MINI REVIEW



The effect of selective dorsal rhizotomy on the improvement of the quality of life of children with stage GMFCS IV and V cerebral palsy: Pain, nursing, positioning, and dressing

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Abstract

Aim The objective of this study is to evaluate the benefit of selective dorsal rhizotomy on the quality of life of patients with severe spasticity with significant impairment of gross motor functions (GMFCS stages IV and V) according to 4 items: pain, nursing care, positioning, and dressing.

Materials and methods We conducted a monocentric retrospective cohort study including patients who underwent selective dorsal rhizotomy between March 2008 and May 2022 at the University Hospital of Marseille.

Results Seventy percent of patients showed an improvement in quality of life criteria: dressing, nursing, positioning, and pain at the last follow-up. A small proportion of patients still showed a worsening between the first 2 follow-ups and the last follow-up.

Postoperatively, 27.3% of patients were free of joint spasticity treatment, and we have shown that there was a significant decrease in the number of children who received botulinum toxin postoperatively. However, there was no significant reduction in the number of drug treatments or orthopaedic procedures following RDS.

For the CPCHILD[©] scores, an overall gain is reported for GMFCS IV and V patients in postoperative care. The gain of points is more important for GMFCS IV patients. Improvement was mainly observed in 2 domains, "comfort and emotions" and "hygiene and dressing". For the "quality of life" item, only 3 parents out of the 8 noted a positive change.

Conclusion Our study shows an improvement in nursing care, positioning, and dressing which are associated with a reduction in pain in children with a major polyhandicap GMFCS IV and V who have benefited from a selective dorsal rhizotomy.

Keywords Cerebral palsy · Spasticity · GMFCS IV · GMFCS V · Selective dorsal rhizotomy · Pain

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Introduction

Selective dorsal rhizotomy (SDR) is becoming a standard neurosurgical procedure for the treatment of spasticity in children with cerebral palsy. This surgical technique first appeared in the 1900s and was improved by French teams in Montpellier and Lyon at the end of the twentieth century [1].

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Selective dorsal rhizotomy has been established as one of the techniques for the surgical treatment of spasticity in children with cerebral palsy along with intrathecal baclofen.

The results of the various studies show a reduction in spasticity and a significant long-term benefit in the area of "body structure and function", but there is no evidence of the long-term influence of SDR in the area of "activity and participation" of the International Classification of Functioning [2, 3].

SDR is the preferred intervention in the neurosurgical field for ambulatory patients with spastic diplegia whose primary goal is to improve walking [4]. Most studies target GMFCS I, II, or III children [3–5].

In the literature, few articles describe the benefits of SDR in GMFCS IV and V patients for whom intrathecal baclofen is proposed as the first-line surgical treatment. The study by Kan et al. [6] shows an overall reduction in lower limb spasticity after SDR in GMFCS III–V patients, as evidenced by a significant improvement in the Ashworth scores of the lower limbs, over and above that obtained by intrathecal baclofen. The study by D'Aquino et al. [7] confirms the significant decrease in spasticity after SDR according to the Ashworth scale.

Furthermore, it has been shown that for children with significant spasticity, SDR versus intrathecal baclofen treatment significantly reduces the number of additional orthopaedic procedures postoperatively [6].

In most cases, children with cerebral palsy GMFCS IV and V present a motor deficit, secondary musculoskeletal disorders, and cognitive and communication disorders in parallel with spasticity, all of which lead to a significant limitation in most activities of daily life. The evaluation of these different domains by the patients themselves is often not possible.

The quality of life of patients and their families should be included in the evaluation of proposed treatment regimens and in medical and/or surgical decision-making.

Several scales exist to assess the quality of life of children with motor disabilities, but few have been developed for children with severe multiple disabilities [8]. We used the CP-CHILD[©] scale, validated in GMFCS IV and V cerebral palsy children, to assess the effectiveness of interventions in these children in six life domains [9].

The aim of our study is to show the interest of selective dorsal rhizotomy in the improvement of the quality of life of GMFCS IV and V patients, by retaining as primary evaluation criteria: nursing care, positioning in equipment, dressing, and pain.

The secondary endpoints are, on the one hand, a review of joint treatments for spasticity and/or its orthopaedic consequences before and after surgery and, on the other hand, an evaluation of the quality of life of the caregivers according to the CP-CHILD[©] questionnaire in children operated on from 2018 to 2022, in 8 patients.

Materials and methods

Study population

The study group included 41 children who underwent SDR between March 2008 and May 2022 at the University Hospital of Marseille, France. All procedures were performed by the same neurosurgeon (DS). The chart reviews were performed between April 2022 and July 2022.

All selected patients presented preoperatively with significant spasticity with severe motor involvement defined by a Gross Motor Function Classification System (GMFCS, Palisano level) score of IV or V.

The preoperative clinical evaluation and interview were carried out by a team composed of a rehabilitation physician and a neurosurgeon at the Marseille University Hospital. Postoperative evaluations were carried out in rehabilitation centres in the Marseille region by rehabilitation doctors, and during control visits with the neurosurgeon.

At follow-up appointments, the assessment included questioning the carers/family about the execution of nursing and dressing, positioning in the equipment, and pain. Outcomes in each domain were recorded as "improved", "worsened" or "unchanged". For spasticity, we averaged the modified Ashworth scale scores for the quadriceps, hamstrings, adductors, and sural triceps. Follow-up was at 1 month, 3 months, 1 year, and at the last date of consultation notified in the files.

The review of the files also made it possible to list the oral treatment of spasticity, orthopaedic procedures on the soft parts and bones, botulinum toxin injections carried out on the lower limbs and upper limbs, and treatment with intrathecal baclofen pre- and postoperatively.

In addition, a telephone interview with the families/ carers was carried out. We used the CP-CHILD[©] questionnaire validated in France for children with cerebral palsy stage GMFCS IV and V. The different domains covered are activities of daily living/personal care (9 items); positioning, transfer, and mobility (8 items); comfort and emotions (9 items); communication and social interaction (7 items); health (3 items); and global quality of life (1 item). Each item was scored from 0 to 6 "0 = impossible", "6 = no problem", completed by a score according to the level of assistance from 0 to 3 "0=total assistance", "3 = independent".

The officially validated questionnaire concerns the assessment of changes over a period of 2 weeks prior to the study. We have adapted it to allow a reliable retrospective study. Thus, we selected a sub-population of patients operated between 2018 and 2022, to ensure the reliability of collection and analysis. A preoperative and a postoperative score were assigned retrospectively during the

same telephone interview in July 2022. The questionnaire was addressed to 13 carers/parents, of which, 8 parents responded to the questionnaire, 3 did not respond to the phone calls, and 2 did not respond due to a language barrier.

Surgical procedure

All children underwent selective dorsal rhizotomy using the same protocol: lumbosacral skin incision exposing the blades of L1 to S1; laminotomy with motor from L5 to L1 and laminectomy of S1 with Kérisson's clamp, opening of the dura mater, root stimulation of L5, S1, and S2; dissection of the sensory contingent and section of 70 to 80% of the L2, L3, L5, and S1 roots. For the S2 contingent, the percentage of fibres sectioned depended on the pre-existing vesico-sphincter disorders (7 patients Sect. 0%, 33 patients Sect. 50%). The L4 contingent was sectioned between 50 and 70% depending on the child's transfer and verticalization abilities. Suture of the dura mater; repositioning of the lamellar flap fused with Striker blades.

Statistical analysis

A descriptive analysis of the data was performed to evaluate the primary endpoint.

A Friedman test was used to determine statistically significant changes in the Ashworth score (between the pre-SDR assessment and the postoperative intervals of 1 month, 3 months, 1 year, and final follow-up).

For the evaluation of the management of spasticity associated with selective dorsal rhizotomy, McNemar's test was performed to assess the statistically significant decrease in joint treatments postoperatively. p < 0.05 was considered statistically significant.

The results of the questionnaire were processed to obtain a score out of 100 for each domain, and then, an average of the 6 domains was used to obtain the final score. Pre- and postoperative scores were compared.

Missing data was managed by pairwise deletion for each variable studied.

Results

Population characteristics

Forty-one GMFCS IV and V patients underwent selective dorsal rhizotomy, (10 GMFCS IV, 31 GMFCS V). The median age of patients was 11 years [IQR 7–14]. In 68% of the patients, spasticity was due to cerebral palsy of perinatal origin, 4 patients had cerebral malformation, 3 patients had sequelae of prematurity, 18 patients had sequelae of perinatal anoxia, 3 had maternal-foetal infections, 6 had encephalopathy of genetic origin, 1 had transverse myelitis, and 1 patient had a traumatic SCI.

Eighty-five percent of patients had motor involvement such as spastic tetraparesis (n, 35), and 15% had spastic diplegia (n, 6).

Regarding the associated secondary diagnoses, 46% of the patients had a mixed spastic and dystonic involvement (n, 19). For more than half of the patients, secondary lesions related to spasticity already existed preoperatively (51% sco-liosis, 54% hip dislocation).

The median follow-up was 38 months [IQR 18–66 months] (Table 1).

The objectives of the surgery are listed in the files during the preoperative appointment with the neurosurgeon and summarised in Table 2.

Quality of life for children: Pain, nursing, positioning, and dressing

Before the operation, 43% of the patients presented difficulties in the equipment installation (wheelchair, seat corset, bed), 53% had a clear limitation in positioning, and only 3% of the patients had no difficulty reported.

Regarding dressing, 58% of patients reported difficulties, 34% had limited dressing (incomplete dressing), and 8% had no difficulty.

Table 1 Characteristics of the patients

Gender, <i>n</i> (%)	
Men	20 (49%)
Women	21 (51%)
Age, median [IQR] years	11 [7–14]
GMFCS stage, n (%)	
GMFCS IV	10 (24%)
GMFCS V	31 (76%)
Aetiology spasticity, n (%)	
Cerebral malformation	4 (9.75%)
Prematurity	3 (7.31%)
Perinatal anoxia	18 (43.9%)
Maternal-foetal infection	3 (7.31%)
Genetic encephalopathy	6 (14.63%)
Acute transverse myelitis	1 (2.43%)
Spinal cord injury	1 (2.43%)
Preoperative associated secondary diagnosis, n (%)	
Tetraparetic	35 (85%)
Diplegic	6 (15%)
Dystonia	19 (46%)
Scoliosis	18 (44%)
Hip dislocation	21 (51%)
Epilepsy	22 (54%)
Gastrostomy	18 (44%)

Table 2	Surgical	indications,	п	(%)
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29 (71%)
36 (88%)
36 (88%)
28 (68%)
18 (44%)
9 (22%)

For nursing care, more than half, 58% of the patients, had difficulties in carrying out this task, 31% had a restriction in hygiene care, and 10% were able to benefit from hygiene care without difficulty.

Finally, for 68% of the patients, pain was considered to be part of the operative indication.

Postoperatively, there was a clear improvement in all four items at 1 month. No patient reported an initial worsening in positioning, nursing care, dressing, and pain. The trend for the 4 items during the follow-up is an initial major improvement, then over time a decrease in the rate of improved children, associated with an increase in the number of those presenting an aggravation.

Regarding positioning, at 1 month postop, 91% of patients were improved, and this improvement remained stable at 3 months. None of the patients reported any worsening, although 9% of the patients were still in the same position at 1 month. At 1 year, 73% of the children showed improvement, 21% were unchanged, and 5% showed worsening. At the last follow-up, the proportion of children with worsening increased to 15%, but the majority of children were still improved (69%).

For dressing, at 1 month post-op, 93% of patients showed an improvement in dressing compared to pre-op and 6% showed no change. The rate of improvement decreased over time. At the last follow-up, 69% of the children showed an improvement when dressing, for 24% this action remained unchanged, and for 7% dressing was more difficult than in the postoperative period.

In nursing care, the trend was similar to the two previous items, with an initial improvement in 84% and no change in 15%. The improvement increased at 3 months and then decreased at 1 year and at the last follow-up (respectively 97%, 80, 70%). There was an aggravation for 12% of patients at the last follow-up.

Concerning pain, the initial improvement was less significant than for the three previous items (80%, n = 25 patients collected). However, this improvement remained stable at 1 month, 3 months, and 1 year. At the last follow-up, the decrease was the same as for the previous items at 68% (n=22 patients collected), and the worsening was greater for 9.4% of patients (i.e. 3 patients) (Fig. 1).

Reduction of spasticity according to the Ashworth scale

The mean preoperative score according to the modified Ashworth scale on the muscle groups of the lower limbs was 3.00 (range, 0-4). After SDR, there was a significant reduction in lower limb spasticity scores at 1 month, maintained at 3 months, 1 year, and at the last postoperative follow-up (Friedman test, p < 0.005). The mean reduction at 1 month, 3 months, and 1 year was 0.8, 1, and 1.1 points, respectively, and was 1.3 (range, 0-3) at the last follow-up (Fig. 2).

Management of joint spasticity

Regarding the treatment of spasticity and its complications associated with SDR, we were interested in per osseous treatment of spasticity, botulinum toxin injections,



time for the items: positioning, dressing, nursing, pain





intrathecal baclofen treatment, and orthopaedic bone and musculotendinous procedures.

Preoperatively, 38 of the 41 patients (93%) had received one or more treatments for spasticity. Thirty-six patients (88%) had received botulinum toxin injections, 21 patients (51%) had received drug treatment, and 17 patients (41.5%) had undergone orthopaedic surgery (39% of which were tenotomies).

After the selective dorsal rhizotomy, 27.3% of patients who had received preoperative treatment (all treatments combined) were free of co-management. A total of 72.7% had required additional treatment for spasticity.

Regarding botulinum toxin injections, there was a significant decrease in the number of injections following selective dorsal rhizotomy (McNemar Test p < 0.001). Of the 36 patients for whom we had pre- and postoperative data, 33 had received injections preoperatively, and 3 had not. In the postoperative period, the 3 toxin-naive patients were not injected. For patients already injected preoperatively, 39.4% (n, 13) were injection-free, and 60.6% (n, 20) continued to receive toxin injections in addition to the SDR.

Fifteen patients underwent tenotomy procedures postoperatively, 6 of whom had already had the same muscles treated preoperatively. It is noted that the average age of SDR for these 15 patients was 9 years and 3 months (range, 3–14 years). The most frequently treated muscles were the hamstrings and gastrocnemius.

Hip surgery was (excluding spinal arthrodesis) the most common bone surgery, performed in 7 individuals preoperatively and in 3 individuals postoperatively. The other surgical procedures concerned the foot (n, 3) and 1 patient benefited from a tendon transfer. Orthopaedic surgery was performed on average 3.6 years after RDS, with a range of 0.5 to 8 years maximum.

We cannot conclude that there was a significant reduction in orthopaedic bone and musculo-tendon procedures following SDR (McNemar Test p > 1.00).

One patient was implanted with an intraventricular baclofen pump postoperatively; after review of the file, it was a mixed spastic and dystonic tetraparesis; the indication was given in front of an increase of dystonia postoperatively.

Of the 41 patients, 35 had prescriptions for medication in the pre- and postoperative files, 19 of which had been given an anti-spastic treatment per os in the preoperative period. Postoperatively, 9 patients stopped treatment (47.4%), and 10 continued it (52.6%). Four patients started an oral antispastic treatment after the SDR procedure. In conclusion, there was no significant decrease in the use of antispastic treatment postoperatively (McNemar Test p=0.267).

Assessment of primary caregivers using the CPCHILD $^{\!\!\!\odot}$ score

Eight parents answered the questionnaire by phone. The 6 domains were scored from 0 to 100, with the final score also out of 100. We gave a score in pre- and post-surgery. 100 was the best score and 0 the worst.

The median age at which the children were operated on was 9.2 years. The mean time from surgery to completion of the questionnaire was 27 months. Fifty percent of the patients had GMFCS stage IV, and 50% had GMFCS stage V. The patient characteristics are summarised in Table 3.

In the analysis of the total scores, we note an improvement in 6 of the 8 patients postoperatively, associated with an average gain of 7.15 points. For 1 patient, the 2 scores were identical. Patient 7 showed a decrease in the final score of 3.1 points in the postoperative period compared to the preoperative score. The caregiver interviewed reported the

Table 3	Characteristics	of the	patients
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Gender, <i>n</i> (%)	
Men	5 (62.5%)
Female	3 (37.5%)
Operative age, median [IQR] years	9.2 [3–17]
Time to surgery, months	27
GMFCS stage, n (%)	
GMFCS IV	4 (50%)
GMFCS V	4 (50%)

appearance of a painful hip dislocation following the operation (Fig. 3).

The mean total scores for GMFCS IV children were 57.9 preoperatively and 66.8 postoperatively. For GMFCS V patients, the mean scores are 36.8 preoperatively and 42.4 postoperatively.

A comparison of the patients' total scores with the CPCHILD[©] reference scores was carried out. The reference scores are summarised in Fig. 4.

For GMFCS V patients, the score of 36.8 is within the low standard deviation of the reference scores (44.4 [31.8–57]), while the postoperative score of 42.4 is within the average.

For GMFCS IV patients, the score of 57.9 is in the middle, and 66.8 is in the high standard deviation of the reference scores (56.3 [48.2–64.4]).

Figure 5 summarises the post/preoperative score gains or losses for each patient, which allows us to assess trends of worsening or improvement in each domain following RDS.

All parents (8/8) reported an improvement in the "comfort and emotions" domain postoperatively, with an average gain of 11.9 points/100. The "hygiene and dressing" domain was also improved for most patients (7/8). In this domain, the items improved were mainly as follows: "dressing of lower body" and "changes of protection/underwear". Average gain of 9.25 points.

In the "installation, transfer and movement" domain, 5 patients showed an improvement (average gain of 5.0 points/100). Patient number 8 showed a deterioration in this domain due to a loss of strength in the lower limbs postoperatively, limiting his transfer abilities.

It is interesting to note the improvement in the "communication and social interaction" domain in half of the postoperative patients, with the most frequently improved item being "making yourself understood by people who don't know you".

The quality of life domain included only one item "how would you rate your child's quality of life" scored from 0 to 5 and then reported to a score of 100. Three parents described an improvement in their child's overall quality of life, and 5 parents did not note any difference in daily life.

Discussion

For children with severe motor and cognitive disabilities, the major issues in the management of spasticity are improving comfort in the installations, reducing and facilitating nursing care, reducing pain, and slowing the progression of musculoskeletal deformities.



Fig. 3 CPCHILD[©] pre- and postoperative total score

CPCHILD-TOTAL SCORES BY GMIPCS Level				
GMFCS Level				
(n = 67)				
I	II		IV	V
84.4 (12.8)	79.2 (2.9)	67.9 (13.8)	56.3 (8.1)	44.4 (12.6)

CDCHILD[©] Total Sector by CMECS Loval

Fig. 4 CPCHILD[©] reference score: mean and standard deviations for each population group

In our study, we have shown that there is an ease in dressing, improved nursing, positioning, and reduced pain reported for up to 70% of children following selective dorsal rhizotomy and this benefit is maintained in the long term.

The cohort we studied is, to our knowledge, the largest to date to evaluate the effect of selective dorsal rhizotomy on these criteria in non-walking spastic children. The results found in our study corroborate those of the study by Buizer et al. where 24 GMFCS IV and V patients were studied (improvement for 16/24 children in dressing, 12/24 in nursing, 10/24 in comfort) [10].

In parallel, we observed a significant decrease in lower limb spasticity in the short and long term, which has also been reported in previous studies [6, 7].

Regarding the therapeutic management of joint spasticity, after selective dorsal rhizotomy, there is a significant decrease in postoperative botulinum toxin treatment.

In this group of spastic children, who are operated on late, toxin injections are often continued to treat residual spasticity and possible dystonia.

However, we were not able to demonstrate a significant reduction in the need for orthopaedic bone and soft tissue procedures following selective dorsal rhizotomy.

This last finding may be related to the late age at which the operation was performed in our patients (average age 11 years), who already presented orthopaedic complications preoperatively. For 50% of them, we noted a scoliosis or a hip dislocation preoperatively. Similar figures have been reported in various studies [11, 12].

Bad orthopaedic prognosis factors have been demonstrated in the literature: patient age [12], a high GMFCS stage, and major spasticity of the adductors for hip dislocations [11].

In contrast, the predictive criteria for a good outcome of rhizotomy, such as those of Peacock and Oswestry [13], initially favoured populations of young, walking children or children with a goal of walking, GMFCS I, II, or III (age < 5 years, absence of associated chronic pathology, intelligence quotient > 70, motivated child, solid social environment, no previous neuro-orthopaedic intervention), but the main objective was functional.

Whatever the objective, functional, comfort, or prevention of musculoskeletal complications, "age" remains a priority element in the decision tree. Other criteria could be added to guarantee a better result. As the population is very heterogeneous, these criteria must remain flexible and not be exclusive.

For GMFCS IV and V patients, prognostic criteria could be defined for a good outcome of SDR based on comfort and nursing objectives in addition to age, which seems to be the predominant indicator, such as the perioperative medical and para-medical environment



Fig. 5 Trend in postoperative scores, by the domain of the CPCHILD[©] questionnaire

(multidisciplinary team, hospitalisation in a rehabilitation centre after a scheduled operation, equipment consultation), as well as a "solid" family environment.

The "age" component must be a priority for the GMFCS IV and V patient population, as the older the child, the greater the risk of neuro-orthopaedic deformities in association with significant spasticity.

Studies confirm these two hypotheses. It has been shown that performing SDR in children with spastic diplegia at an early age (2 to 4 years) significantly reduces the rate of subsequent orthopaedic operations [14] and that the rate of post-SDR intervention is higher in non-walking children [15].

Despite a significant decrease in the number of patients receiving postoperative toxins in our study, 60% remain dependent on this procedure. The factors responsible for this dependence are not known. However, advanced age at the time of SDR and orthopaedic deformities already present are probably involved. It would be interesting to evaluate which types of muscles are still spastic and injected and what doses are used. Such a study of the treatment regimen and doses used for our patients could be carried out in a second phase.

For several years, increased attention has been paid to the well-being and quality of life of children with severe multiple disabilities. However, assessment in cerebral palsy is complex. Many quality-of-life scales are not suitable for children with severe impairment [16]. We decided to use the CP-CHILD scale, as it is a validated assessment instrument for measuring change over time or following surgery in children with major multiple disabilities. It would be interesting to reproduce this scale, once the sensitivity tests for changes over time have been validated, which has not been done to date.

Another limitation of the CP-CHILD evaluation criteria is related to the time between the intervention and the questionnaire. We arbitrarily chose to interview children operated on between 2018 and 2022, which could lead to a response bias for the oldest children operated on.

We showed a gain in points in the area of "communication and social interaction" for children who completed the questionnaire. Effects on cognitive functions have already been reported in various studies; the study by Craft et al. showed a significant improvement in attention and audiovisual learning tasks, as well as an effect on the speed of task performance in children operated [17].

To date, the effects on the improvement of supra-segmental functions such as the reduction of upper limb spasticity and the gain in cognitive function are not yet clearly elucidated. This could be due to improved mood, reduced physical discomfort, or possible cortical effects of SDR. This effect was observed in our study population despite the more severe motor and cognitive handicaps. The main study limitation is the retrospective nature of the study, resulting in missing or incomplete data. However, this study could serve as a basis for the design of a future prospective study, with validated measurement scales.

One assessment method that is increasingly used in practice and research is Goal Attainment Scaling. It aims to evaluate the effectiveness of a treatment on the objectives chosen by the patient and his/her family and to follow the evolution over time [18].

The objectives defined by the team and the patient can be multiple and varied, thus they can cover all the fields of the International Classification of Functioning [19]. One of the constraints of this scale is the setup, as all criteria have to be defined in advance.

Conclusions

This study has allowed us to show the benefit of RDS in the "activity and participation" domain of the International Classification of Functioning, with positioning, nursing, and dressing playing a major role in the quality of life of these children.

We also observed a reduction in pain in the aftermath of the intervention for more than half of the patients. RDS could become an additional tool in the therapeutic arsenal for the management of chronic pain in children with multiple disabilities.

A significant reduction in the number of botulinum toxin injections following RDS was shown to be associated with a reduction in postoperative spasticity.

Finally, it is encouraging to note a beneficial outcome of the intervention in areas such as communication and social interaction as revealed by the family interview, as these areas are often treated as secondary in children with a major multi-disability.

These preliminary results pave the way for this surgical procedure to be performed in new indications. Along with intrathecal baclofen treatment, selective dorsal rhizotomy could be offered more frequently to non-walking children GMFCS IV and V. However, in order to optimise the results of SDR, it seems necessary to establish solid criteria and objectives preoperatively, taking into account the singularities of each patient and family.

Author contribution JMS, MK, CK and DS wrote the main manuscript; PB and MAR studied the bibliography; JMV and CB reviewed the manuscript; JMS and DS elaborated the aim and methodology of the study.

Declarations

Conflict of interest The authors declare no competing interests.

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