



Quality of life after selective dorsal rhizotomy: an assessment of family-reported outcomes using the CPQoL questionnaire

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Abstract

Background Selective dorsal rhizotomy (SDR) is widely accepted as an effective procedure for management of lower limb spasticity in children with cerebral palsy. However, effects of the procedure on quality of life are not widely reported and less so using a structured and validated quality of life tool such as Cerebral Palsy Quality of Life Questionnaire (CPQoL). Here, we present complete data for CPQoL outcomes for SDR patients operated in a single institution at 2 years follow-up.

Methods Patients were operated over a 5-year period by the same surgeon using the same technique in a single institution. CPQoL questionnaires were completed by patients and families pre-operatively and at 6 months, 1 year and 2 years post-operatively. Data was collected prospectively.

Results A total of 78 patients (58 male, 20 female), age range 2.6–13.8 years (median 6.33) were included whom underwent SDR between October 2012–November 2017. All had complete follow-up up to 2 years post-procedure (most recent November 2019). Four patients were excluded due to incomplete follow-up data. Statistically significant improvement was seen across five out of seven CPQoL domains and this was sustained to 2 years post-SDR.

Conclusions We demonstrate using a validated Quality of Life Tool that SDR has a beneficial effect on the quality of life for patients with cerebral palsy at this length of follow-up.

Keywords Rhizotomy · Cerebral palsy · Quality of life · CPQoL

Introduction

Cerebral palsy (CP) is a group of permanent conditions arising due to damage to the immature brain either in utero, at birth or soon after birth [1]. Cerebral palsy is characterised by the presence of one or combination of movement disorders (spasticity, dystonia, chorea, athetosis or ataxia) with or without other comorbidities (including disorders of learning, communication, behaviour, sleep, vision, hearing, feeding, salivation and epilepsies). Although the brain injury is static, resulting

musculoskeletal problems are often progressive and become more evident as the child grows [1]. Spasticity is the most prevalent movement disorder in cerebral palsy and can be unilateral, bilateral, lower- or upper-limb predominant. Spasticity causes considerable stiffness and discomfort [1, 2]. Accompanying spasms are painful and can interfere with the child's functioning and the ability of caregivers to care for children. Spasticity-relieving interventions available for CP are physiotherapy, orthotics, oral medications, targeted injections of botulinum toxin, orthopaedic surgery, intrathecal baclofen and selective dorsal rhizotomy (SDR) [3].

SDR is a surgical procedure that aims to reduce spasticity and improve mobility in lower limb spasticity resulting from cerebral palsy. The treatment concept of lumbosacral dorsal rhizotomy for previously termed *congenital spastic paraparesis* was first described by Sherrington in a cat model of cerebral palsy in 1893 and 1898 [4, 5]. The first human subjects were described by Foerster in 1908 using a technique of complete, non-selective, division of the posterior roots of L2, L3, L4, L5 and S1. This led to a marked improvement in spasticity, but complications were frequent including muscle

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weakness and loss of proprioception [4–6]. When proprioception is lost, a patient's ability to stand and walk becomes severely impaired or is lost altogether. Further experiments on the use of dorsal rhizotomy were then abandoned for several decades. As a result of work by Gros [7] and Fasano [8], the concept dorsal rhizotomy was refined further with electrophysiological-guided partial section of the nerve rootlets thought to be contributing to spasticity, with good long-term results [8]. This work transformed the non-selective, complete dorsal rhizotomy of Sherrington and Foerster, into a selective procedure with neurophysiology-guided partial section of the nerves—creating selective posterior rhizotomy or selective dorsal rhizotomy (SDR) as it is now commonly known. In 1982, Peacock and Arens presented their series of 20 children treated with this technique, reporting a significant reduction in tone resulting in improvement in motor function in every case [9].

These outcomes led to global interest in SDR; however, there remained questions over optimal patient selection and optimisation of the surgical technique itself. Peacock described a multi-level laminectomy from L1/2 to S1 and others have performed laminoplasties. There is debate in the literature about the risk of spinal deformity associated with multi-level versus single-level spinal approaches, and this is made more complex by some surgeons performing laminoplasty and others laminectomy [9–14]. Furthermore, spinal deformity in cerebral palsy is a complex matter due to the natural course of the condition, the severity of spasticity, the potential presence of pre-existing spinal deformity before surgery, the age at surgery, as well as factors such as seating and postural management in general.

In 1993, Park et al. described SDR performed through a minimal access 1–2 level laminectomy, with the rhizotomy performed at the level of the conus [15]. His report of 20–28-year follow-up of 95 patients reported that 31/95 (31%) developed scoliosis but only 3% (3 patients) required surgical treatment for this. Of note is that many centres have now adopted this single-level approach instead of the originally described multi-level laminectomy/laminoplasty approach.

SDR is now widely considered to be a standard and accepted neurosurgical procedure for the treatment of spasticity associated with CP [3]. Numerous studies have reported the efficacy of SDR in reducing spasticity [16–27]. Several of these studies have reported long-term maintenance of the loss of spasticity at 5, 7, 10 and 20–28 years [17, 21, 23, 24, 26, 28]. Benefits in range of movement (ROM), gait analysis measures, Gross Motor Function Classification System (GMFCS) and Gross Motor Function Measure (GMFM) have also been shown in studies [11, 18, 21–23, 25, 26, 29, 30]. The gains in ROM have been reported to increase initially at 3 years but decline again by the 10-year mark [21, 22]. The improvement in GMFM has been seen to be greatest in children of GMFCS levels II and III [23]. Tedroff et al. reported that GMFM scores were found to decrease between the 3- and 10-year follow-up [21].

Fewer studies have published results on quality of life (QOL) measures after SDR. Improvements in activities of daily living (ADLs), self-care and independence have been reported [17, 23, 25, 26]. Hurvitz et al. found that, of 88 patients, 38% still had residual pain and spasticity but reported good to excellent health and satisfaction in their lives [31]. It was also found that 65% believed that SDR had had a beneficial impact and these participants reported that they would recommend the surgery to others [31]. This report of satisfaction has been found in further studies [29, 30]. Park et al. found that 38% had pain in the back and lower limbs and that 9% had constant leg pain [30]. Despite this, 91% believed that SDR had been personally beneficial and 88% would recommend SDR to others [30].

SDR aims to improve the functional outcomes for patients with CP by reducing lower limb tone. The sustained reduction in spasticity has been overwhelmingly reported. However, there have been some discrepancies with respect to the other functional outcomes. Despite this, as already outlined, numerous papers have found that the majority of CP patients who underwent SDR are satisfied and rate their personal health as good. To better understand the quality of life outcomes following SDR, this study follows a cohort of 78 children with complete data, pre-op and at 6 months, 1 year and 2 years post-SDR using a standardised quality of life measure.

Methods

Participants and data collection

The data was collected prospectively from a study cohort of 102 children who underwent SDR at Leeds General Infirmary from October 2012. Patients were included if there was complete follow-up for 2 years post-operatively. Prospective data collection occurred throughout this period and with data collection and subsequent analysis using Microsoft Excel. Assessment of statistical significance was made using the paired two-tailed *t* test.

The selection criteria for SDR surgery were the following: (1) spastic diplegic cerebral palsy; (2) preterm birth or full term with typical signs of spastic diplegia; (3) aged 2+; (4) MRI confirmation of periventricular leucomalacia or white matter injury of prematurity, with no evidence of injury to the thalami, basal ganglia or cerebellum; (5) GMFCS levels II-III; (6) definite dynamic spasticity in lower limbs affecting function and mobility; (7) no dystonia; (8) no evidence of genetic or progressive neurological illness; (9) mild-to-moderate lower limb weakness with ability to maintain antigravity postures; (10) no significant scoliosis or hip dislocation.

Patient selection for SDR was decided by a multidisciplinary team including a consultant paediatric neurosurgeon (Senior Author), a consultant paediatric neurologist or consultant in paediatric neurorehabilitation and a highly specialised

paediatric physiotherapist. Paediatric orthopaedic surgery input was also available on request. Patients were assessed in a multi-disciplinary spasticity treatment clinic for selection for SDR surgery. Pre-operative assessment of GMFM and 3D gait analysis was performed immediately prior to surgery, and then repeated at 4–6 months, 12 months and 24 months post-operatively. Ongoing follow-up reviews of these patients will be performed at 5 years and 10 years post-operatively.

Procedure

SDR was carried out by the same neurosurgeon (Senior Author), using Park's method [15, 28]. A single-level laminectomy was performed at the level of the conus medullaris. This level was confirmed using ultrasound in the operating theatre by the senior author. The sensory nerve roots of L1-S1 were then isolated from the motor nerve roots and the lower sacral nerve roots. Under neurophysiology guidance, each nerve root was then divided into 3-rootlets and tested to determine the activity of each rootlet. Of the three rootlets tested, the most active two were then divided, equating to 66% section of each dorsal root. Following surgery, patients were admitted to HDU for 36–48 h with epidural pain relief, before transfer to the ward. Physiotherapy rehabilitation commenced on day 3–4 post-operatively and continued for 3 weeks (15 working days). This was delivered mainly as an outpatient-based therapy service. Patients were then discharged to their usual community physiotherapy team with a recommended program of exercise and rehabilitation.

Measures

Post-operative outcomes were collected prospectively. Participants were assessed at baseline, at 6 months, 1 year and 2 years. Each assessment consisted of evaluation by the physiotherapy team and consultant paediatric neurosurgeon. The assessments of GMFM-66, Modified Ashworth Score, Range of Movement and Muscle Power were assessed and recorded by the physiotherapy team. In addition, X-rays of the spine and hips were undertaken to assess for deformity and hip subluxation. VICON 3D gait analysis was undertaken and reported by a specialist Gait Lab team (reported separately). Results from this data will be published in a separate manuscript.

Before the procedure and after each assessment, parents were issued with a Cerebral Palsy Quality of Life Questionnaire (CPQoL) to complete [2]. The parents were asked to complete this with their child but without recourse to their previous answers. Following questionnaire completion, this was uploaded to the spreadsheet and archived.

Quality of life validation tool: CPQoL

The CPQoL is an internationally validated questionnaire specifically designed to report data for children with cerebral palsy. Questionnaires are designed for parent completion (child aged 4–12 and 13–18), patient-completion (age 9–12, 13–18) [2]. The domains evaluated using the questionnaire were “social well-being and acceptance”, “feelings about functioning”, “participation and physical health”, “emotional well-being and self-esteem”, “access to services”, “pain and impact of disability” and “family health” [2].

Each question on this form is worded in a way such as “How do you think your child feels about...” and requires an answer from 1 to 9 where 1 = Very unhappy, 5 = Neither happy nor unhappy and 9 = Very happy. Each score was converted to a score from 0 to 100 using the CPQoL data manual.

To enable comparison with previous answers, we used the parent report questionnaire throughout the study period. The results for each QoL domain were collated and averaged for the cohort.

Results

Out of a total of 82 patients, four patients were excluded from analysis due to incomplete follow-up data. Therefore, 78 patients (58 male, 20 female) were included with an age range at SDR 2.6–13.8 years (median 6.33). These patients underwent SDR between October 2012 and November 2017. All had complete follow-up up to 2-year post-procedure (most recent November 2019).

Table 1 demonstrates the CPQoL results pre-operatively, at 6 months, 1 year and 2 years post SDR with significant values in italics.

Across the seven domains, there was improvement seen but no statistically significant improvement in the domains of “Social well-being and acceptance” or in “Family health” following SDR.

There was however a highly significant improvement in the domains of “Participation and physical health”, “Feelings about functioning”, “Access to services” and “Pain and impact of disability” at 6 months, 1 year and 2 years post-op. “Emotional well-being and self-esteem” however took 1 year to demonstrate a significant improvement as there was borderline non-significance at 6 months post-procedure ($p = 0.069$).

Discussion

In this article, we present the outcomes specifically for patient quality of life (as reported predominantly by parents) after SDR. Although still a relatively new procedure, there are many published studies reporting outcomes as long as 28 years

Table 1 Table demonstrating mean CPQoL percentages pre-operatively at 6 months, 1 year and 2 years post-selective dorsal rhizotomy in 78 patients

Domain	No. of patients	Mean Pre-op %	Mean 6-month post-op %	<i>p</i> value	Mean 1-year post-op %	<i>p</i> value	Mean 2-year post-op %	<i>p</i> value
Social well-being and acceptance	78	79.9	86.9	0.16	87.5	0.38	86.4	0.17
Feelings about functioning	78	70.8	80.7	< 0.001	82.4	< 0.0001	80.7	< 0.0001
Participation and physical health	78	51.3	70.1	< 0.0001	72.4	< 0.0001	69.9	< 0.0001
Emotional well-being and self-esteem	78	80.2	86.3	0.069	87.2	< 0.0001	85.9	< 0.001
Access to services	78	59.4	67.3	0.004	67.5	< 0.0001	66.9	0.0013
Pain and impact of disability	78	35.0	25.4	< 0.0001	25.2	< 0.0001	26.1	< 0.001
Family health	78	69.0	73.6	0.26	73.1	0.079	73.7	0.10

after the procedure. However, these articles tend to focus on functional outcomes such as GMFMS-66, Modified Ashworth Score, range of movement and muscle power [17, 21, 23, 24, 26, 28, 32].

Whilst these outcome measures are highly important, it is also crucial to assess impact of SDR on patient and family quality of life. Some studies have assessed these important parameters, however, the measures used have typically been basic and internationally validated systems like the CPQoL for SDR patients have not been previously reported [33, 34].

Patient selection

Whilst this paper is focussed on the quality of life outcomes following SDR, we also would like to address our patient selection for this surgery. There is ongoing discussion as to which patient groups would benefit most from SDR, especially in the longer term. Since this surgery is performed to reduce spasticity in cerebral palsy, it can potentially be used for children at any GMFCS level. Our experience to date is that we have only performed SDR for children functioning at GMFCS level II or III. When we initiated our SDR program in 2012, we particularly selected children in this group as we felt there was more data supporting SDR for them. However, we have assessed children on either side too. In general, we have found that those functioning at GMFCS level I can have their tone managed effectively with targeted botulinum toxin injections and/or oral anti-spasticity treatments.

Where GMFCS level II or III children are usually looking to improve their functional mobility, for children at GMFCS levels IV or V, the goals are more centred around comfort and pain relief rather than mobility. Since painful spasms often arise from spasticity, that certainly supports the role of SDR for these children too. However, one of the important things for children at GMFCS level IV is that they may rely on their quadriceps tone to help them stand, thereby facilitating undertake standing transfers. For this group, since SDR will reduce the quadriceps tone, it may reduce their ability to undertake standing transfers, with a consequent negative functional

outcome. For these reasons, in general, we tend to find ourselves recommending intrathecal baclofen therapy because it can be tailored to the child's needs and can also be reversible if it is reducing their functionality.

These challenges are less with the GMFCS level V children as they tend to rely more upon hoist transfers, however, they have other complex needs that again make an SDR decision challenging. These include the presence of other movement disorders such as dystonia or ataxia. There have also been long-term studies that raise questions regarding the longevity of SDR benefits in these children.

It is also our experience that children functioning at GMFCS level IV or V often have a more complex brain injury than simply PVL—one which involves the thalami or basal ganglia. This in turn means that they more frequently have other movement disorders such as dystonia. This is considered to be a contraindication to proceeding with SDR.

CPQoL

The term 'Quality of Life' is used with much inconsistency and it is felt that clinical practice benefits from uniform understanding and consensus-driven definition such as using a scoring system such as CPQoL [35]. This has been put into practice in one observational cohort study performed across five centres that did use the CPQoL. Here, there was found to be a beneficial outcome in Quality of Life for SDR patients and this combined with positive functional outcomes led to SDR being funded by a national health system [36].

Assessment of quality of life is a complex task due to the need to balance the subjective perception about quality of life for the individual child/family, together with the need to consider disease-specific factors, as well as general measures of health, functioning and the impact of a disability. This is made more complex by varying definitions of quality of life across disciplines. The CPQoL questionnaire was developed as the first cerebral palsy condition-specific tool for quality of life assessment [37]. It is based on the International Classification of Function and the WHO definition of quality of life—

assessing “an individuals’ perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [38]. It was developed by an international team, with contributors in Australia, America, Germany and Scotland, and was coordinated by a research team in the University of Melbourne. The first questionnaires developed were for families/caregivers of children aged 4–12 years, with the addition of a child-report questionnaire (for ages 9–12) and subsequently a teen questionnaire (for ages 13–18) [39]. The CPQoL tool was validated by the international development team, including confirmation of the construct validity, test-retest validity, internal consistency and to compare it with other measures of QoL, health and function [37, 40]. It has been translated into over 20 different languages since its launch in 2007 and has been validated for use for children of all GMFCS levels [2, 37, 39–43]. Research has also confirmed that the CPQoL items correspond with perspectives provided by children and their parents/caregivers who discussed the quality of life of their child [42]. We therefore chose this tool since it was a disease-specific tool with international validation and applicable to quality of life as defined by WHO.

Benefit of SDR for QoL

Clearly, there is more to SDR than simply functional outcomes, and in this article, we present our experience in a single institution with a single operating surgeon. In 78 patients at 2 years follow-up, we found SDR to have a beneficial effect on Quality of Life across five out of the seven domains for CPQoL. These were “Feelings about functioning”, “Participation and physical health”, “Emotional well-being and self-esteem”, “Access to services” and “Pain and impact of disability”. Interestingly, apart from “Emotional well-being and self-esteem”, which took 1 year to show significant improvement, all these domains showed improvement at 6 months post-operatively that was sustained to 2 years after SDR. SDR did not have a statistically significant effect on feelings of “Social well-being and acceptance” and “Family health”, however, as the *p* values appear close to significance, with a larger number of patients, a statistically significant improvement may have been observed. In any case, clearly both of these domains are highly complex and multifaceted and are affected by numerous factors aside from solely a patient’s physical functioning. “Social well-being and acceptance” for example is affected by the presence of other comorbidities (including learning difficulties), school and social environmental factors and support structures [44, 45]. Certainly, our results support the benefit of SDR for quality of life as well as the functional outcomes supported in the literature.

Study limitations

This study does carry limitations not least that we are still collecting data for 5 years and 10 years post-SDR. In this study, we included 78 patients with complete follow-up data at 6 months, 1 year and 2 years post-operatively. We excluded four patients whom had incomplete data to allow comparison of a single complete cohort at these intervals of follow-up. It is also important to recognise that the CPQoL tool was not designed for long-term patient follow-up, although the method used in our centre of blinded completion of the questionnaires appears to have resulted in consistent comparative data for the presented cohort of patients. Another challenge we face in reviewing the long-term data is that, as children get older, the question dataset will change, making future comparison of outcomes more challenging.

Historic challenges have been raised to SDR-related outcomes that patients and their families will report improvements simply because they receive an improved level of input from physiotherapy and specialist multidisciplinary teams. This is a valid concern which we appreciate. The challenge comes in how to address that with respect to a control group of patients. Finding an appropriately sized, age- and function-matched control group to compare with the SDR cohort would be extremely difficult. Furthermore, whilst families are meant to access an increased level of community physiotherapy following SDR surgery, we found that this increased access has not been universal, and many families reported having to self-fund additional therapy sessions.

Whilst this data points to the positive effect on quality of life of management of spasticity by SDR, we acknowledge that this surgery is only addressing one aspect of the complex set of complications associated with cerebral palsy.

It is important to acknowledge that the data provided is an analysis of parent/caregiver reported quality of life for children with cerebral palsy. Several of the parents reported completing the questionnaire with their child, but this was not standardised across the cohort and was not specifically indicated on the response form. Whilst it has been widely accepted that parental reports provide an appropriate proxy for child quality of life, recent studies have pointed to important differences in quality of life reporting in these two groups [44]. In addition, due to the young age of the patient cohort at the time of surgery, it is difficult to address this and deliver patient-reported measures that can be collected from before surgery and into the follow-up period.

Finally, and importantly, the funding of SDR surgery through this study has been partly through NHS pathways and partly through self-funding pathways, where patients have paid the hospital costs, but private fees were not levied, to increase the accessibility of the surgery. Naturally, these families are highly motivated but may also be conflicted in having high expectations of improvement from SDR. This

combination could lead to an inherent selection bias for such patients and families which affects the validity of a subjective qualitative measure such as CPQoL.

In spite of these limitations, we feel that this article adds useful data regarding quality of life after SDR to improve our understanding of another aspect of outcome from this surgery. We present a large prospective cohort of patients operated by the same surgeon using the same technique and the same post-operative therapy protocol with complete follow-up at consistent intervals. We also present underreported information on family-reported outcomes using an internationally validated tool.

Despite the limitations of this study, the improvement across the CPQoL domains that we demonstrate in this study present a structured indication of the child's and family's personal feelings after a major operation for children with long-term disability from cerebral palsy.

Conclusions

Using the CPQoL assessment tool, we have demonstrated statistically significant improvement in five of the seven domains as reported predominantly by parents or caregivers. These were most highly significant for “Participation and physical health”, followed by “Feelings about functioning” and “Pain and impact of disability” then, “Emotional well-being and self-esteem” and “Access to services”—in order of significance at 1 year and 2 years post-operatively.

These quality of life data add an important additional dimension to the existing literature base which has largely focussed on physical post-operative measures after SDR surgery. Ongoing data collection and analysis will determine whether this is sustained at 5 years and 10 years post-procedure.

Compliance with ethical standards

Conflict of interest None of the authors have any conflict of interest.

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