell ADL scale was used for evaluation of 39 patients who could understand verbal instructions and also had a relatively high basic ADL (> 30 points on the Barthels scale [7]). It was also used in two patients who were unable to understand verbal instructions, but whose basic ADL capacity was relatively high, bringing the total number of Klein and Bell ADL assessments to 41.

Since the patients were given verbal instructions, reaching to defined body parts could only be evaluated in 67 cases. The results showed that the patients were able to perform most of the tests for reaching. For care given there was a broad variation in terms of physical effort (between 0 and 28 points) and the variation in terms of time consumption was also large. Most patients did not use many hours for resting, while some needed long periods of rest. Assessment of pain could be determined in 62 cases and showed quite low values, although with great variation. Fifteen parents refused to answer the questions

Table 4 Data on 100 patients with paralytic scoliosis (*I* impairment, *D* disability, *H* handicap – all according to the WHO International Classification of Impairments, Disabilities, and Handicaps [14])

Variables	No. evaluated	Results	
Mental level normal or deficient (I)	100	46 are deficient	
Persistent discoloration of skin (I)	100	41 have skin discoloration	
Understand verbal instructions (D)	100	67 understand	
Use of wheelchair (H)	100	85 use wheelchair	
Use of brace (H)	100	36 have brace	
		Median	(range)
Sitting balance 1–7 (I)	100	4	(1–7)
Weight distribution when sitting at one seating surface in % (I)	69	94	(53–100)
Angle of scoliosis in degrees (Cobb) (I)	94	83.5	(32–158)
Reaching 0–60 (I)	67	54	(0–60)
Pain estimation 1–15 (I)	62	1	(1–12)
ADL Barthel 0–100 (D)	100	25	(0–100)
ADL Klein & Bell 0–303 (D)	41	243	(117–303)
Care given (physical effort) 0–30 (H)	85	16	(0–28)
Care given (time consumption in minutes) (H)	85	170	(0–490)
Time use for resting (h/week) (H)	100	1	(0–101)
Seating supports in wheelchair 0–7 supports (H)	100	2	(0–7)

concerning care given. Since we had not planned at the beginning of the study to include the EMED system for testing weight distribution on the sitting surface, this information is missing in 31 patients.

The Scoliosis Research Society classification

Because the material was heterogeneous, the patients were grouped according to the Scoliosis Research Society Classification of diagnoses: upper motor neuron lesions (group 1), lower motor neuron lesions (group 2), myopathies (group 3), and congenital abnormalities (group 4). The results of this grouping are shown in Table 5.

The group of patients with upper motor neuron lesions ($n = 45$) included those with cerebral palsy, Rett's syndrome, injury of spinal cord, Aicardis syndrome, Charcot-Marie-Tooth, encephalopathy, and microcephaly. The sitting balance was low and all except four were wheelchair users. Most of the mentally retarded patients were found in this group; less than half of the patients with upper motor neuron lesions understood verbal instructions, which restricted the use of ADL Klein and Bell and reaching and assessment of pain.

Lower motor neuron lesion patients ($n = 39$) included those with myelomeningocele, spinal muscle atrophy, poliomyelitis, central core disease, and Guillian Barré. Most of the patients in the group with lower motor neuron lesions were wheelchair users and had a low sitting balance. We could not use ADL Klein and Bell in this group because these patients had weak muscle function, which leads to low a ADL Barthel score in spite of quite a wide

reaching ability. All the patients in this group could understand verbal instructions.

Cases of myopathy ($n = 10$) included myopathy, muscle dystrophy Duchenne and Becker, and arthrogryposis. For this group, reaching ability was limited and they had a low ADL Barthel score because of weak muscle function. In spite of that, they did not need to rest during the day. All except one were wheelchair users, and this group had poor sitting balance. All except one understood verbal instructions.

In the group with congenital abnormalities ($n = 6$), which included congenital abnormalities multiple, chromosomal abnormalities, and Prader Willi's syndrome, most of the patients were ambulatory with a normal sitting balance, a large proportion were mentally retarded, and half of the group did not understand verbal instructions. They had an independent ADL Barthel with a low level of care with respect to physical strain and time consumption. The patients in this group did not need to rest during the day.

A comparison was done with Kruskal-Wallis test and Chi-square test between all groups (Table 5): upper motor neuron lesion (group 1), lower motor neuron lesion (group 2), myopathies (group 3), and congenital abnormalities (group 4). The groups differ at impairment level (I) in mental ability and in sitting balance and angle of scoliosis. At disability level they differ (D) in understanding/not understanding verbal instructions and in ADL Barthel. At handicap level the groups differ in (H) use of a wheelchair and care given in physical effort and time consumption, time spent resting during the day, and seating supports in wheelchair.

Table 5 Comparison between paralytic scoliosis patients with upper motor neuron lesions (group 1), lower motor neuron lesions (group 2), myopathies (group 3), and congenital abnormalities (group 4)

Variables	Upper motor neuron lesion (group 1)		Lower motor neuron lesion (group 2)		Myopathies (group 3)		Congenital abnormalities (group 4)		P-value between groups
	n	Results	n	Results	n	Results	n	Results	
Mental level normal or deficient (I)	45	36 are deficient	39	3 are deficient	10	2 are deficient	6	5 are deficient	0.001***
Persistent discoloration of skin (I)	45	18 have skin discoloration	39	20 have skin discoloration	10	2 have skin discoloration	6	1 has skin discoloration	0.1707 NS
Understand verbal instructions (D)	45	16 understand	39	39 understand	10	9 understand	6	3 understand	0.0001***
Use of wheelchair (H)	45	41 use wheelchair	39	35 use wheelchair	10	8 use wheelchair	6	1 uses wheelchair	0.001***
Use of brace (H)	45	15 use brace	39	17 use brace	10	3 use brace	6	1 uses brace	0.5234 NS
	<i>Median (range)</i>		<i>Median (range)</i>		<i>Median (range)</i>		<i>Median (range)</i>		
Sitting balance 1–7 (I)	45	3 (1–7)	39	4 (1–7)	10	4 (1–7)	6	7 (6–7)	0.0147*
Weight distribution when sitting at one seating surface in % (I)	31	91 (53–100)	30	99 (57–100)	5	98 (54–100)	4	75.5 (67–81)	0.2979 NS
Angle of scoliosis in degrees (Cobb) (I)	45	68 (35–158)	33	92 (43–158)	10	65 (32–110)	6	95.5 (63–140)	0.0119**
Reaching 0–60 (I)	16	48.5 (0–60)	39	57 (0–60)	9	38 (0–60)	3	53 (49–54)	0.0811 NS
Pain estimation 1–15 (I)	13	1 (1–12)	39	1 (1–11)	8	5 (1–9)	2	3 (1–5)	0.8082 NS
ADL Barthel 0–100 (D)	45	5 (0–100)	39	35 (0–100)	10	22.5 (0–100)	6	80 (30–100)	0.0001***
ADL Klein & Bell 0–303 (D)	12	223.5 (117–303)	22	248 (132–303)	2	263 (223–303)	5	230 (137–282)	0.6638 NS
Care given (physical effort) 0–30 (H)	37	18 (0–28)	35	14 (0–22)	8	15.5 (0–22)	5	8 (4–18)	0.0395*
Care given (time consumption in minutes) (H)	37	252.5 (0–485)	35	125 (0–490)	7	180 (0–420)	5	60 (15–110)	0.0354*
Time use for resting (h/week) (H)	45	7 (0–56)	39	0 (0–101)	10	2 (0–9)	6	0	0.0001***
Seating supports in wheelchair 0–7 supports (H)	45	3 (0–7)	39	1 (0–5)	10	2 (0–6)	6	0	0.0018**

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$

Classification of patients based on their ability or lack of ability to understand verbal instructions

We classified the patients into subgroups: one comprised patients who understand verbal instructions ($n = 67$) and can be more active in their daily living, and the other comprised patients who do not understand verbal instructions ($n = 33$). The latter group had either a lower or no ADL score, more seating supports in the wheelchair, a greater need for care given by others, required more time for rest during the day, and were mentally handicapped compared to the group who understand verbal instructions (Table 6).

We could use the total evaluation instrument, including evaluation of performance in ADL, reaching, and estimation of pain, for the group who understood verbal instruc-

tions. For the other group of patients, who did not understand verbal instructions, it was necessary to use a reduced part of the instrument (Table 7), including evaluation of care given, need for rest, and seating posture.

In the group that understood verbal instructions ($n = 67$) a correlation of -0.74 ($P < 0.001$) (Spearman's rank correlation) was found between ADL Barthel and physical effort involved in the care given, and a correlation of -0.80 ($P < 0.001$) was found between ADL Barthel and time consumption for the care given. For this group there were also correlations between ADL Barthel and sitting balance ($r = 0.75$; $P < 0.001$), ADL Barthel and seating supports ($r = -0.70$; $P < 0.001$), and between ADL and reaching ($r = 0.63$; $P < 0.001$). For patients who did not understand verbal instructions ($n = 33$), the correlations were weak or non-existent.

Table 6 Comparison of patients who understand and those who do not understand verbal instructions

Variables	Understands verbal instructions <i>n</i>		Does not understand verbal instructions <i>n</i>		<i>P</i> -value
Mental level normal or deficient (I)	67	13 are deficient	33	33 are deficient	0.0001***
Persistent discoloration of skin (I)	67	30 have skin discoloration	33	11 have skin discoloration	0.274 NS
Use of wheelchair (H)	67	56 use wheelchair	33	29 use wheelchair	0.5715 NS
Use of brace (H)	67	26 use brace	33	10 use brace	0.4049 NS
	<i>Median (range)</i>		<i>Median (range)</i>		
Sitting balance 1–7 (I)	67	4 (1–7)	33	3 (1–7)	0.0731 NS
Weight distribution when sitting at one seating surface in % (I)	44	97.5 (53–100)	26	90.5 (60–100)	0.841 NS
Angle of scoliosis in degrees (Cobb) (I)	61	85 (32–158)	33	72 (35–150)	0.94 NS
Reaching 0–60 (I)	67	54 (0–60)	0	–	–
Pain estimation 1–15 (I)	62	1 (1–12)	0	–	–
ADL Barthel 0–100 (D)	67	40 (0–100)	33	0 (0–80)	0.001***
ADL Klein & Bell 0–303 (D)	39	245 (117–303)	2	186 (137–235)	0.2037 NS
Care given (physical effort) 0–30 (H)	60	14.5 (0–28)	25	19 (8–28)	0.001***
Care given (time consumption) in minutes (H)	60	110 (0–490)	25	335 (50–485)	0.001***
Time use for resting in h/week (H)	67	0 (0–101)	33	7 (0–28)	0.0007***
Seating supports in wheelchair 0–7 supports (H)	67	1 (0–7)	33	3 (0–7)	0.005**

** $P < 0.01$; *** $P < 0.001$

Table 7 The variables in the set of instruments used with the two subgroups of patients: those who could understand verbal instructions and those who could not

Understands verbal instructions	Does not understand verbal instructions
General information and activities and function	General information and activities and function
Mental level normal or deficient (I)	Mental level normal or deficient (I)
Persistent discoloration of skin (I)	Persistent discoloration of skin (I)
Use of wheelchair (H)	Use of wheelchair (H)
Use of brace (H)	Use of brace (H)
Sitting balance (I)	Sitting balance (I)
Weight distribution on sitting surface (I)	Weight distribution on sitting surface (I)
Angle of scoliosis (I)	Angle of scoliosis (I)
Reaching (I)	ADL Barthel (D)
Pain estimation (I)	Care given in physical effort (H)
ADL Barthel (D)	Care given in time consumption (H)
ADL Klein & Bell (D)	Time use for resting (H)
Care given in physical effort (H)	Seating supports in wheelchair (H)
Care given in time consumption (H)	
Time use for resting (H)	
Seating supports in wheelchair (H)	

Discussion

Various diseases affecting the neuromuscular system can cause spinal deformities, and as Shook and Lubicky [11] pointed out, neuromuscular diseases are a diverse group of disorders that can affect different sites in the brain, spinal cord, peripheral nerves, neuromuscular junctions, and muscles. As a whole, patients with these neuromuscular disorders present a mixed clinical picture not only of weakness and spasticity, but also of mental deficiency

with associated difficulties in understanding treatment programs [3].

Patients with neuromuscular diseases have an altered life-style because of the disease itself. Progressive spinal deformities, which can be expected in most of these patients, are probably the reason for dysfunction. The proper timing of appropriate treatment will preserve their life-style and minimize their handicap.

Evaluation of activities and function in patients with neuromuscular diseases and paralytic scoliosis has not

usually been carried out. Reports have included data on changes in Cobb angles and rates of postsurgical complications. Bradford [2] pointed out that in patients with neuromuscular spinal deformities, surgical treatment may prevent progressive deformity and back pain and free the upper extremities for activities of daily living. Berned-Müller et al. [1] evaluated 14 patients with myelomeningocele, surgically treated with Harrington instrumentation, in terms of motor skills, activities of daily living, and ambulation. Brown and co-workers [4] presented a retrospective study of gross motor activities pre- and postoperatively in patients with spinal muscle atrophy fused with Harrington instrumentation, which resulted in a slightly improved sitting balance. Other retrospective studies have been presented: Cassidy et al. [5], for example, pointed out that fused patients with cerebral palsy were more comfortable and generally better off after surgery than non-fused patients.

In this study we used a set of instruments to describe a heterogeneous population according to ICIDH. Its future use is aimed at attaining knowledge about how surgery influences all levels: impairment, disability, and handicap.

The 100 patients with 18 different diagnoses who underwent spinal fusion and segmental instrumentation were heterogeneous with respect to most of the chosen variables. When the groups were classified according to The Scoliosis Research Society Classification, we found that the material was heterogeneous even within the subgroups, especially concerning ability to understand verbal instructions.

Classification according to the Scoliosis Research Society showed that the groups with some ability to function and perform activities were the groups with lower motor neuron lesions and myopathies. These groups were very similar, including in their ability to understand verbal instructions. However, most of the patients in these groups had a weak muscle function, which leads to poor performance on ADL Barthel. Since the patients had poor function many subitems in Klein and Bell were not possible to be performed even if they were able to understand verbal instructions. The possible alternatives in the scale are can or cannot perform the activity and a scale with more alternatives might have been more sensitive to describe performance. Another issue arises when measuring ADL over time, as this is complicated by the fact that for those who still are growing children, ADL skills can be developed and changed. Another issue is that some children get more help in ADL than they seem to need, due to being overprotected. On the other hand, difficulties with ADL skills can be caused by cognitive dysfunctions, which can lead to problems, for instance, dressing.

The group with upper motor neuron lesions and the diagnosis of cerebral palsy, for example, included patients

who were spastic as well as those who were athetotic or atactic, with various levels of function, including mental function, which made it difficult to evaluate them as a homogeneous group.

Classifying patients according to ADL level has its restrictions, because the ability to understand verbal instructions within these subgroups is not homogeneous. When the group that understood verbal instructions was studied, a relationship was found between ADL Barthel and the physical effort and time consumption involved in their care, sitting balance, seating supports, and range of motion. This was not true for those who did not understand verbal instructions. This shows that assessment of ADL is influenced by factors other than motor function, such as cognitive and mental factors. This diminishes the possibilities of measuring and classifying patients according to ADL.

The advantage of classifying the patients into two subgroups – those who understand and those who do not understand verbal instructions – is that we can evaluate activity and function in terms of impairment, disability, and handicap in the group who understand verbal instructions and use the total set of instruments. For the other group, who do not understand verbal instructions, it is more important to evaluate function and the level of dependence in terms of impairment and handicap and adjust the instruments accordingly. Thus, the patients in these two subgroups differ at the levels of disability and handicap, but do not differ at the impairment level. Therefore, methods for evaluating function and performance of activities of patients with paralytic scoliosis must be chosen according to ability to understand verbal instructions. Using this subgrouping model, patients with peripheral neuromuscular disorders and patients with central neuromuscular disorders who understand verbal instructions represent one group, with the other group comprising patients with central neuromuscular disorders who do not understand verbal instructions. The expected postoperative changes will differ in the different groups.

Conclusions

The choice of assessment instruments must be guided by the patient's ability to understand verbal instructions, irrespective of his/her disorder. Use of the three levels – impairment, disability, and handicap – to focus on the different outcomes in the two groups with respect to the patient's total situation, is of great importance.

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