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National surveillance of oral medication prescription for children with dystonic cerebral palsy

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Abstract:

Aim: Oral medications are often first line medical management for children with cerebral palsy who have generalised dystonia, however evidence for their effectiveness is limited and dosing practices are inconsistent. As a first step to improve consistency, this study aimed to examine current clinical

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practice of expert doctors for prescribing medications for children with dystonic cerebral palsy including prescribing patterns and combinations of medications used.

Methods: This was a prospective surveillance study of medical doctors working in major Australian centres who manage children with cerebral palsy. Each week over a continuous six-month period, doctors completed a custom developed online survey for children seen that week with dystonic cerebral palsy for whom they prescribed a new medication to treat dystonia.

Results: Twenty-five doctors consented to participate, 16 of whom prescribed new medications for dystonia in children with cerebral palsy over the study period. There were 77 children who were prescribed new medications. Baclofen and gabapentin were prescribed most, followed by levodopa, trihexyphenidyl and diazepam. The most common combinations of medications were baclofen and diazepam or baclofen and gabapentin. Dosage regimens were variable, particularly for trihexyphenidyl and diazepam.

Conclusion: Inconsistencies in dosing regimens remain for oral medication prescription by Australian doctors when managing dystonia in cerebral palsy. Future studies using consensus of expert clinicians will be conducted to develop guidelines in an area where the evidence for individual medications is extremely limited.

Keywords: dystonia, cerebral palsy, medication

What is already known on this topic

1. Oral medications are usually first line medical management for generalised dystonia in cerebral palsy
2. A range of oral medications are used to manage dystonia in cerebral palsy
3. There is limited evidence for the effectiveness of most medications used in dystonic cerebral palsy

What this paper adds

1. The most common medications prescribed for children with dystonic cerebral palsy are baclofen, gabapentin, diazepam, levodopa and trihexyphenidyl, often in combination
2. Dosage regimens are variable, particularly for trihexyphenidyl and diazepam
3. Clinical guidelines for medication prescription developed through consensus of expert clinicians are urgently required

Introduction

Dystonia, a complex movement disorder commonly seen in cerebral palsy, is characterised by involuntary sustained or intermittent muscle contractions that cause twisting and repetitive

movements, abnormal postures, or both [1]. In cerebral palsy, dystonia is a subset of dyskinetic cerebral palsy, which is the second most common type after spastic cerebral palsy [2, 3]. Dyskinetic cerebral palsy can have many causes, including perinatal hypoxia–ischaemia in infants born near to term, neonatal hyperbilirubinaemia, brain maldevelopment, intracranial haemorrhage, stroke, or cerebral infection [3]. Dystonia may be associated with basal ganglia and cortical/subcortical lesions typically arising late in gestation or around birth [4]. Oral medications are usually the first line medical management for children with generalised dystonia in cerebral palsy to manage this difficult movement disorder, however, there is limited evidence regarding their effectiveness [5] and effectiveness might be influenced by aetiology of the dystonic cerebral palsy. A systematic review of pharmacological and neurosurgical interventions for managing dystonia in cerebral palsy [5] informed the development of the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) Dystonia Care Pathway (<https://www.aacpdm.org/publications/care-pathways/dystonia>). For oral medications, there were few studies that met the inclusion criteria specific to dystonia in cerebral palsy; only five studies on trihexyphenidyl, one for levodopa, and none for oral baclofen, benzodiazepines, clonidine, or gabapentin. Trihexyphenidyl was found to be possibly ineffective for reducing dystonia and there was inadequate evidence to support other oral medications for reducing dystonia and improving motor function, decreasing pain, and easing caregiving [5]. Current pharmacological management of dystonia in cerebral palsy is therefore based largely on clinical expert opinion.

Studies examining prescribing practices have shown that a range of oral medications are used to manage dystonia in cerebral palsy, the most common being baclofen, gabapentin, trihexyphenidyl, diazepam and clonidine [6, 7]. Dosage regimens for most medications vary considerably both within and between doctors, particularly for gabapentin and diazepam [6]. These two prior studies informed the current study.

This study builds from a single centre Australian study of prescribing practices of physicians which was limited in size, scope and did not consider combination of medications used [6] and is the second step in consensus of expert paediatric doctors. The aim of the study was to examine current clinical practice of doctors working in Developmental Medicine, Rehabilitation, Neurology and General Paediatric departments in major hospitals across Australia for prescribing medications for children with dystonic cerebral palsy including prescribing patterns and combinations of medications used.

Participants and Methods

This was a prospective surveillance study of prescribing practices of medical doctors over a continuous six-month period. All participating doctors provided informed consent and the study was approved by the Royal Children’s Hospital Melbourne Human Research Ethics Committee (HREC # 36146B).

Participants and recruitment.

Included were medical staff who manage children with cerebral palsy and were working within the General Paediatric, Developmental Medicine, Neurology and Rehabilitation departments at major hospitals across Australia and New Zealand. There were no exclusion criteria. Potentially eligible participants were recruited via email through networks of the authorship team and the national Dyskinesia Research Group. In addition, the study was advertised through a network of paediatric rehabilitation specialists. Within Australia, children with dystonic cerebral palsy are primarily

managed at a number of major tertiary care institutions in capital cities, and state-wide services for rural and remote children. There are seven major services in Australia.

Outcome measure

The primary outcome measure for this study was a custom developed online survey using the Research Electronic Data Capture (REDCap) electronic data capture tool hosted at the Murdoch Children's Research Institute (<https://redcap.mcri.edu.au/>). REDCap is a secure, web-based application for building and managing online databases.

The survey had two parts: 1) demographic data for the prescribing doctor, including years of experience, type of work setting, and areas of training/specialty. This was collected once at the beginning of the study, and 2) Information on each new medication prescription, including clinical presentation of the child, type of drug prescribed, indication for use, the dosage regime implemented, other concomitant medications to manage movement disorders and method for monitoring effectiveness of the medication. The survey was a combination of open and closed questions. See Appendix for a copy of the two parts of the survey.

Procedures

Potentially eligible doctors were emailed an information statement and invited to participate. Those choosing to participate were then directed to the online initial survey which included the consent form. Once consented they completed the initial online survey regarding their experience and work setting. They were then emailed weekly reminders on a Friday to complete the online survey for each child they had seen that week with dystonic cerebral palsy for whom they had commenced a new medication to treat dystonia. The data collection period was six months for all doctors and began once they completed consent and the initial survey.

Data analysis

This was a descriptive study with data presented as frequencies and proportions. For some variables multiple responses were possible, such as comorbidities and current medications and reason for new medication. For these multi response variables each response was treated as a separate variable with the denominator the entire cohort of children. Data was analysed using Stata 16.1 (StataCorp, College Station, TX).

Results

Seventy doctors were invited via email to participate in this study. Of those, 25 consented to participate (36% recruitment rate). There were 19 rehabilitation specialists, two developmental paediatricians, three general paediatricians, and one neurologist. All participants had experience in managing dystonic cerebral palsy, with the majority (n=18) currently managing more than 20 children with dystonic cerebral palsy. Doctors years of experience with managing dystonic cerebral palsy ranged from less than 5 years (n=4), 5-10 years (n=8), 11-20 years (n=8) and greater than 20 years (n=5). The doctors primarily worked in metropolitan paediatric hospitals (n=24), with fewer working in rural hospitals (n=4), metropolitan or rural community settings (n=4) and private practice (n=6). A number worked in more than one setting. Doctors represented sites from Victoria, New South Wales, Queensland, South Australia, Western Australia, and New Zealand.

Of the 25 who consented to participate, 16 doctors prescribed new medication for dystonia in children with cerebral palsy over the period of the study. There were 77 children and young people who were prescribed new medications for dystonia in total. Table 1 displays the characteristics of

the children prescribed medication. There was a spread of ages and 61% were male. The majority (75.5%) were classified within Gross Motor Function Classification System (GMFCS) levels IV or V and there were relatively even numbers classified as predominantly dystonic (46.8%) versus mixed dystonic/spastic (49.4%).

[insert Table 1 here]

Table 2 displays information on the medications prescribed. The most common current medications children were receiving were baclofen and diazepam. For new medicines prescribed, the most common were baclofen and gabapentin, followed by levodopa, trihexyphenidyl and diazepam. Most children were already on at least one (82%) or two (13%) medications. The most common combinations of medications were baclofen and diazepam or baclofen and gabapentin. In most cases one new medication (94%) and infrequently two new medications (5%) were prescribed. Common reasons for prescribing new medications included to reduce pain/spasms (46%), improve ease of care (29%), improve sleep (26%), improve mobility (27%) and improve upper limb function (20%). Less common reasons were perioperative care (14%) and to improve speech and oro-motor function (9%).

[Insert Table 2 here]

Table 3 displays monitoring and assessment practices of clinicians. Monitoring for adverse events and effectiveness was primarily through review appointment, telephone contact or email follow-up. Monitoring effectiveness using recognised outcome measures was done in only 25% of cases.

[Insert Table 3 here]

Dosage regimens were variable, particularly for trihexyphenidyl and diazepam. Baclofen was prescribed on 23 occasions with the majority starting at 2.5-5mg daily (15/23), with the same dose escalation amount per week, and maximum dose 2-3 mg/kg/day (14/23). Gabapentin was prescribed on 23 occasions and the majority started with 100mg daily (11/23) with weekly increases to a maximum of 200-300mg TDS (16/23). Levodopa was prescribed in 10 occasions with the majority starting with 1mg/kg/day (6/10), variable escalation, and max dose 50-100mg TDS (6/10). Trihexyphenidyl was prescribed on eight occasions with little consensus except to start low, go slow and increase until effective without side effects. Diazepam was prescribed on eight occasions, essentially as required with variable starting (from 0.5mg-5mg), escalation and maximum doses (1-15mg per day). The remaining medications were prescribed infrequently and thus little information is available for patterns of prescribing.

Discussion

This prospective survey study utilising a representative sample of Australian paediatric doctors found the most common drugs newly prescribed for children with dystonic cerebral palsy were baclofen and gabapentin followed by levodopa, diazepam and trihexyphenidyl. Most children were on a combination of two or three medications primarily involving a combination of gabapentin, baclofen and/or diazepam. Common indications for prescribing medication included to reduce pain and spasms and improve comfort, sleep, and function. As predicted, dosage regimens were variable, particularly for trihexyphenidyl and diazepam. The results will be instrumental in guiding further studies to achieve consensus amongst expert clinicians for the consistent prescription of oral medications for children with dystonic cerebral palsy.

The findings of this study are similar to recent studies [6, 7]. A smaller pilot study of 11 doctors from one tertiary care centre focused specifically on dystonic cerebral palsy and found that oral baclofen was first choice for 10 of 11 doctors and gabapentin and baclofen were the most frequently prescribed [6]. Dosage regimens varied between and within doctors, particularly for the use of gabapentin and diazepam [6]. A study from the United Kingdom of 275 children and young people with cerebral palsy that included all motor types not specific to dystonia found the most commonly used medications for abnormal tone/movement were baclofen, trihexyphenidyl, gabapentin, diazepam and clonidine. Baclofen was often used when both spasticity and dystonia were present whereas trihexyphenidyl, gabapentin and clonidine were all infrequently used if dystonia was not present [7]. The study did not, however, examine combinations of medications nor dosing regimens.

Despite the widespread use of baclofen, gabapentin, trihexyphenidyl and levodopa to manage dystonia in children with cerebral palsy, a systematic review found extremely limited evidence for their effectiveness, while trihexyphenidyl is considered possibly ineffective [5]. A Cochrane review of benzhexol hydrochloride (trihexyphenidyl) for dystonia in cerebral palsy found only one randomised controlled cross-over trial providing low quality evidence, thus insufficient evidence regarding its effectiveness for reducing dystonia and improving function and participation [8]. A retrospective observational study of gabapentin in 69 children with dystonia (not specific to those with cerebral palsy) found improvements in sleep quality, sleep amount, mood & agreeableness, pain, general muscle tone, involuntary muscle contractions and seating tolerance [9]. More recently a pilot study of gabapentin for managing pain in 13 children with dystonic cerebral palsy found improvements in pain behaviour and pain related goals but insignificant improvements in dystonia [10].

Presence of a seizure disorder, which was commonly found in the children within this study, can influence the choice or dosing of medication to manage dystonia. In some cases, the dose of anticonvulsant medication may need to be increased to manage any breakthrough seizures associated with the introduction of for example, baclofen. In contrast, often the management of pain and dystonia has been observed to reduce the frequency of seizures. In particular, gabapentin is useful as it has additional benefits as an anticonvulsant. Whilst this study did not analyse these medication interactions in detail, this is an avenue of further research worth pursuing.

As further proof of limited and conflicting evidence, a systematic review of 16 studies of oral pharmacological treatments in dyskinetic cerebral palsy found contradictory results for trihexyphenidyl and levodopa and low efficacy for diazepam, dantrolene sodium, perphenazine, and etybenzatropine [11]. The authors state that tetrabenazine, gabapentin and levetiracetam should be studied in more detail and overall suggested that the limited evidence does not support any therapeutic algorithm for the management of dyskinetic cerebral palsy.

There are evidence-based guidelines for the pharmacologic treatment of spasticity in children and adolescents with cerebral palsy [12] to guide clinicians. This was, until more recently, lacking for

dystonia in cerebral palsy. While the AACPDM Dystonia Care Pathway is a useful guide, the pathway is based on a limited evidence base and largely revolves around clinical expertise without the use of stringent consensus processes. An important factor in effective management of dystonia in cerebral palsy is parental engagement with use of medication. In clinical practice, most children would be offered a medication trial. Whilst data on the uptake of these trials is not available, we feel more than half would agree to a trial. Close follow up during a medication trial is important for compliance.

Monitoring for effectiveness of medications in this study was primarily through subjective feedback from parents, with only a quarter of clinicians stating they used recognised outcome measures. This is similar to a previous study which found that objective measurement tools were only used in the context of a multidisciplinary rehabilitation team [6]. It is important that clinicians use reliable and valid tools to measure dystonia severity, pain, and impact on functional activities, including a focus on individualised goal setting to determine each child's response to treatment. Knowledge translation activities to embed feasible measurement into routine clinical care are required.

This study along with previous reviews of medication prescription [6, 7] and recent systematic reviews [5, 11] all strongly suggest that there remains a limited evidence base for oral medication prescription for children with dystonic cerebral palsy. This lack of evidence has likely resulted in inconsistent management across Australia and internationally. Disappointingly, there continues to be inconsistent approaches to dosing regimens, an area that clearly needs further exploration. There are several possible reasons as to why there were inconsistencies in dosing regimens found in this study. When starting new medications in complex movement disorders, most clinicians will start at a low dose and increase the dose of medication slowly to titrate against effect and side effects. The presence of comorbid conditions, pain and sleep disturbances, severity of presenting symptoms, parental goals, and past history of medication use and tolerance will all influence starting dose and rate of escalation.

In the absence of strong evidence and consensus, individual clinical expertise and preference will continue to drive decision-making. The complex and heterogeneous cerebral palsy population is inherently difficult to study using randomised controlled trials. Consequently, alternate methods harnessing best available evidence and clinical expertise using robust techniques such as Delphi methods to obtain consensus are required to guide clinicians. The results of this study will inform such a process for oral medication prescription, particularly for dosing regimens.

This survey study is limited by the response rate of eligible doctors who were invited to participate. Of those who did consent to participate, only 16 took part. Most children with dyskinetic cerebral palsy are managed at tertiary centres, of which there are nine major sites within Australia. Not all doctors at those sites would manage dyskinetic cerebral palsy, which has a lower prevalence compared to spastic cerebral palsy. Therefore, we feel the response rate and total number of doctors participating in this study are reflective of current Australian practice. The low response rate might also relate to the six-month period the doctors were required to participate. The results of this study reflect practices of Australian and New Zealand physicians only, therefore can only be generalised to these two countries. Information on aetiology of the cerebral palsy which could provide further detail on response to medication was not collected. Additionally, the survey did not request information on whether children had trialled other medications previously and were not keen to trial again. Despite these limitations, the results provide important information for guiding future clinical research.

In conclusion, doctors prescribe a range of medications, often in combinations, to manage the effects of dystonia in children with cerebral palsy. The most commonly prescribed are baclofen, gabapentin, diazepam, levodopa and trihexyphenidyl. With inconsistent dosing regimens evident, future studies using consensus of expert clinicians is required to develop guidelines for clinicians in an area where the evidence for individual medications is extremely limited.

Table 1. Demographics of the children prescribed new medication

Characteristics of the children	n (%)
Number of Patients	77 (100)
Age	
< 2 years	4 (5.2)

2 - 5 years	19 (24.7)
6 - 10 years	28 (36.4)
11 - 15 years	19 (24.7)
16 – 21 years	7 (9.1)
Sex	
Male	47 (61.0)
Female	30 (39.0)
GMFCS	
I	3 (3.9)
II	10 (13.0)
III	9 (11.7)
IV	22 (28.6)
V	33 (42.9)
MACS	
I	3 (3.9)
II	23 (29.9)
III	11 (14.3)
IV	17 (22.1)
V	23 (29.9)
Motor Impairment Distribution	
Right hemiplegia	1 (1.3)
Left hemiplegia	4 (5.2)
Diplegia	5 (6.5)
Quadriplegia	67 (87.0)
Movement Disorder	
Predominant dyskinesia	36 (46.8)
Mixed spasticity and dyskinesia	38 (49.4)
Predominant spasticity	3 (3.9)
Comorbidities (note – multiple comorbidities can exist)	
None	17 (22.1)
Gastrostomy/PEG feeds	22 (28.6)
Seizures within the past 6 months - on medication	23 (29.9)
Seizures within the past 6 months - not on medication	5 (6.5)
Intellectual disability - mild	15 (19.5)
Intellectual disability - moderate	24 (31.2)
Intellectual disability - severe	12 (15.6)
Number of comorbidities	
0	17 (22.1)
1	27 (35.0)
2	16 (20.8)
3	17 (22.1)
Recent Interventions (note multiple interventions can occur)	
None	38 (49.4)
Current intrathecal baclofen pump	3 (3.9)
Orthopaedic surgery in the past 6 months	8 (10.4)
Botulinum toxin A injections in the past 3 months	26 (33.8)
Deep brain stimulation	1 (1.3)
Other	5 (6.5)

GMFCS; Gross Motor Function Classification System, MACS; Manual Ability Classification System

Table 2. Medications prescribed for the included patient episodes.

Medication	n (%)
Current Medications	
Note – multiple medications can be prescribed	

Oral Baclofen	29 (37.7)
Trihexyphenidyl	3 (3.9)
Levodopa	5 (6.5)
Diazepam	14 (18.2)
Gabapentin	6 (7.8)
Clonazepam	0 (0.0)
Tetrabenazine	1 (1.3)
Clonidine	0 (0.0)
Other (medical cannabis oil, anticonvulsants, Botulinum toxin A)	5 (0.06)
Number of current medications	
0	2 (2.6)
1	63 (81.8)
2	10 (13.0)
3	1 (1.3)
4	1 (1.3)
Multiple current meds (n=12)	
Oral Baclofen + Diazepam	n=7
Oral Baclofen + Gabapentin	n=2
Diazepam + Gabapentin	n=1
Oral Baclofen + Diazepam+ Trihexyphenidyl	n=1
Oral Baclofen + Diazepam+ Gabapentin + Levodopa	n=1
New Medications Prescribed	
Note – multiple medications can be prescribed	
Oral Baclofen	23 (29.9)
Trihexyphenidyl	8 (10.4)
Levodopa	10 (13.0)
Diazepam	8 (10.4)
Gabapentin	23 (29.9)
Clonazepam	0 (0.0)
Tetrabenazine	1 (1.3)
Clonidine	5 (6.5)
Other (chloral hydrate, fluvoxamine)	2 (2.6)
Number of new medications prescribed	
0	1 (1.3)
1	72 (93.5)
2	4 (5.2)
2 new meds prescribed (n=4)	
Diazepam + Gabapentin	n=3
Diazepam + Oral Baclofen	n=1
Reason for new medication	
Note – multiple reasons can be chosen	
Reducing pain/spasms	35 (45.5)
Improving ease of care	22 (28.6)
Improving sleep disturbances	20 (26.0)
Improving mobility	21 (27.3)
Improving upper limb function	15 (19.5)
Improving speech and oro-motor function	7 (9.1)
Peri-operative management	11 (14.3)
Other (anxiety, drooling, excessive movements causing injury)	11 (14.3)

Table 3. Monitoring and assessment of effects of medication by clinicians

Monitoring and assessment	n (%)
Monitoring for Adverse Reactions	
Note – multiple options can be chosen	
Review appointment	43 (55.8)
Email contact	16 (20.8)
Telephone call	50 (64.9)
Other	11 (14.3)
None	0 (0.0)
Monitoring for Effectiveness	
Note – multiple options can be chosen	
Review appointment	52 (67.5)
Email contact	16 (20.8)
Telephone call	27 (35.1)
Clinical assessment using recognised outcome measures	19 (24.7)
Other	13 (16.9)
None	0 (0.0)
Outcome measures used	
Note – multiple options can be chosen	
Multi-disciplinary team setting	33 (42.9)
Treating doctor in the clinic setting	46 (59.7)
Medication effectiveness is not routinely measured	9 (11.7)
Reasons why outcome measures not routinely used	
Note – multiple options can be chosen	
Limited time	6 (7.8)
Limited access to allied health support	3 (3.9)
Limited experience and/or confidence using the tools	0 (0.0)
Not considered a priority	3 (3.9)

- [1] Sanger TD, Delgado MR, Gaebler-Spira D, Hallett M, Mink JW, Task Force on Childhood Motor D. Classification and definition of disorders causing hypertonia in childhood.[see comment]. *Pediatrics*. 2003; **111**: e89-97.
- [2] ACPR Group. Report of the Australian Cerebral Palsy Register, Birth years 1995-2012. 2018.
- [3] Himmelmann K, V M, Hagberg G, Uvebrant P, Krägeloh-Mann I, Cans C. Dyskinetic cerebral palsy in Europe: trends in prevalence and severity. *Archives of Disease in Childhood*. 2009; **94**: 921-926.
- [4] Himmelmann K, Horber V, De La Cruz J, et al. MRI classification system (MRICS) for children with cerebral palsy: development, reliability, and recommendations. . *Dev Med Child Neurol*. 2017; **59**: 57-64.
- [5] Fehlings D, Brown L, Harvey A, et al. Pharmacological and neurosurgical interventions for managing dystonia in cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology*. 2018; **60**: 356-366.
- [6] Harvey A, Reddihough D, Scheinberg A, Williams K. Oral medication prescription practices of tertiary-based specialists for dystonia in children with cerebral palsy. *J Paediatr Child Health*. 2018; **54**: 401-404.
- [7] Lumsden D, Crowe B, Basu A, et al. Pharmacological management of abnormal tone and movement in cerebral palsy. *Archives of Disease in Childhood*. 2019; **104**: 775-780.
- [8] Harvey A, Baker L, Reddihough D, Scheinberg A, Williams K. Trihexyphenidyl for dystonia in cerebral palsy. *Cochrane Database of Systematic Reviews*. 2018.
- [9] Liow N, Gimeno H, Lumsden DE, et al. Gabapentin can significantly improve dystonia severity and quality of life in children. *European Journal of Paediatric Neurology*. 2016; **20**: 100-107.
- [10] Harvey A, Antolovich G, Waugh MC, et al. A pilot study of gabapentin for managing pain in children with dystonic cerebral palsy. . *Developmental Medicine & Child Neurology*. 2019; **61**: 179.
- [11] Masson R, Pagliano E, Baranello G. Efficacy of oral pharmacological treatments in dyskinetic cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology*. 2017; **59**: 1237-1248.
- [12] Delgado MR, Hirtz D, Aisen M, et al. Practice parameter: pharmacologic treatment of spasticity in children and adolescents with cerebral palsy (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society. *Neurology*. 2010; **74**: 336-343.

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