Utility of data linkage for orthopaedic service planning in the paediatric population with cerebral palsy at Starship Children's Hospital

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ABSTRACT

AIMS: To determine the accuracy of orthopaedic surgical procedure coding (ICD-10-AM/ACHI/ACS) for children with cerebral palsy (CP) at Starship Children's Hospital, use data linkage with the New Zealand Cerebral Palsy Register (NZCPR) to obtain demographic and clinical information for children with CP requiring orthopaedic surgical services in the Auckland District Health Board catchment area, and to determine if trends in the clinical and demographic data are useful for future service planning for children with CP.

METHODS: Surgical admission data for children with CP aged 0–18 years at the time of their first procedure were extracted from Auckland District Health Board records for 2013–2018, and information on demographics and Gross Motor Function Classification System level were obtained from the NZCPR. The ICD-10-AM/ACHI/ACS codes for surgery/intervention were matched with the operation notes in the electronic health records using NHI numbers and assessed for accuracy.

RESULTS: During the study period, 261 paediatric patients with CP underwent orthopaedic procedures, which could be grouped broadly into five categories (spine, upper limb, lower limb, Botulinum-A toxin injection only, and other) with a coding accuracy of 95%. Clinical and demographic data could be obtained from the NZCPR for 232 (88.9%) of the 261 patients.

CONCLUSIONS: Using orthopaedic surgical procedure codes, we could identify broad categories of procedures received by children with CP and the demographic and clinical characteristics of these children, which will assist with service planning and identify trends in care delivery.

Cerebral palsy (CP) is an umbrella term used to describe a group of permanent disorders of movement and posture that occur in the developing foetal brain.[1] Patients with CP have ongoing activity limitations and require multiple clinical services over a lifetime, particularly during childhood and adolescence. Information regarding the types and frequency of procedures performed in these children and knowledge of their demographic and clinical profiles would be helpful for service planning, including theatre space and rehabilitation needs, and ensuring consistency of health service delivery and outcomes.

Data linkage involves using a common link between different databases/coding systems to match up clinical information for analysis. An example is linkage using PREDICT software, which prospectively links data collected by general practitioners in New Zealand to assess patients' risk profiles for cardiovascular disease to nationwide International Classification of Diseases (ICD) coded hospitalisation and mortality databases to identify prognostic predictors based on a New Zealand cohort.[2] Data linkage affords an opportunity to make the most out of information stored in our health system for research and planning purposes.

Linkage of health administrative datasets to CP registers has been trialled in other countries to inform delivery of healthcare services,[3] monitor the outcomes of orthopaedic strategies to prevent complications such as hip dislocation,[4] and to characterise hospital admissions in children with CP.[3] The unique clinical information regarding the severity of CP collected by CP-specific registers has facilitated an understanding of the healthcare needs of this patient population[5] and increased use of secondary care services[6] through linkage of CP registers with routinely collected health datasets. The Gross Motor Function Classification System (GMFCS)[7] is widely used to classify the functional ability of a child with CP. This is an ordinal scale of I–V, with children functioning at level V being the most severely affected by CP. The GMFCS predicts the need for surgery, in that children with GMFCS III–V are at higher risk of hip

displacement[4,8,9] and spinal deformity,[10,11] as well as the likely success rate of orthopaedic surgical procedures in these children. The GMFCS is used by clinicians assessing children with CP and their scores are routinely entered into the New Zealand Cerebral Palsy Register (NZCPR). The GMFCS score could be matched against the procedure code through data linkage, enabling analysis of procedures performed for CP according to severity.

To perform data linkage using our hospital dataset, we needed to verify the accuracy of the coding in the National Minimum Dataset. Specifically, we wanted to know whether these codes alone, without review of the clinical notes, could be linked with the data in the NZCPR to provide clinically useful demographic and clinical information.

The aims of this study were to (i) determine the accuracy of procedure codes for orthopaedic surgical procedures received by children with CP (ICD-10-AM/ACHI/ACS), (ii) use data linkage with the NZCPR to describe the demographic and clinical characteristics of children with CP who access orthopaedic surgical services at Starship Children's Hospital, and iii) determine if trends in the clinical and demographic data are useful for future service planning for children with CP.

Methods

Study setting

Starship Children's Hospital provides paediatric surgical services for all children living in the Auckland and Waitematā district health boards catchment areas and tertiary level surgical care for patients nationwide when necessary. Therefore, the total catchment area represents about 250,000 children aged 0–19 years.[12] Data for all children with an ICD-10-AM diagnostic code for CP (G80.9) who underwent surgical intervention in the Orthopaedics Department at Starship Children's Hospital between July 2013 and July 2018, and were aged 0–18 years at the time of their first procedure were extracted from the Auckland District Health Board (ADHB) database by a business intelligence data analyst. These data, including procedure codes, are sent to the Ministry of Health for inclusion in the National Minimum Dataset. Data for children over the age of 18 years at the time of the index surgery were excluded.

Data sources

Since 1993, the New Zealand Ministry of Health has routinely collected all public and private hospital inpatient and day-stay discharge information, including clinical and procedural details, in the form of the National Minimum Dataset (also known as Hospital Events data).[13] Each district health board is required to code and report this information to the Ministry of Health at monthly intervals. The National Health Index (NHI) number is a unique electronic identifier for each patient in New Zealand. Primary and secondary diagnoses at the time of discharge are coded using the International Statistical Classification of Diseases (ICD). CP (inclusive of all subtypes) is classified using ICD-10 diagnostic code G80.9. ICD 10th Revision Australian Modification (ICD-10-AM/ACHI/ACS) codes for all inpatient procedures, including surgeries, are checked against each event using the NHI number.

The NZCPR is a national register that was established in 2015. It collects health information relevant to CP (including demographic data, birth history, and clinical information such as type, topography, and severity). The NZCPR has estimated that there are approximately 2,490 individuals aged 0–19 years with CP in New Zealand.[14,15] A recent audit completed by the NZCPR at the request of the Health and Disability Ethics Committee found that coding for CP had a 99% accuracy rate for all ADHB hospital discharges from 2007 to 2017.[16]

Clinical records were accessed electronically through the ADHB portal. Study participants were identified by their NHI number only, and their clinical information was extracted and stored for review.

Coding accuracy

The raw data extracted by the analyst were processed initially using Microsoft Excel (Redmond, WA, USA) to extract variables of interest. The ICD-10-AM/ACHI/ACS codes for surgery/intervention were reviewed against the operation notes held within the electronic health records using the NHI. The surgical procedures were divided into five mutually exclusive categories (spine surgery, upper limb surgery, lower limb surgery, Botulinum (BTX)-A injection alone and "other") based on the coding information. The accuracy with which the ICD-10-AM/ACHI/ACS codes could be used to determine the procedures when matched against the operation notes in the medical records was assessed by two of the authors (WH, NW). If in-hospital events were recorded using more than one procedure code, the codes recorded were reviewed to determine the main procedure performed. The decision was made based on

whether the codes gave sufficient information to identify the surgical procedure when used alone.

Data linkage

We used the NHI number to bring together information from different parts of the National Minimum Dataset. The ICD10-AM G80.9 (International Classification of Diseases diagnosis code for Cerebral Palsy) and ICD-10-AM/ACHI/ACS (International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification [ICD-10-AM], the Australian Classification of Health Interventions [ACHI], and Australian Coding Standards [ACS]) are the coding systems used in New Zealand hospitals. These systems were developed by the World Health Organization and modified with permission for funding, service planning, research and audit purposes by the Australian Government. Data for sex, ethnicity, and GMFCS level were extracted from the NZCPR and linked to intervention codes using the NHI.

Data analysis

The intervention codes were interpreted to obtain further information about the anatomical site and type of procedure/surgery performed and supplemented with information from the clinical notes. Descriptive statistics for the type of surgical intervention and patient demographics were generated from the available data. Some children identified as ADHB admissions were not included in the NZCPR. Therefore, no demographic information could be extracted for these children.

Ethics approval

The ADHB Research Office approved this research as part of a service specific audit. Collection of health information for children and adults with CP from the NZCPR was approved by the Health and Disability Ethics Committee (approval number: 13/NTA/130). Individuals with CP who agree to their demographic and clinical information being collected and stored by the NZCPR also consent to their data being available for research purposes. Furthermore, after linkage, only de-identified data were available for analysis. Therefore, the requirement for informed consent was waived.

Results

Clinical information (in the form of clinical records and procedure code data extracted for hospital admissions) was available for 271 children. After exclusion of two patients whose medical notes did not include a diagnosis of CP and eight who were older than 18 years at the time of the index surgery, data for 261 children were included in the analysis. Two children reached the age of 18 years during the study period and were included in the study despite being older than the upper limit of age at the time of subsequent surgeries.

During the five-year study period, 261 children with a diagnosis of CP underwent 772 surgical procedures. The mean age at the time of the procedure was 8.46 years (range 1–22). Each child underwent a median of two procedures (range 1–10), and each procedure required an admission.

When determining the types of procedures performed and the accuracy of the ICD-10-AM/ACHI/ACS codes for categorising each procedure into one of the five broad types, we found that the codes had high accuracy for spine surgery (100%), BTX-A injection (100%), lower limb surgery (91%), and "other" types of surgery (95%). However, their accuracy for upper limb procedures was lower at 45%.

Following data linkage to the NZCPR, clinical and demographic information could be extracted for 232 (88.9%) of the 261 children. Table 1 summarises the patient demographics according to type of intervention received. Each hospital event and subsequent procedures were grouped into one primary type of surgery. Figure 1 shows the GMFCS level according to type of intervention performed. The GMFCS level was I–II in 57% of the 232 children, III in 11%, and IV–V in 32%.

Discussion

This study describes the orthopaedic surgical procedures performed for children with CP over a five-year period at the Starship Children's Hospital, a tertiary healthcare referral hospital in Auckland. In most cases, the ICD-10-AM/ACHI/ACS procedure code predicted the broad category of CP-related surgical intervention (upper limb, lower limb, spine, BTX-A, or "other"). Linkage of these data with the NZCPR identified the demographic and clinical characteristics of these children. The distribution of GMFCS levels in our study population (57% for grades I–II, 11% for grade III, and 32% for grades IV–V) is similar to that in the Australian Cerebral Palsy Report for 2018 (62%, 12%, and 26%, respectively).[17]

Data for specific surgical case numbers by clinical characteristics would help with service planning, including theatre space, perioperative care, and rehabilitation needs. For example, five

to six children with CP had spinal surgery each year during the five-year study period. Each case would typically require a bed in the paediatric intensive care unit and be the only patient on a whole day operating list. At the other end of the spectrum, approximately 100 children per year received BTX-A injections, with most requiring physiotherapy post-procedure. Demographic data could help with prediction of the perioperative care needs of these children. For example, the rehabilitation needs of a 3-year-old are different from those of an 18-year-old. Similarly, ethnicity data could help care providers to factor in the potential need for ancillary services, such as interpreters for some children and their families.

Similar to previous analyses of the characteristics of children with CP requiring hospital admission,[3,5,6] we found that linkage of procedural coding data with the demographic and clinical information in the NZCPR was helpful for descriptive analysis of children with CP requiring hospital level care. Building on local knowledge from similar methods used previously, we have validated the use of data linkage in New Zealand by linking data from the NZCPR with those in the National Minimum Dataset. For this project, we focused on the types of orthopaedic services required by children with CP according to their clinical and demographic characteristics, drawing on previous research that focussed on admissions data[3,5,6] to look more specifically at the surgical needs of children with CP.

Grouping of surgical interventions based on procedure codes allowed a broad understanding of the accuracy of our coding system. Prediction of surgical intervention was most accurate for spinal surgery and BTX-A injections. One difficulty with BTX-A injection is that it has only one code, so it is unknown if the procedure involved an upper or lower limb or which muscles were injected without reference to the clinical notes. The least accurate predictive ability was for upper limb surgery, which may reflect the typically generic codes used for upper limb procedures (e.g., "4796300, Open tenotomy, not elsewhere classified" and "4795700, lengthening of tendon, not elsewhere classified"). Therefore, without looking at the clinical records, it was impossible to determine if this procedure was for the upper or lower limb. Moreover, we noted instances of multiple codes, and at times duplicate codes, being used to describe the same procedure. For example, the ACHI code, "4842701 Osteotomy of proximal femur with internal fixation" was sometimes used for both varus de-rotation osteotomy and de-rotation osteotomy of femur. Therefore, the effectiveness and efficiency of this process may be limited when using ICD-10-AM/ACHI/ACS procedure codes alone as the sole source of information for data linkage.

The New Zealand Coding Authority at the Ministry of Health has quality assurance processes in place for resolving coding issues to ensure that the data entered into the National Minimum Dataset are collected accurately and consistently.[18] However, we encountered difficulties when using only the information from the procedure codes to inform the type of operation received. This could reflect both a limitation of the codes available that can be used in combination to accurately reflect the procedure and the process of selecting codes used immediately following a procedure in the operating room. Motivation to use the correct code or a combination of codes may be low among surgeons working in the public health system if these codes are not seen as valuable for monitoring clinical outcomes or needed for billing purposes (as in the private sector). However, with the increasing focus on quality and improvement of patient outcomes in the public health system, correct coding by clinicians is likely to become a focus of attention. The limitations in coding and data accuracy identified in this research were also noted in other data linkage studies.[3,5] Therefore, there is a need for better protocols for entering data into healthcare databases and more accurate coding of hospital data in the future. However, it should be borne in mind that although the accuracy of codes for surgical procedures has implications for research and audit activities, it is unlikely to affect resource utilisation in clinical practice. For example, a varus versus a de-rotation osteotomy of the femur will likely have a similar resource footprint.

In this study, we were able to link 88.9% of surgical procedures performed at Starship Children's Hospital over a five-year period to demographic and clinical data held by the NZCPR. Out of the 261 children included in the study, we could obtain information regarding the sex, ethnicity and GMFCS levels for 232 of them following data linkage. The demographic information was not extracted in the original dataset by the ADHB analyst.

The NZCPR is a relatively new register and presently has better data ascertainment for younger children with CP. Furthermore, since its introduction in 2004,[19] the GMFCS level has become easier to obtain in younger patients and

Table 1: Demographic and clinical data for paediatric patients with cerebral palsy obtained by linkage with the New Zealand Cerebral Palsy Register according to type of surgical intervention.

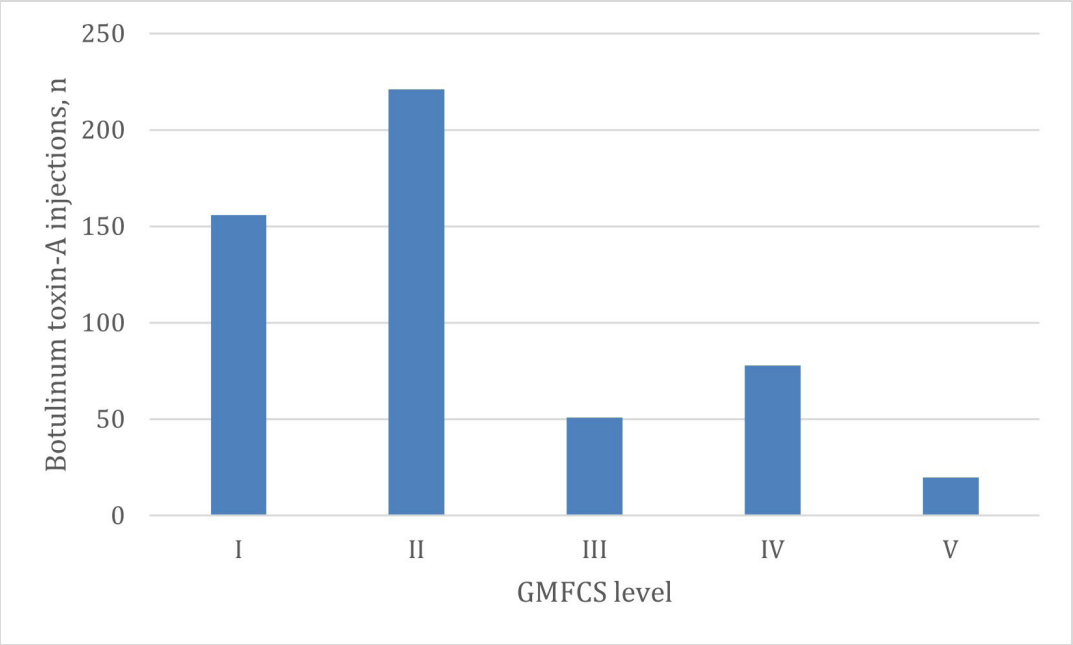
	Spinal surgery	**BTX-A only**	**Lower limb surgery**								**Upper limb surgery**		
	n=28*	**n=549****	**Single-event multilevel surgery, n=9*****	**Surgery for hip subluxation Soft tissue and bony surgery, n=33********	**Surgery for hip subluxation Metalware removal, n=23*****	**Foot surgery ± BTX-A, n=32[+]**	**Isolated calf operation, n=16[++]**	**Cast change/ removal of metal ware, n=18********	**Other, n=16[+]**	**Derotation of femur, n=4**	**Fusion ± BTX-A, n=4**	**Soft tissue ± BTX-A, n=38[+++]**	**Other, n=2*****
Mean age, years (SD)	12.83 (2.73)	7.43 (3.75)	10.89 (4.04)	8.09 (4.54)	9.04 (4.47)	12.06 (2.85)	11.38 (3.40)	11.17 (4.36)	12.6 (4.54)	11.25 (1.71)	15.25 (1.70)	11.5 (3.78)	12 (4.24)
Age range, years	6–19	1–19	5–16	2–16	2–17	6–18	4–16	3–16	3–22	9–13	13–17	2–19	9–15
Sex, M:F	9:13	320:212	5:3	19:11	14:8	12:15	9:3	8:7	6:5	2:2	4:0	14:22	1:0
GMFCS I	0	156	0	0	0	6	6	3	1	0	0	12	0
GMFCS II	0	221	4	1	8	6	4	7	2	4	1	12	1
GMFCS III	0	51	3	6	4	10	1	3	2	0	0	1	0
GMFCS IV	8	78	0	14	7	3	0	1	3	0	1	10	0

Table 1 (continued): Demographic and clinical data for paediatric patients with cerebral palsy obtained by linkage with the New Zealand Cerebral Palsy Register according to type of surgical intervention.

	Spinal surgery	**BTX-A only**	**Lower limb surgery**								**Upper limb surgery**		
	n=28*	**n=549****	**Single-event multilevel surgery, n=9*****	**Surgery for hip subluxation** **Soft tissue and bony surgery, n=33********	**Surgery for hip subluxation** **Metalware removal, n=23*****	**Foot surgery ± BTX-A, n=32⁺**	**Isolated calf operation, n=16⁺⁺**	**Cast change/ removal of metal ware, n=18********	**Other, n=16⁺**	**Derotation of femur, n=4**	**Fusion ± BTX-A, n=4**	**Soft tissue ± BTX-A, n=38⁺⁺⁺**	**Other, n=2*****
GMFCS V	14	21	0	9	3	2	0	1	3	0	1	1	0
Ethnicity, NZ European: Māori: PP: Other	13:4:4:1	367:50:41:74	7:0:0:1	14:11:4:1	13:7:2:0	21:2:2:2	8:1:1:2	10:2:2:1	7:2:1:2	4:0:0:0	2:0:2:0	23:8:1:4	0:1:0:0

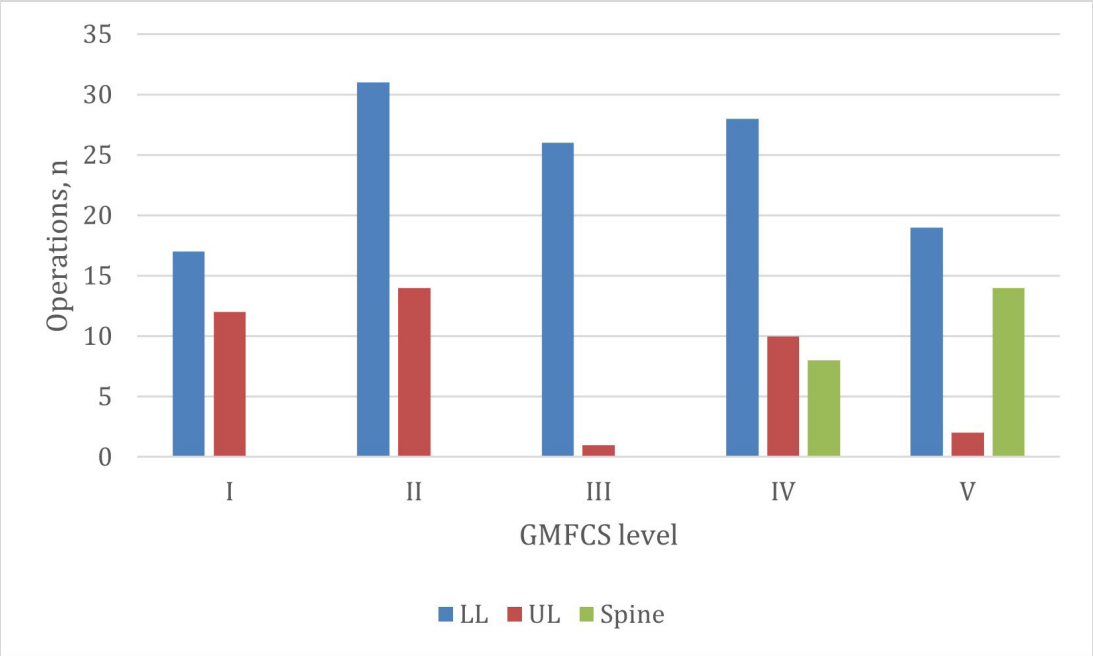
*No data linkage possible for 6 children.
**No data linkage possible for 17 children.
***No data linkage possible for 1 child.
****No data linkage possible for 3 children.
⁺No data linkage possible for 5 children.
⁺⁺No data linkage possible for 4 children.
⁺⁺⁺No data linkage possible for 2 children.
Other, all other ethnicities. BTX-A, Botulinum toxin-A;
GMFCS, Gross Motor Function Classification System;
PP, Pacific Peoples;
SD, standard deviation.

Figure 1a: Number of botulinum toxin-A injections administered according to GMFCS level.



GMFCS, Gross Motor Function Classification System.

Figure 1b: Number of surgical interventions according to GMFCS level.



GMFCS, Gross Motor Function Classification System; LL, lower limb surgery; UL, upper limb surgery.

its use has been slowly increasing in clinical practice.[20,21] An ability to compare the GMFCS levels and surgical needs of patients with CP would help to show trends in their utilisation of healthcare resources and predict future service demands. We hope that complete data linkage will be possible when the NZCPR becomes more established and GMFCS levels are more readily available.

An audit reported in 2003 found that the diagnostic coding used for the National Minimum Dataset required some form of change in 22% of cases and a change in the principal diagnosis in 11%.[22] Since then, coding practices have improved to the point that the data recorded are now accurate enough to be used for research purposes.[23] However, our study covered a period of five years, and there may have been some variations in both diagnostic and procedural coding practices over this time. These inconsistencies would be a limitation to using these codes alone for interpretation of procedures performed.

Whilst this study was designed to investigate the use of data linkage, it also identified potential ethnic disparity in the utilisation of orthopaedic surgical interventions. Under the principles of Te Tiriti o Waitangi, Māori have the right to input regarding decisions about the planning, development, and delivery of their healthcare services, to receive at least the same level of healthcare as non-Māori, and to have Māori cultural concepts safeguarded.[24] Further work aimed specifically at identifying inequities in service provision is needed to identify potential sources of systemic bias. The Royal Australasian College of Physicians regards the inequitable health outcomes experienced by Indigenous children as unacceptable and affirms that it is committed to taking action to eliminate those inequities at the individual, community and service levels.[25]

In conclusion, the findings of this study show that data linkage could help to inform the orthopaedic surgical needs and demographic and clinical characteristics of children with CP managed at Starship Children's Hospital. Data linkage could also be used at the national level to identify regional differences and assist with surgical planning. Furthermore, potential inequities in the health system have been identified. Ongoing partnership with Māori Health researchers and the NZCPR is needed to advocate for elimination of inequities in health care in children living with CP in Aotearoa New Zealand.

Accessibility of protocol, raw data and data linkage information

The raw NZCPR data analysed in this study can be made available by the NZCPR upon request.

COMPETING INTERESTS
Nil.

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