Original Article

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Bilateral pallidotomy to status dystonicus in children from public health system: case series and technical note

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Background: Dystonia is the second most common pediatric movement disorder after spasticity and may occasionally present as status dystonicus (SD), a life-threatening neurological emergency. Medical management of SD remains challenging and sometimes ineffective, therefore neurosurgical alternatives such as intrathecal/intraventricular baclofen administration, deep brain stimulation and pallidotomy may be needed in severe refractory cases.
Objective: To evaluate the safety and effectiveness of bilateral pallidotomy in children with severe, drug-resistant dystonia, including cases of status dystonicus.
Methods: This retrospective study analyzed five pediatric patients (mean age: 8.23 years) treated between January 2024 and February 2025 at a tertiary public hospital in Brazil. All had a Dystonia Severity Score (DSS) ≥3 and underwent bilateral pallidotomy. Clinical outcomes, DSS changes, medication use, and postoperative medications were assessed.
Results: All patients showed clinical improvement, including resolution of status dystonicus. The average time to symptom stabilization was 6.8 days. The number of medications decreased by 22.86% postoperatively. No major complications were observed. Two patients had minor postoperative radiologic findings without clinical repercussions.
Conclusion: Bilateral pallidotomy appears to be a safe and effective option in the management of severe, drug-resistant dystonia in children, particularly status dystonicus. These preliminary results highlight its potential role in selected pediatric cases. Larger studies are needed to confirm long-term efficiency and safety of bilateral pallidotomy in this context

Keywords: dystonia, pallidotomy, status dystonicus, children

INTRODUCTION

Dystonia is one of the most common movement disorder observed in children (1) and can be defined as involuntary and sustained muscle contractions causing twisting and repetitive movements, abnormal postures, or both (2). Dystonic symptoms may arise from a huge variety of different neurological or systemic conditions, genetic or acquired. It may be highly debilitating both for children and adult patients, leading to functional disability, social isolation and pain. Although the pathological mechanism of dystonia remains unclear, research suggests that low activation of the GPi decreases its inhibitory effect on the thalamus, leading to increased cortical excitability and hyperkinetic symptoms (3). Primary generalized dystonia (PGD) can manifest at any age, with earlier diagnosis (before the age of 26) associated with more severe disease (4). The medical management of dystonia depends on the underlying pathology causing dystonic symptoms, but in general involves GABA agonists, levodopa, dopamine depleting agents, benzodiazepines and botulinum toxin. Intrathecal baclofen and botulinum toxin injections can be useful in treating dystonia, but results are variable, particularly for symptoms in the upper limbs (5) Although medication remains the first-line therapy for symptom relief, options are limited, and evaluating therapeutic response is even more challenging due to developmental, behavioral, and speech delays that are often comorbid in the pediatric population.

MATERIALS AND METHODS

This study involves a retrospective analysis of children with severe dystonia treated between January 2024 and February 2025 at a public national reference center for high-complexity pediatric care in Brazil. Five children with a Dystonia Severity Scale (DSS) of 3 or higher were included. All patients underwent bilateral pallidotomy for the treatment of severe drug-resistant generalized dystonia

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Surgical Technique:

During the surgical procedure, a stereotactic frame (Micromar®, São Paulo, Brazil) was fixed so that its base was parallel to the orbitomeatal line, and a computed tomography (CT) (1x1 mm voxels) was acquired. These images were then transferred to a stereotactic planning software (MNPS®, São Paulo, Brazil) and fused with the previously obtained MRI sequences in order to anatomically mark the target and obtain the stereotactic coordinates (X, Y, Z, ring/alpha, and arc/beta).

The procedure was performed under general anesthesia due to the severity of the clinical condition, using total intravenous anesthesia with continuous Remifentanil and intermittent doses of Propofol. No muscle relaxants were used in order to allow intraoperative clinical assessment, e.g. tonic muscle contraction in case of inadvertent co-stimulation of the internal capsule. Bispectral index (BIS®) monitoring, with a target range of 60–70 during evaluation periods, ideally allowing for some spontaneous movement to enable clinical assessment of responses to intraoperative stimulation.

Stereotactic CT scan is then transferred to the planning station and fused with the MRI images. Anterior and posterior commissures are marked on MRI images. Targets were defined by direct visualization of the anatomical structure on scans. The patient was positioned supine with straight headboard and neutral position. The stereotactic coordinates were set on the frame and confirmed by at least two other team members. A burr hole was made, and dura coagulated before the insertion of the radiofrequency (RF) electrode. Stimulation is useful in patients to rule out adverse events (Garg, 2020).

The target was confirmed through intraoperative fluoroscopy, impedance evaluation (white vs gray matter differences), intraoperative neurophysiological monitoring, including neuromyography to map adjacent structures, such as internal capsule response during macrostimulation, before radiofrequency ablation was ultimately performed. Lesions were made based on target coordinates obtained through fusion of the stereotactic CT and MRI sequences, aiming classical ventroposteromedial GPI initially. Thermal ablative radiofrequency lesions were done, with a 2mm exposed tip (1,27mm diameter) canula, initially at 45 Celsius degrees (°C) for 1 minute (evaluate any possible deficits), followed by 3 to 4 definitive lesions at temperatures of 70°C for 60 seconds, using a 40V radiofrequency device in a distal-to-proximal direction, parallel to internal capsule, aiming a complete craniocaudal GPI lesion. Clinical and neurophysiological evaluations were done between each lesion, without any changes in initial response patterns.

After the procedure, the patients underwent volumetric non-contrast cranial computed tomography to confirm the lesion site and assess for potential complications.

RESULTS

Between January 2024 and February 2025, a total of five patients underwent bilateral pallidotomy for the treatment of severe dystonia. Out of these, four were male and one was female, whereas the mean ± SD (range) age of the patients was 8.23 ± 3.81 (1-12) years (table 1).

Table 1- Patient demographics, baseline dystonia characteristics and DSS.

	Dystonia Etiology	Trigger Factors	Medications before (n)	Medications after (n)	Dose reduction?
Male, 8 y	DYT 4 likely	Yes, UTI	8	6	Y
Male, 9y	Cerebral palsy (kernicterus)	No	6	6	Y
Male, 11y	Cerebral palsy (kernicterus)	Yes, URTI	6	5	Y
Male, 12y	Wilson's disease	Yes, Elective gastrostomy	7	5	Y
Female, 1y2mo	Cerebral palsy (possible	Yes, Pneumonia and Upper	7	5	Y

Legend: N: number; UTI: Urinary Tract Infection; URTI: Upper Respiratory Tract Infections; Y: yes.

A variety of dystonia etiologies were identified in these patients, including cerebral palsy due to kernicterus, cerebral palsy presented with corpus callosum dysgenesis and craniofacial dysmorphic features suggestive of a possible genetic syndrome, Wilson's disease and genetic dystonia with a probable association with DYT4 (table 2).

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The patients in this study were using an average of 7 (range 6-8) medications to control the dystonia before undergoing pallidotomy. This number reduced to 5.4 after the procedure, which represents a decrease of about 22.86%. Of the five patients who underwent the procedure, only one was not in dystonic status, presenting a DSS of 3. This patient had a history of oscillatory DSS.

Among the patients in dystonic status classified as DSS 4 or 5, the main triggering factors included infectious episodes such as upper respiratory tract infections and urinary tract infections, as well as elective surgical procedures, including gastrostomy placement and postoperative periods following upper gastrointestinal endoscopy.

The Dystonia Severity Score (DSS) was reassessed postoperatively and compared with preoperative values. All patients demonstrated clinical improvement following pallidotomy. The mean ± SD (range) time required to resolve dystonic status was 6.8 ± 5.49 days (range: 2–14), with three out of five children recovering in less than five days. DSS assessments were conducted at both 3- and 12-month follow-up intervals; however, some 12-month data remain incomplete, as certain patients are still undergoing follow-up (table 2).

Table 2- Dystonia Severity Scale (DSS) follow-up.

	DSS preoperative	DSS postoperative	DSS 3mo	DSS 6mo	DSS 12mo	SD resolution (days)
Case 1	5	1	1	1	1	13
Case 2	3-4	1	1	1	2	2
Case 3	5	2	1	1	NA	2
Case 4	5	1	1	1	NA	3
Case 5	5	3	3	3	NA	14

Legend: Mo: months; NA: non-available

No complications associated to the surgical procedure were noted in this series. However, subtle asymptomatic findings were evidenced in the postoperative CT scan of two patients, including a small subdural hematoma and the presence of pneumocephalus, both without clinical repercussions.

Following surgery and hospital discharge, caregivers were invited to report on their experience regarding potential clinical improvements and overall satisfaction with the surgical treatment during the first 3 months FU. A Likert scale (1 to 5) was used for assessment, where 5 indicated the highest level of satisfaction. Assessments were conducted at the 3-month postoperative follow-up (table 3).

Table 3- Caregiver Satisfaction Level

	3 mo	12 mo
Case 1	5	5
Case 2	5	5
Case 3	5	NA
Case 4	4	NA
Case 5	4	NA

Legend: 1- Very Dissatisfied; 2 Dissatisfied; 3- Neutral; 4- Satisfied; 5-Very Satisfied; NA- non-available

DISCUSSION

Status dystonicus (SD), the most severe form of dystonia, is a medical emergency with significant morbidity, including metabolic derangement, respiratory/bulbar dysfunction, fractures and pain. Children in SD often require care in the intensive care for sedative infusions, airway management and other lifesaving procedures. Up to 12.5% of severe cases of SD result in death. (7). Status dystonicus is a neurological emergency in children with severe dystonia, with significant complications and a high mortality rate. It is often triggered by events such as fever, infections, drug exposure or sudden drug withdrawal. This condition can rapidly lead to rhabdomyolysis, metabolic failure, and bulbar complications, requiring admission to the intensive care unit (ICU) for sedation and ventilation (8).

There are numerous scales to measure the severity of dystonia (e.g., the Burke-Fahn-Marsden Dystonia Rating Scale and the Barry-Albright Dystonia Scale). Limitations of these scales include their time-consuming nature, the need for considerable training, a plateau effect that limits their utility in the most severely affected cases and concerns about reliability and minimal detectable differences, particularly in acquired dystonias, which are more commonly observed in childhood (9).

A 5-point scale developed at Evelina London Children's Hospital to pragmatically classify dystonia severity (DSAP), proposing a workup flow, with scores of 4 to 5 representing status dystonicus (9). Lumsden, 2020 (10) related 63 episodes of dystonia exacerbation, 34 were classified as grade 3 on presentation, but about one third (n=11) of them, later progressed to grades 4 or 5. The assessment of dystonia severity commonly relies on that scale originally published by Lumsden et al, in 2013 (9). A modified version,

denominated as Dystonia Severity Scale (DSS), incorporating appropriately mapped treatment guidelines, has been developed to serve as a supplementary tool for determining the severity of dystonia for the purpose of triaging and initiating clinical care pathways. Additional parameters have been integrated to help identify when to initiate the acute dystonia pathway versus the refractory status dystonicus pathway or when escalation of care may be warranted. These parameters also guide clinicians in determining when to adjust maintenance medications. Major electrolyte abnormalities are defined as hyperkalemia with serum potassium levels > 5.5 mEq/L. Renal failure is defined as a serum creatinine level greater than 1.5 times the baseline, accompanied by reduced urine output (7).

The current literature on the management of status dystonicus is scarce and lacks homogeneous methodology and clarity in follow-up data, which complicates the assessment of results, treatment consolidation and reproducibility. Among the various clinical scales for dystonia, the DSS has proven to be practical, quick to execute, and treatment-directed, making it an interesting tool for evaluating patient's profile. As for medications in continuous use, they may add additional burdens related to posology, associated side effects, and also the financial impact on family and caregivers. Therefore, the fact that pallidotomy led to a decrease of the amount of medications to control dystonic symptoms in our series adds to the positive impact of the procedure on the patient's functional outcome.

Status dystonicus may be refractory to traditional pharmacological therapy. Alternative and invasive strategies have been developed, but no unequivocal guidelines for its treatment have been defined. Literature reports reveal that a gradual multistage approach may be necessary, ranging from enteral pharmacologic therapy to ICU procedures and surgery (continuous intrathecal or intraventricular baclofen infusion, thalamotomy, pallidotomy or deep brain stimulation) (11).

Early surgical treatments for movement disorders targeted the ventrolateral thalamic nuclei and showed satisfactory results with up to 70% symptom reduction using the thalamus as a target. However, these results were not replicated in other studies, and the risk of developing dysphagia and dysarthria after bilateral thalamotomy was high, leading to the search for new targets such as the internal globus pallidus (12).

Pallidotomy was first used to treat refractory dyskinesias in patients with advanced Parkinson's disease and soon became the preferred target for dystonia. However, trends changed since the introduction of deep brain stimulation (DBS) in the 80's. (13). The advantage of DBS is the ability to control stimulation-related adverse effects, such as dysphagia or dysarthria, through parameters adjustments. However, it brings another set of risks, including a higher rate of hardware-related complications in children with dystonia. Data from multicenter collaborations demonstrate a remarkable rate of DBS-related adverse events during childhood, with hardware-related issues being the most common. Each complication is challenging and usually requires hospitalization, greatly impacting patients' quality of life. This should be considered when advising patients and their families about this therapeutic option. There is a trend toward a higher complication rate in very young children, which should be considered when evaluating early-age DBS, when brain function and plasticity for neuromodulation are highest (14). Kaminska, 2016 (15), cited the most common as being surgical site infection (10.3%) and electrodes issues, such as fractures, migrations, among others (18.4% combined).

The target is determined using the sagittal, coronal, and axial MRI planes of 1-mm thickness obtained with volumetric sequences. The sagittal plane is used for determination of the anterior commissure (AC) and posterior commissure (PC). A line between these two structures is used to determine the direction of the coronal planes. Coronal planes are obtained perpendicular to the AC-PC line. The pallidal target is determined based on the coronal plane. The mammillary bodies are identified as well as the internal capsule. The target is located in this coronal plane, just lateral to the internal capsule and above the amygdala, before reaching the lateral cerebral fissure, and 2 mm above and lateral to the optic tract (16). The measurements given by these authors for Parkinson's disease patients are not readily applicable to children with cerebral palsy or other acquired conditions because of the variability of the size and shape of their brain (17).

From an anatomical perspective, the expected size of the nucleus is likely smaller than in adults, especially in the context of acquired forms of generalized dystonia, where atrophy and encephalomalacia are frequent findings, which requires high-quality and targeted imaging of the area of interest. Clinical, particularly the verification of the proximity to the internal capsule with motor macrostimulation and continuous electroneuromyography, were successfully applied in most patients; however, in some cases, the parameters were higher than those published in the literature, which are standardized for adults. Late control cranial MRIs were performed to assess the correlation between planning and the final result, providing useful information for this discussion, in preparation for future publications.

Stereotactic surgical procedures require precise target positioning, which has been enabled by the advancement and improvement of imaging techniques. The FGATIR sequence was based on a standard T1-weighted MP-RAGE

sequence but incorporated the concept of signal suppression found in FLAIR and short tau inversion recovery (STIR): suppression of CSF signal (as in FLAIR) and fat signal suppression (as in STIR). This allowed for white matter signal suppression and an image in which the brain parenchyma consisted only of gray matter signal. The preferential suppression of white matter signal by FGATIR enables excellent delineation of gray matter structures surrounded by highly myelinated areas, such as the basal ganglia (18).

Dystonic children usually have low weight, in our experience, from 10-15 kg to a maximum around 30 kg, but on average, they range between 20-25 kg, which increases the risk of complications. During stereotactic halo placement, pediatric fixation pins with blunt tips and limiters should be used to avoid iatrogenic fractures. For children under 2 years of age, the skull is often not rigid, with the risk of displacement of the arc during surgery, turning the procedure unfeasible. There are reports of using rigid supports to reduce the chances, but this is not well established in the literature. (19). Furlanetti, 2015 (20) had shown a high rate of complications in children under 1 year of age, 18%, compared with 3.6% in children over 3 years of age, with 5% overall being related to frame fixation. Anesthetic technique care lacks protocols and may possibly difficult neurophysiological monitoring, in addition to the fact that, in status dystonicus, the use of continuous sedatives for days or weeks probably also impairs response.

The major concern with bilateral pallidotomy is the possibility of transient or permanent bulbar complications, such as dysphagia and dysarthria. Additionally, patients may experience emotional, behavioral and cognitive deficits (21). Bilateral pallidotomy has been reported to be associated with permanent parkinsonism, including postural instability and gait disturbances that are refractory to medication (22).

Simultaneous bilateral pallidotomy resulted in symptom improvement in all patients with acquired generalized dystonia, with more than 40% improvement in most cases. Status dystonicus responds to bilateral pallidotomy. Bulbar complications remain a concern but have a low incidence (23). In this specific population that already has high morbidity, the possible complications cited in literature such as dysarthria, dysphagia and motor deficits would generate minimal functional loss and are sometimes not even noticed, in addition to the chance of spontaneous recovery.

Compared to definitive lesion procedures, deep brain stimulation (DBS) was associated with a longer time to resolution of status dystonicus (SD). Pallidotomy led to a faster resolution, with an average time of 21.8 ± 20.2 days, versus 34.8 ± 19 days following DBS. Although this difference was not statistically significant, it may still be clinically relevant. DBS is a neuromodulation technique that gradually restores the electrical stability of neuronal networks. It is well established that, in uncomplicated dystonia, the therapeutic effects of DBS often take weeks to months to manifest. In contrast, pallidotomy may provide more immediate benefits by anatomically disrupting a dysfunctional circuit, thereby enabling the remaining motor pathways to function more effectively in a shorter time frame (24).

CONCLUSION

Bilateral pallidotomy proved to be a safe and potentially effective neurosurgical intervention for the management of severe, drug-refractory dystonia in pediatric patients in our cohort, allowing progressive decrease in the amount of antidystonic medications in use. No major postoperative complications were reported. These findings support bilateral pallidotomy as a viable therapeutic option in selected cases of severe life-threatening pediatric dystonia, particularly for patients with refractory status dystonicus. Further studies with larger cohorts and longer follow-up are needed to validate these preliminary results and assess long-term outcomes.

DISCLOSURES

Ethical approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the local Ethics Committee, number: 153670588

Consent to participate

The patients gave consent to use their information and images for research purposes. *Consent for publication*

The patient gave consent to use his information and images for publication.

Conflict of interest

The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper

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Artificial intelligence

No artificial intelligence assistance were employed in the preparation of this manuscript

CONTRIBUTIONS

-**Antônio Jorge Barbosa de Oliveira**: Conceptualization, Data curation, Formal Analysis, Investigation, Methodology, Project administration, Supervision, Validation, Writing – original draft, Writing – review & editing
-**Arthur de Melo Monteiro Bastos**: Methodology, Project administration, Writing – review & editing
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