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ORIGINAL STUDY

The effect of Luque-Galveston fusion on curve, respiratory function and quality of life in Duchenne muscular dystrophy

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The aim of this retrospective study was to evaluate the long-term effect of the Luque-Galveston spinal fusion in Duchenne muscular dystrophy (DMD) patients. Twenty patients had undergone this operation at a mean age of 15.3 years (surgical group, A). The correction of their scoliosis amounted to +/-55.8%, after an average follow-up period of 3 years. This is in accordance with the literature. The authors would therefore advise to perform spinal fusion in an early stage of the disease, once a rapid evolution of the scoliosis is seen. The decline of respiratory function slightly diminished after surgery, but not significantly. This means that no expectations should be made to improve respiratory function, as respiratory function decline continues relentlessly. Most authors agree with this statement. Patient satisfaction after surgery was relatively high, mainly because of an improved sitting balance, but only 60% of the questionnaires were available. Twenty-five other patients were not operated upon (non-surgical group, B). They had better results at ages 15.3 and 18.3, but this was mainly due to the fact that group B contained more benign cases according to the Oda classification.

Keywords : Duchenne muscular dystrophy ; scoliosis ; Luque-Galveston stabilisation ; respiratory function ; quality of life.

INTRODUCTION

Duchenne muscular dystrophy (DMD) is an X-linked recessive disease, characterized by progressive muscle weakness. Approximately 1 out of 3500 boys is born with this condition, caused by a mutation in the gene for dystrophin, located on the Xp-21 region of the X chromosome (*7,35*). Both skeletal and cardiorespiratory muscles become affected, resulting in a reduced life expectancy. Affected boys usually die in their late teens or early twenties (*8,10,30,31*). Respiratory failure following recurrent pulmonary infections and cardiac failure are the main causes of death (*8,10*).

Progressive proximal muscle weakness leads to a loss of ambulatory function at an average age of 9.5 years (*9,30*). Once wheelchair-bound, almost 90% of the DMD patients develop scoliosis, which progresses relentlessly. From the onset, progression of scoliosis can be extremely rapid, affecting the unsupported sitting ability, and deteriorating the respiratory function, already compromised by the disease (*9,14,37*). As a consequence, the quality of life of DMD patients can be severely reduced (*14,17,22,30*).

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Duchenne muscular dystrophy remains a fatal affliction, without any curative agents available. Current therapeutic modalities are however capable of improving life expectancy and quality of life (*35*). Steroids positively influence muscle strength, thereby postponing the loss of ambulatory function and onset of scoliosis, while improving pulmonary and cardiac function, without major complication rates (*1,2,13,18,38*).

Surgery is the preferred treatment of severe progressive scoliosis in patients with DMD. Orthoses often diminish the already limited lung function in these patients (*5*). Most authors agree that non-operative treatment can only be considered when the patient refuses surgery or when the general health condition has begun to collapse (*16,19,20,33*). It has been shown that posterior segmental fixation offers the best results (*16,19,20,29,31*). Current recommendations include the use of the Luque-Galveston segmental instrumentation. This technique allows for posterior instrumentation at every level of the spinal construct through the use of sublaminal wiring. The use of the Galveston fixation to the pelvis permits firm correction of rigid pelvic obliquity (*5,29*). Most studies conclude that surgery stabilises the scoliosis, but does not influence the deterioration of pulmonary function (*23-25,29*). Significant improvement of quality of life post surgery has been documented (*3,4,11*).

The progression of the spinal curvatures varies among DMD patients. Oda *et al* (*26*) distinguish 3 types. This classification is widely accepted. Type 1 curves follow an unstable course with a progressive scoliosis concomitant with kyphosis. Cobb angles reach 30° before the age of 15, with rapid progression beyond 30°. Surgical stabilization is indicated when angles have reached 30° and before vital capacity has decreased to 30% of predicted value. Type 2 curves are characterized by transition of kyphosis to hyperlordosis in the sagittal plane, combined with a progressive scoliotic deformity. The course of scoliosis in type 2 patients is not uniform. Patients with a double lateral curve show little change in Cobb angle with minimal pelvic obliquity. Patients with long thoracolumbar curves show gradual increase of deformity. Patients with single lumbar curves, may show gradual or sudden increase. Type 3 curves show minimal progression, with Cobb angles never exceeding 30°. There is no indication for surgical intervention for type 3 curves. Therefore, it is necessary to distinguish type 1 and type 2 cases from these type 3 cases as early as possible to establish surgical indications.

MATERIALS AND METHODS

Forty-five case records of patients with DMD were reviewed. All patients were boys with an onset before the age of 5 years. The diagnosis was based on history, clinical presentation and muscle biopsy. Other dystrophies, such as Becker's disease, were not included.

The patients where divided into two groups (Table I) : the surgical group A (20 patients), and the non-surgical group B (25 patients). The surgical group A included 15 Oda type 1, and 5 Oda type 2 patients ; their total radiographic follow-up period was 6.5 ± 2.5 years, their post-operative follow-up period 3 ± 1.5 years. The non-surgical group B included 5 Oda type 1, 11 Oda type 2 and 9 Oda type 3 patients ; their total follow-up period was 6.3 ± 2.6 years. Group B included many benign cases Oda type 3. The primary evaluation was based on analysis of consecutive anteroposterior (AP) and lateral radiographs of the spine : the Cobb angle, kyphotic index, sacral angle and pelvic obliquity were measured. All patients were then categorized according to the Oda classification.

The age at loss of ambulatory ability was determined from the medical records. Patients were considered to have lost ambulation when they became unable to walk independently without lower extremity braces or an other support. The pulmonary function was assessed as a

Table I. — Classification of the patient population

	Number of patients	Oda type 1	Oda type 2	Oda type 3
Group A (surgical)	20	15	5	0
Group B (non-surgical)	25	5	11	9
Total	45	20	16	9

percent of predicted forced vital capacity (%FVC). Armspan measurements were used for the calculation of predicted values, since accurate measurements of body height are difficult in DMD patients.

The Luque-Galveston technique with segmental sublaminal wiring was used for surgical stabilisation. From Th3 or Th4 to the sacrum or to the pelvis, with bilateral wiring at all levels. A lumbar lordosis and a dorsal kyphosis were moulded into the rods. A mixture of autologous bone grafts, obtained from the spinous processes, and allografts was always used.

A questionnaire was sent to all surgical patients and their parents. The questions focused on comfort, nursing needs, postoperative (in)conveniences and global satisfaction.

Analysis of variance (ANOVA) was used to compare group means.

RESULTS

Twelve patients were deceased at follow-up (Table IV). Pulmonary infection followed by respiratory insufficiency was the main cause of death. Five of these patients were in the surgical group ; their mean age at death was 19.6 years. Seven were in the non-surgical group B ; their mean age at death was 23.1 years. All other patients were still alive, with an average age of 21.5 years (range 15-29.3 years).

Ambulation

In the study population as a whole, 20 patients were labelled as Oda type 1, 16 patients as type 2 and 9 patients as type 3. Type 1 patients became wheelchair bound at an average age of 9.9 years (range 8-12 years), type 2 patients at an average age of 10.7 years (range 8-17.1 years), and type 3 patients at an average age of 12.4 years (range 10.8-14.8 years). At follow-up one type 2 patient and two type 3 patients still had good ambulatory function ; their average age at that time was 20.5 years (range 19.6-21 years).

Scoliosis

Twenty patients (group A) underwent spinal surgery. Their average age at surgical intervention was 15.3 years (range 12.8-17.8 years). This mean age was used to compare both groups and was considered as the pivot age for the non-operative group B. The mean Cobb angle at surgery was 44.7° (range 23-98°). In the non-surgical group B the average Cobb angle at the pivot age (15.3 years) was 23.5° (range 4-58°). The postoperative Cobb angle measured on an average 15.5° (range 7-36°) ; this means an average correction of 64.2 % (range 40-85%). The average radiographic follow-up after surgery was 3 years (range 0.5-8 years). At final follow-up, at age +/-18.3, the average Cobb angle in the surgical group was 18.7° (range 8-40°), meaning an ultimate correction of +/- 55.8%. In the non-surgical group B, the average Cobb angle at the same age of 18.3 years was 27.6° (range 13-74°), corresponding to an annual increase of 1.7°/year. Table II and table III provide an overview of the results of both study groups, respectively A and B.

Complications and postoperative care

There were no perioperative deaths, temporary tracheostomies, pseudarthroses, failures of instrumentation, or neurological sequelae. Three infections required débridement, resuturing and antibiotics. The mean stay in the intensive care unit was 24 hours (range 12-48 hours). All patients were mobilised within 7 days. The average hospital stay was 17 days (range 7-59 days).

Respiratory decline

Patients from the surgical group A presented preoperatively (Table IV), at a mean age of 15.3 years, with an average %FVC of 46.2% (range 78-35%). Their mean preoperative follow-up period of pulmonary function was 5.6 years (range 1.2-13 years). Their mean postoperative follow-up of pulmonary function was 3 years. Patients from the non-surgical Group B still reached a %FVC of 65.1% (range 94-14%) at the same age of +/- 15.3 years. Their mean pre-pivot follow-up of pulmonary function was 6.5 years (range 0.9-14.8 years). At final follow up, the pulmonary function in the surgical group had declined to an average of 21.5 %FVC (range 6- 41%). In group B,

Table II. — Surgical group A and its subtypes. Means and standard deviations

	Oda type 1	Oda type 2
# patients deceased	2	3
Age at death (years)	19.4	19.7
Age at loss of ambulation (years)	9.8 ± 1.2	9.6 ± 1.1
Preoperative Cobb angle	44.7 ± 17.8	44.6 ± 28.1
Postoperative Cobb angle	15.0 ± 7.7	17.0 ± 10.3
Cobb angle at final follow-up	17.9 ± 10.4	21.0 ± 12.4
Postoperative correction of scoliosis (%)	65.6 ± 12.6	59.9 ± 13.1
Correction of scoliosis at final follow-up (%)	58.4 ± 19.1	48.2 ± 27.6
Preoperative FVC% (Forced Vital Capacity)	47.3 ± 11.4	43.2 ± 8.8
FVC% at final follow-up	22.5 ± 10.9	19.4 ± 10.5
Postoperative follow-up (years)	2.9 ± 1.5	3.2 ± 2.9
Preoperative annual decline FVC%	8.3 ± 3.3	7.9 ± 2.4
Postoperative annual decline FVC%	6.1 ± 4.4	5.0 ± 3.5

Table III. — Non-surgical group B and its subtypes. Means and standard deviations

	Oda type 1	Oda type 2	Oda type 3
# patients deceased	3	3	2
Age at death (years)	29	18.1	21.6
Age at loss of ambulation (years)	10.2 ± 1.1	10.7 ± 1.1	13.3 ± 2.8
Cobb angle at 15.3 years (pivot-age)	48.4 ± 26.2	20.0 ± 9.7	14.0 ± 18.3
Cobb angle at 18.5 years	63.0 ± 40.1	24.6 ± 11.1	16.5 ± 18.3
FVC% at 15.3 years (pivot-age)	56.3 ± 30.0	62.1 ± 20.2	75.5 ± 17.8
FVC% at 18.3 years	20.5 ± 15.7	40.3 ± 30.1	53.0 ± 25.6
Annual decline FVC% pre-pivot	6.3 ± 3.2	4.8 ± 2.3	3.4 ± 2.1
Annual decline FVC% post-pivot	5.9 ± 3.3	4.2 ± 2.2	3.9 ± 2.2

the average %FVC at a similar age of 18.3 years was 41.9% (range 6-92%). The average annual respiratory decline in the preoperative period was 8.2 %FVC/year for group A, and in the pre-pivot period 4.6 %FVC/year for group B. Postoperatively, the average annual respiratory decline for group A was 5.7 %FVC/year, or slightly less. Statistical analysis revealed that the differences between preoperative and postoperative measurements was not significant ($p > 0.1$). The average annual respiratory decline for group B in the post-pivot interval was 4.8 %FVC/year, or practically unchanged.

Steroids

Thirteen out of 45 patients were treated with steroids for at least 6 months. In the other 32 patients either treatment was not started or treatment was cancelled during the first 6 months due to adverse reactions or to patient refusal. The average age at which ambulation was lost in the treated group was 11.9 years, compared to 10.2 years in the non-steroid cohort. At first sight this would plead for a positive effect of the steroids, but the small numbers and the variability of dose tolerance and duration of treatment made that no significant conclusions could be drawn.

Quality of life

Questionnaires were mailed to 17 out of 20 surgical patients and their parents ; 12 responded. Two patients were not contacted because of their critical condition, and one patient was deceased. Fifty

Table IV. — Surgical Group A and Non-surgical Group B. Means and standard deviations

	Group A (n = 20)	Group B (n = 25)
# patients deceased	5	7
Age at death (years)	19.6 ± 1.0	23.1 ± 8.2
Age at loss of ambulation (years)	9.7 ± 1.0	11.5 ± 2.0
Cobb angle at 15,3 years (= avg time of fusion in the surgical group)	44.7 ± 20.3	23.5 ± 18.6
FVC% at 15.3 years (Forced Vital Capacity)	46.2 ± 10.7	66.3 ± 21.6
Cobb angle at final follow up	18.7 ± 10.6	28.0 ± 23.7
FVC% at final follow up	21.5 ± 10.5	42.0 ± 28.1
Total radiographic follow-up (years)	6.5 ± 2.5	6.3 ± 2.6
Postoperative/post-pivot follow-up (years)	3.0 ± 1.5	3.0

percent of the parents reported an increased difficulty in the nursing of their son ; the other 50% reported either a status quo or a slight improvement in the nursing care. The main reasons for the increased difficulties were a reduced mobility and a reduced functionality of the upper limbs. Ten patients experienced a significant improvement in sitting balance and comfort, with a prolonged sitting ability. In 7 patients, pain was significantly reduced after surgery. However, 2 patients experienced an increase in pain, which was located around the hips. Three patients never had a pain problem. All patients and all parents were satisfied with the aesthetic improvement after surgery, due to straightening of the curve. All 12 patients and parents reported to be very satisfied and to be ready to accept the surgery again if in the same circumstances. All parents would recommend the surgery to others with an affected son.

DISCUSSION

Validity of the Oda classification

Scoliosis occurs in over 90% of patients with DMD. Oda *et al* described 3 types according to the evolution of the curvature (*26*). The current study confirmed that there was a marked difference between the 3 types (Table II and III). Indeed, the most severe presentation, in both the surgical and non-surgical group, was found in patients classified as type 1. All 20 type 1 patients presented with vast spinal deformities and a reduced pulmonary function. Fifteen of these 20 patients required surgery. The 16 type 2 patients presented with less pronounced curves and a higher %FVC. The 9 type 3 patients had a slight curvature below 20°, and their pulmonary function was better. Moreover, they remained ambulatory for a longer period. None of the type 3 patients required a surgical intervention. All these findings confirm the validity of the Oda classification.

Scoliosis

Literature evidence indicates that posterior instrumentation provides good reduction and stabilisation of the deformity in DMD (*3,19,20,29*). The long term correction of +/-55.8 %, achieved in group A, is comparable to the correction reported in previous studies : 52% (*3*), 60% (*5*), 59% (*11*).

Respiratory decline

DMD is characterized by progressive muscle weakness resulting in a progressive decline in respiratory function. Previously, it was shown that vital capacity in DMD patients increases over the first decade to reach a plateau around the age of 12 years, followed by a progressive deterioration (*6,28*). The level of this plateau phase is very important, since low plateau levels are associated with a faster deterioration (*6*). A rapid decline of pulmonary function coincides with rapidly evolving scoliotic deformity (*26*). Therefore, a thorough evaluation of pulmonary function is necessary when assessing the operative need in a DMD patient with scoliosis. In the past, many authors have suggested

to perform spinal fusion as early as possible to reduce the risk of pulmonary complications. It was believed that surgery on patients with pulmonary function lower than 30-35 %FVC would be unsafe, with a high risk for severe complications (*15,22,24, 27,30,36*), but other authors demonstrated that spinal fusion can be safely performed even in patients with pulmonary function around 25 %FVC (*12,21,21,33*). Most authors agree that spinal fusion does not influence the continuous deterioration in pulmonary function (*23-25,29*). However, Galasko *et al* (*34*) reported a stabilisation of pulmonary function up to 36 months after surgery (*9*). Furthermore, Velasco *et al* (*34*) reported a significant reduction of postoperative annual respiratory decline. In the current study the average preoperative decline was 8.14 %FVC/ year and the average postoperatively decline 5.71 %FVC/year. This would plead for a slight improvement, but the difference was not significant.

Steroids

Several authors have claimed that steroids improve the quality of life of DMD patients (*1,2,18, 38*). The current study seemed to plead in favour of steroid treatment, but the data were not significant.

Quality of life

Previous studies reported high satisfaction rates after surgery (*3,4,11,32*). This was confirmed by the 12 families who filled in the questionnaire. No information was obtained from the 8 other families : a worst case analysis would lead to the conclusion that all 8 might be dissatisfied with the operation.

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