Hospital admissions in children with cerebral palsy: a data linkage study

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ABBREVIATIONS

ITB	Intrathecal baclofen
VAED	Victorian Admitted Episodes Dataset
VCPR	Victorian Cerebral Palsy Register
WIES	Weighted inlier equivalent separation

AIM The overall aim was to investigate the feasibility and utility of linking a cerebral palsy (CP) register to an administrative data set for health services research purposes. We sought to compare CP hospital admissions to general childhood population admissions, and identify factors associated with type and frequency of admissions in a CP cohort.
METHOD The CP register for Victoria, Australia was linked to the state's hospital admissions database. Data pertaining to the admissions of a CP cohort (n=1748) that took place between 2007 and 2014 were extracted. Population data were also obtained.
RESULTS Overall, 80% of the CP cohort (n=1401) had at least admission between 2007 and 2014, accounting for 11 012 admissions or 1.5% of all admissions in their age group. Compared to general population admissions, CP admissions were more costly and more likely to be elective (66% vs 57%; p<0.001), medical (71% vs 57%; p<0.001), and to take place in metropolitan hospitals (92% vs 78%; p<0.001). Increased CP severity and complexity were associated with having more admissions and a higher proportion of admissions attributable to respiratory illness.
INTERPRETATION By linking with administrative data sets, CP registers may be useful for health services research and inform health service delivery.

Cerebral palsy (CP) is an umbrella term for a group of permanent disorders of movement and posture that are caused by an injury or other disturbance to the developing brain.[1] Population-based CP registers exist in each Australian state and territory,[2] as well as in a number of defined regions of Europe,[3] Canada,[4] and the USA.[5] Traditionally, their primary function was to monitor trends in the incidence of CP. However, by linking CP registers to other data sets, researchers have been able to investigate a range of topics including antenatal and perinatal risk factors,[6–8] mortality,[9] and immunization coverage[10] in population CP cohorts.

In recent years, the ability of disease registers to inform health service management and evaluation through linkage with other data sets has been recognized, and internationally, cancer registries have been used extensively to investigate morbidity and health service use in this patient group.[11–13] Roder et al.[14] describe the role of the cancer register in this type of research as 'the data spine', around which data from other sources are linked to demonstrate patterns of service use in this population. Geographically-defined CP registers are well placed to play such a role in investigating the health service needs of individuals with CP.

The availability of population-based data on medical service use in the CP population is important given that CP is the most common cause of physical disability in children, and the need for specialist medical care in this group remains high throughout childhood and adolescence, and into adulthood. Though primarily a disorder of movement and posture, children with CP are more likely than their peers with typical development to experience other medical problems including epilepsy, feeding difficulties, compromised respiratory function, and progressive musculoskeletal pathologies.[15]

Published data describing the use of hospital inpatient services among children with CP would assist management decision-making, provide an objective basis for service planning, and ensure that any changes to health service

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delivery for this group are evidence based. In addition, improved understanding of the frequency, type, and characteristics of admissions experienced by this group, and how these vary depending on the severity and complexity of a child's condition, could assist parents and health care professionals involved in caring for children with CP.

The primary aim of this study was to investigate the feasibility and utility of linking the CP register for the Australian state of Victoria to the state's hospital admissions database. In doing so, we hoped to estimate the proportion of hospital admissions throughout Victoria within a specific age range that were attributable to CP. Secondary aims were to compare admission characteristics between the CP cohort and the general population, and to identify clinical factors associated with the frequency and characteristics of admissions in the CP cohort.

What this paper adds

- Cerebral palsy (CP) admissions are more costly than general childhood admissions.
- More admissions in children with CP are elective, occurring at metropolitan hospitals.
- Greater severity is associated with more emergency, multiday, and respiratory admissions.
- Neurological, respiratory, musculoskeletal, and digestive diseases account for most CP admissions.
- It is feasible to use CP registers for health services research.

METHOD

Study design and setting

This was a retrospective data linkage study. The study was conducted at the Melbourne Children's campus, and was approved by the Human Research Ethics Committee of the Royal Children's Hospital, Melbourne.

Data sources

The Victorian Cerebral Palsy Register

Victoria is the second most populated state in Australia, with a population of approximately 5.8 million people and 70 000 live births per year.[16,17] The Victorian Cerebral Palsy Register (VCPR) collects data on individuals born or living in the state from 1970 onwards. New cases of CP are registered as soon as possible after diagnosis. Clinical information is obtained from the child's medical records soon after registration and it is updated around the time of their fifth birthday.

The CP cohort included in this study comprised registered cases born between 1st July 1995 and 30th June 2009 (i.e. aged 5–18y at the end of the study period – June 30th, 2014). Clinical information on each case extracted from the VCPR included severity of the gross motor impairment, as measured by the Gross Motor Function Classification System (GMFCS),[18] topography, primary motor type, epilepsy status, and use of a gastrostomy tube or intrathecal baclofen (ITB) pump.

The Victorian Admitted Episodes Dataset

The Victorian Admitted Episodes Dataset (VAED) contains data on all patient admission activity, including same-day admissions, at all public and private acute hospitals in Victoria. Data are collected by the Victorian Department of Health and Human Services. Collected data are categorized as follows: (1) admission data (e.g. date of admission, admission type, and intended duration of stay); (2) demographic data (e.g. age, sex, area of residence); (3) diagnosis and procedure data (one principal and up to 39 secondary diagnoses and up to 40 procedures per admission, coded using the 10th revision of the International Statistical Classification of Diseases and Related Health Problems [ICD-10][19]); and (4) separation data (e.g. date of discharge, length of stay, and funding arrangement).[20]

Victorian public hospitals are funded by a combination of casemix and other funding systems. Casemix funding is based on a patient episode that is cost-weighted according to the reason for the admission and length of stay. A cost-weighted separation is called a weighted inlier equivalent separation (WIES). In general, the longer a patient stays in hospital, the more costly the episode will be, and the more WIES that will be allocated.

The VAED is internally linked, which means that individual patients can be followed up over time and data on all of their hospital admissions can be obtained. Data pertaining to all Victorian hospital admissions between July 2007 and June 2014 that involved individuals in the CP cohort were extracted from the VAED. Population control data were also obtained – that is, non-identifiable data pertaining to all admissions to Victorian hospitals during the study period where the patient had a date of birth between 1st July 1995 and 30th June 2009. Unqualified newborn admissions (i.e. routine newborn admissions where the child was not admitted to a special or neonatal intensive care unit) were excluded.

Data linkage

Data linkage between the VCPR and the VAED was undertaken by the Victorian Data Linkages Unit, situated within the Victorian Department of Health and Human Services. The linkage was undertaken using a stepwise deterministic approach. Deterministic linkage is one of the basic data linkage methodologies in existence (the second being probabilistic linkage). Deterministic linkage requires an exact match between linkage variables. Consequently, if any data entry errors were present, for example incorrect date of birth recorded on admission, true matches between the VCPR and the VAED would have been missed.

With the exception of 12 members of the CP cohort, all had a unit record number from one or both of the state's two tertiary paediatric hospitals. As the VAED is internally linked, once a patient is matched once, all of their other VAED encounters (i.e. admissions to other hospitals) can be identified. Consequently, for this project, linkage variables were identified as both tertiary hospitals' codes and unit record numbers, as well as date of birth and sex.

For step 1 of the linkage process, VCPR records were linked to the VAED records by the first tertiary hospital's code and unit record number. Those VCPR records that

linked with a VAED ID were considered 'matched'. For step 2, the second tertiary hospital's code and unit record number, as well as the other linkage variables, were used to link the remaining 'non-matched' VCPR records to the VAED. Linked data files were de-identified before being returned to the research team.

Statistical analysis

The principal discharge diagnoses, which describe the main reason for each admission after investigation, were classified according to the ICD-10 standard grouping of diseases.[19] For the CP cohort, relative risks (risk ratios) and 95% confidence intervals were calculated to compare the risk of having at least one admission over the study period across dichotomized groups of GMFCS, topography, primary motor type, epilepsy, gastrostomy tube, and ITB pump. Descriptive statistics were used to make comparisons between the CP and general population admissions, and between various subgroups of the CP cohort according to admission frequency, admission type, length of stay, diagnostic related groups, hospital region, and discharge diagnoses; the χ^2 test was used for categorical variables and the Wilcoxon rank sum (Mann–Whitney) test for continuous variables. Minimum and maximum values, medians, and interquartile ranges are presented for skewed data, and *p*-values are provided. All data analysis was carried out using Stata 14 (StataCorp, College Station, TX, USA).

RESULTS

Overview of findings

The CP cohort comprised 1748 individuals. Of these, 25% (*n*=445) had a severe gross motor impairment (GMFCS levels IV/V), 1080 (62%) had bilateral CP, 28% (*n*=493) had epilepsy, 13% (*n*=221) had a gastrostomy tube inserted, and approximately 2% (*n*=30) had an ITB pump in situ (Table I). Spasticity was the primary movement disorder in the majority of children (*n*=1515; 87%) (Table I). Almost 91% of the CP cohort (*n*=1586) was positively matched with the VAED – that is, 91% was known to have had a hospital admission during their lifetime.

Overall, 80% of the CP cohort (*n*=1401) had at least one admission between July 2007 and June 2014 (same-day

Table I: Description of the cerebral palsy cohort, and proportions that had hospital admissions over the 7y study period, by Gross Motor Function Classification System (GMFCS), topography, primary motor type, epilepsy, gastrostomy tube, and ITB pump use. Data from the Victorian Admitted Episodes Dataset

	Entire CP cohort *n* (%)	≥1 admission (any type) 2007–2014 *n* (%)	≥1 same-day admission 2007–2014 *n* (%)	≥1 multiday admission 2007–2014 *n* (%)
Total, *n* (%)	1748 (100.0)	1401 (80.2)	1245 (71.2)	1132 (64.8)
GMFCS level				
I	629 (36.0)	442 (70.3)	387 (61.5)	294 (46.7)
II	462 (26.4)	366 (79.2)	332 (71.9)	285 (61.7)
III	172 (9.8)	156 (90.7)	140 (81.4)	143 (83.1)
IV	213 (12.2)	194 (91.1)	171 (80.3)	177 (83.1)
V	232 (13.3)	216 (93.1)	194 (83.2)	212 (91.4)
Unknown	40 (2.3)			
Relative risk (95% CI)[a]		1.32 (1.25–1.41)	1.36 (1.24–1.47)	1.96 (1.78–2.14)
Topography				
Unilateral	650 (37.2)	492 (75.7)	439 (88.1)	347 (70.5)
Bilateral	1080 (61.8)	902 (83.5)	802 (88.9)	778 (86.3)
Unknown	18 (1.0)			
Relative risk (95% CI)		1.10 (1.04–1.16)	0.99 (0.96–1.04)	1.22 (1.15–1.30)
Primary motor type				
Spastic	1515 (86.7)	1216 (80.3)	1091 (89.7)	973 (80.0)
Dyskinetic	98 (5.6)	88 (89.8)	78 (88.6)	80 (90.9)
Other	117 (6.7)	90 (76.9)	72 (80.0)	72 (80.0)
Unknown	18 (1.0)			
Relative risk (95% CI)[b]		1.12 (1.04–1.20)	0.99 (0.92–1.07)	1.14 (1.06–1.22)
Epilepsy				
No	1190 (68.1)	924 (77.7)	820 (68.9)	703 (59.1)
Yes	493 (28.2)	443 (89.9)	393 (79.7)	403 (81.7)
Unknown	65 (3.7)			
Relative risk (95% CI)		1.16 (1.11–1.21)	1.16 (1.09–1.23)	1.38 (1.30–1.47)
Gastrostomy tube				
No	1522 (87.1)	1187 (78.0)	1050 (69.0)	924 (60.7)
Yes	221 (12.6)	212 (95.9)	194 (87.3)	207 (93.7)
Unknown	5 (0.3)			
Relative risk (95% CI)		1.23 (1.18–1.28)	1.27 (1.19–1.34)	1.54 (1.46–1.62)
ITB pump				
No	1712 (97.9)	1369 (80.0)	1214 (71.0)	1102 (64.4)
Yes	30 (1.7)	29 (96.7)	28 (93.3)	28 (93.3)
Unknown	6 (0.3)			
Relative risk (95% CI)		1.21 (1.13–1.30)	1.32 (1.19–1.45)	1.45 (1.31–1.61)

[a]GMFCS level V vs GMFCS level I. [b]Dyskinetic vs spastic. CP, cerebral palsy; ITB, intrathecal baclofen; CI, confidence interval.

or multiday); this ranged from 70% in those classified as GMFCS level I to 93% in those classified as GMFCS level V. Increased risks for any admission were also observed for children with epilepsy, ITB pumps, and gastrostomy tubes, and among those with bilateral and dyskinetic CP (Table I).

Between 2007 and 2014, there were 728 990 admissions to Victorian hospitals involving an individual that fell within the age range of the CP cohort. Of these, 11 012 (1.5%) comprised children from the CP cohort (Table II).

Differences between CP and general population admissions

Compared to general population admissions, a higher proportion of the CP admissions were classified as elective (66% vs 57%; $p<0.001$) and medical (71% vs 57%; $p<0.001$). In addition, a higher proportion of the CP admissions were to metropolitan hospitals than to hospitals located in regional areas (92% vs 78%; $p<0.001$). Overall, less variation was found within the assigned discharge diagnoses for children with CP compared to the general population. Four categories of diagnoses – diseases of the nervous, respiratory, musculoskeletal, and digestive systems – accounted for 61% of all CP admissions compared to approximately 36% of general population admissions ($p<0.001$) (Table II).

As outlined in Table III, the median length of stay and the median number of procedures per multiday admission were higher for children with CP compared to the general population of admitted children. The median length of stay for multiday CP admissions that were longer than one night was four nights (compared to three nights for non-CP admissions; $p<0.001$). Among multiday admissions that required at least one procedure, the median number of procedures was 3 (compared to 2 for general population admissions; $p<0.001$) (Table III).

The between group difference in length of stay was greatest for admissions due to respiratory diseases, where the median length of stay was 2.5 times higher in the CP admissions (5 vs 2 nights; $p<0.001$). For number of procedures, the difference was greatest in admissions classified as musculoskeletal (7 vs 4 procedures; $p<0.001$) (Table III).

Overall, multiday CP admissions were more costly than general population multiday admissions, as demonstrated by the WIES allocations. The difference in funding allocated was greatest for admissions due to diseases of the respiratory and musculoskeletal systems. For CP admissions due to respiratory diseases, the median WIES allocation was 76% higher than that allocated for general population admissions, and for musculoskeletal admissions,

Table II: Comparison of cerebral palsy (CP) and general population admissions. Data from the Victorian Admitted Episodes Dataset

	All admissions *n* (%)	General population admissions *n* (%)	CP admissions *n* (%)	*p*
Total	728 990 (100.0)	717 978 (98.5)	11 012 (1.5)	
Age at admission (y)				
0–4	279 147 (38.3)	275 701 (38.4)	3446 (33.3)	<0.001
5–9	212 742 (29.2)	208 597 (29.1)	4145 (37.6)	
10–14	161 889 (22.2)	159 075 (22.2)	2814 (25.6)	
15–18	75 212 (10.3)	74 605 (10.4)	607 (5.5)	
Admission type				
Emergency	278 453 (39.4)	283 843 (39.5)	3607 (32.8)	<0.001
Elective	415 953 (57.1)	408 680 (56.9)	7273 (66.1)	
Maternity	1489 (0.2)	1489 (0.2)	0	
Qualified newborn[a]	23 255 (3.2)	23 178 (3.2)	77 (0.7)	
Statistical[b]	840 (0.1)	785 (0.1)	55 (0.5)	
Length of admission				
Same-day	353 908 (48.6)	369 478 (51.5)	5604 (50.9)	<0.234
Multiday	375 080 (51.5)	348 500 (48.5)	5408 (49.1)	
Diagnostic related group type				
Medical	417 679 (57.4)	409 816 (57.1)	7863 (71.4)	<0.001
Surgical	235 011 (32.3)	232 761 (32.5)	2250 (20.4)	
Other	75 545 (10.4)	74 646 (10.4)	899 (8.2)	
Unknown	755 (0.1)	755		
Hospital location				
Metropolitan	567 041 (77.8)	556 960 (77.6)	10 081 (91.6)	<0.001
Regional	161 018 (22.4)	161 018 (22.4)	931 (8.5)	
Primary diagnosis category				
Nervous	36 608 (5.0)	21 358 (3.0)	3483 (31.6)	<0.001
Respiratory	115 088 (15.8)	113 783 (15.9)	1305 (11.9)	
Musculoskeletal	22 492 (3.1)	21 358 (3.0)	1134 (10.3)	
Digestive	102 226 (14.0)	101 449 (14.1)	777 (7.1)	
Other	451 822 (62.0)	447 509 (62.4)	4313 (39.2)	
Unknown	754 (0.1)	754		

[a]'Qualified newborn'=admitted to special care nursery or neonatal intensive care units, or the second or subsequent live-born of a multiple birth, or remains in hospital after their mother is discharged from hospital, or is admitted to hospital without their mother. [b]Statistical admission, change in care type within the same hospital (e.g. rehabilitation admission after a surgical admission). Missing values were excluded from χ^2 analysis.

Table III: Number of procedures and length of stay for multiday admissions, by disease category of the primary discharge diagnosis – comparison between cerebral palsy (CP) and general population admissions. Data from the Victorian Admitted Episodes Dataset

Primary diagnosis category	Admissions	Number of procedures				Length of stay (d)			
		0	≥1[a]			1	>1[b]		
		n (%)	Med.	IQR	Max.	*n* (%)	Med.	IQR	Max.
All diagnoses (*n*)	General population (348 500)	142 030 (40.8)	2	2–3	40	185 760 (53.3)	3	2–5	470
	CP (5408)	1289 (23.8)	3	2–6	40	1764 (32.6)	4	2–8	242
Respiratory (*n*)	General population (85 229)	45 464 (53.3)	2	2–3	40	60 935 (71.4)	2	2–3	153
	CP (1147)	319 (27.8)	2	1–3	17	283 (24.7)	5	3–9	110
Nervous (*n*)	General population (25 187)	7096 (28.2)	2	1–3	37	15 487 (61.5)	4	3–4	342
	CP (892)	251 (28.1)	3	2–6	23	403 (45.2)	4	2–6	57
Musculoskeletal (*n*)	General population (10 872)	1888 (17.4)	4	2–5	40	5300 (48.7)	4	2–6	156
	CP (744)	21 (2.8)	7	5–10	21	204 (27.4)	4	3–7	147
Digestive (*n*)	General population (22 341)	5156 (23.1)	2	2–3	40	8495 (38.0)	3	2–5	399
	CP (298)	58 (19.5)	3	2–5	29	88 (29.5)	4	3–7	121

[a]In Wilcoxon rank sum (Mann–Whitney) tests of the difference between CP and general population admissions in the number of procedures per admission, $p<0.001$ for admissions due to all diagnoses, and nervous, musculoskeletal and digestive diseases; $p>0.050$ for admissions due to respiratory diseases. [b]In Wilcoxon rank sum (Mann–Whitney) tests of the difference between CP and general population admissions in length of stay per overnight admissions of >1d, $p<0.001$ for admissions due to all diagnoses, and respiratory and digestive diseases; $p<0.050$ for admissions due to nervous diseases; $p<0.005$ for admissions due to musculoskeletal diseases. Min, minimum; Max, maximum; Med, median; IQR, interquartile range (25th–75th percentile).

the median WIES allocation was 120% higher (Figs S1–S5 and Table SI, online supporting information).

Admission frequency and characteristics in the CP cohort

Compared to those classified as GMFCS level I or II, the median number of both same-day and multiday admissions was higher in those classified in GMFCS levels III, IV or V ($p<0.005$). The same pattern existed for those with and without epilepsy, gastrostomy tubes, and ITB pumps (Table IV).

A higher proportion of the admissions involving children functioning at GMFCS level V were classified as emergency (54%) and multiday (68%) compared to those functioning at GMFCS levels I, II, III, or IV. One-quarter of all admissions involving children classified in GMFCS level V were due to respiratory diseases, compared to 12% of GMFCS level IV admissions, and fewer than 6% of admissions involving those classified in GMFCS levels I, II, or III ($p<0.001$ for the difference in

Table IV: Number of admissions over the study period in the cerebral palsy (CP) cohort. Data from the Victorian Admitted Episodes Dataset

	Same-day admissions				Multiday admissions			
	0	≥1[a]			0	≥1[b]		
	n (%)	Med.	IQR	Max.	*n* (%)	Med.	IQR	Max.
CP cohort (1748)	503 (28.8)	3	2–6	40	616 (35.2)	3	1–6	82
GMFCS level (*n*)								
I/II (1091)	372 (34.1)	3	1–6	40	512 (46.9)	2	1–4	30
III–V (617)	113 (18.3)	4	2–6	20	85 (13.8)	4	2–8	82
Topography (*n*)								
Unilateral (650)	211 (32.5)	4	2–7	40	303 (46.6)	2	1–4	30
Bilateral (1080)	278 (25.7)	3	2–6	35	302 (28.0)	3	2–6	82
Motor type (*n*)								
Spastic (1515)	424 (28.0)	3	2–6	40	542 (25.8)	3	1–5	82
Dyskinetic (98)	20 (20.4)	4	2–7	18	18 (18.4)	4	2–8	33
Epilepsy (*n*)								
No (1190)	370 (31.1)	3	1–6	35	487 (40.9)	2	1–4	66
Yes (493)	100 (20.3)	4	2–7	40	90 (18.3)	4	2–9	82
Gastrostomy tube (*n*)								
No (1522)	472 (31.0)	3	1–6	40	598 (39.3)	2	1–4	30
Yes (221)	28 (12.7)	4	2–7	18	14 (6.3)	8	4–14	82
ITB pump (*n*)								
No (1712)	498 (29.0)	3	2–6	40	610 (35.6)	3	1–5	82
Yes (30)	2 (6.7)	6	3–10	15	2 (6.7)	8	6–13	36

[a]In Wilcoxon rank sum (Mann–Whitney) tests of the difference between dichotomized subgroups in the number of same-day admissions over the study period, $p<0.005$ for GMFCS and ITB; $p<0.001$ for epilepsy and gastrostomy tube; and $p>0.050$ for topography and motor type; [b]In Wilcoxon rank sum (Mann–Whitney) tests of the difference between dichotomized subgroup in the number of multiday admissions over the study period, $p<0.001$ for GMFCS, topography, epilepsy, gastrostomy tube, ITB pump, and $p<0.001$ for motor type. Min, minimum; Max, maximum; IQR, interquartile range (25th–75th percentile); GMFCS, Gross Motor Function Classification; IQR, interquartile range; ITB, intrathecal baclofen.

Table V: Differences in admission characteristics between GMFCS levels. Data from the Victorian Admitted Episodes Dataset

	GMFCS level I admissions *n* (%)	GMFCS level II admissions *n* (%)	GMFCS level III admissions *n* (%)	GMFCS level IV admissions *n* (%)	GMFCS level V admissions *n* (%)	*p*
All CP admissions	2382 (21.6)	2522 (22.9)	1181 (10.7)	1647 (15.0)	3108 (28.2)	
Admission type						
Emergency	507 (21.3)	577 (22.9)	211 (17.9)	578 (35.1)	1685 (54.2)	<0.001
Elective	1842 (773.)	1917 (76.0)	948 (80.3)	1055 (64.1)	1397 (45.0)	
Qualified newborn[a]	25 (1.1)	11 (0.4)	9 (0.6)	9 (0.6)	16 (0.5)	
Statistical[b]	8 (0.3)	17 (0.7)	5 (0.3)	5 (0.3)	10 (0.3)	
Length of admission						
Same-day	1582 (66.4)	1559 (61.8)	657 (55.6)	716 (43.5)	1008 (32.4)	<0.001
Multiday	800 (33.6)	963 (38.2)	524 (44.4)	931 (56.5)	2100 (67.6)	
Diagnostic related group type						
Medical	1789 (69.6)	1860 (71.1)	779 (65.1)	1093 (65.6)	2219 (71.0)	<0.001
Surgical	488 (19.0)	540 (20.6)	328 (27.4)	385 (23.1)	470 (15.0)	
Other	105 (4.1)	122 (4.7)	74 (6.2)	169 (10.1)	419 (13.4)	
Hospital location						
Metropolitan	2238 (94.0)	2316 (91.8)	1114 (94.3)	1537 (93.3)	2719 (87.5)	<0.001
Regional	144 (6.0)	206 (8.2)	67 (5.7)	110 (6.7)	389 (12.5)	
Primary diagnosis category						
Nervous	1046 (43.9)	1054 (41.8)	369 (31.2)	436 (26.5)	522 (16.8)	<0.001
Respiratory	132 (5.5)	144 (5.7)	47 (4.0)	201 (12.2)	773 (24.9)	
Musculoskeletal	204 (8.6)	257 (10.2)	202 (17.1)	195 (11.8)	263 (8.5)	
Digestive	105 (4.4)	179 (7.1)	86 (7.3)	144 (8.7)	249 (8.0)	
Other	895 (37.6)	888 (35.2)	477 (40.4)	671 (40.7)	1301 (41.9)	

[a]'Qualified newborn'=admitted to special care nursery or neonatal intensive care units, or the second or subsequent live-born of a multiple birth, or remains in hospital after their mother is discharged from hospital, or is admitted to hospital without their mother; [b]statistical admission, change in care type within the same hospital (e.g. rehabilitation admission after a surgical admission). CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

distribution of primary diagnoses across the five levels of GMFCS).

Admissions in children with better gross motor function were more likely to be due to diseases of the nervous system which includes diagnoses of CP and seizures (43% of GMFCS level I admissions and 41% of GMFCS level II admissions) and diseases of the musculoskeletal system (9% of GMFCS level I admissions, 10% of GMFCS level II admissions, and 17% of GMFCS level III admissions) (Table V, and Tables SII–SIII, online supporting information).

DISCUSSION

Cerebral palsy registers have not traditionally been used for health services research. This study demonstrates the feasibility and utility of linkage between a population-based CP register and an administrative health services data set. Key findings from this linkage project were that: (1) children and young people with CP represent approximately 1.5% of admissions in their age group; (2) compared to general population admissions, higher proportions of CP admissions are elective, medical, and occur in hospitals located in metropolitan areas; (3) children with CP have longer lengths of stay, undergo more procedures per admission, and accrue higher costs, compared to other hospitalized children; and (4) among children with CP, higher GMFCS level is associated with comparatively more admissions, more admissions for respiratory illnesses, and more admissions that are classified as emergency.

Our findings are consistent with those of groups in the USA and Canada.[21,22] In the USA, Murphy et al.,[22] using diagnostic codes to identify children with CP, compared admissions between children with and without CP, and reported longer lengths of stay and more procedures per admission for children with CP. They also reported children with CP to be more likely than other children to receive care in metropolitan and teaching hospitals located in urban areas. Although we were unable to obtain data on individual hospital type, we did find that CP admissions were more likely to occur in hospitals in metropolitan areas, where all the major tertiary and paediatric-specialist hospitals are located. Comparatively greater use of specialist hospitals in children with CP may be attributed to higher levels of medical complexity including technology dependency and the subsequent need for specialist paediatric medical care. In addition, many interventions, for example single event multi-level surgery and intrathecal baclofen therapy, are usually delivered at tertiary centres.

Other groups have also used diagnostic codes to identify children with CP from hospital admissions data sets.[23–25] Limitations associated with this methodology include a lack of data on CP severity and complexity as well as the potential to miss CP admissions where CP is not listed as a discharge diagnosis. In addition, many of these data sets are not internally linked which means that researchers cannot investigate the frequency of admissions in individual patients or ascertain exactly how many patients are responsible for the admissions in question.[23,25] On the other hand, linking a CP register to an administrative health services data set to investigate service use in this population offers a number of advantages. First, it allows researchers to investigate service use in well-defined populations or birth cohorts

of children with CP. Second, it ensures greater accuracy of CP diagnoses and eliminates the need to rely solely on hospital coding. Third, it allows more detailed analysis of how factors such as CP severity and complexity affect the rate of medical service use in children with CP.

In most Australian states, infrastructure support to enable data linkage has only recently become available to researchers.[26] Linkage of multiple data sets is most straightforward when the various data sets use a common unique identifier. Such unique identifiers are assigned at birth in many countries including Norway, Sweden, and Denmark; however, no such routinely captured unique identifier currently exists in Australia. For this reason, a combination of hospital identification codes, sex, and date of birth were used to link the two data sets involved in this particular project. Nonetheless, we were able to successfully match over 90% of our selected CP cohort to the VAED.

Limitations

The design of the VAED is such that all hospitals send a minimum data set of admitted patient data related to their centre's activities to the Victorian Department of Health and Human Services where the data are compiled into the VAED. As such, when data errors or inconsistencies were picked up by the research team, it was not possible to go back to the original data source for verification. It is possible that some members of the CP cohort were incorrectly matched; however, given the size of the study population and the large number of records, any errors would have been unlikely to influence our findings. Finally, although we received linked VAED data (i.e. person-level data) on the CP cohort, we obtained only episode-level data on the controls. Consequently, it was not possible to ascertain the frequency of admissions in the control population or the actual number of children responsible for the admissions in question.

CONCLUSIONS AND FUTURE DIRECTIONS

This project benefited from the use of a population-based CP register and the ability to extract clinical data pertaining to the CP cohort. The availability of patient-level, rather than episode-level, data on the CP cohort meant that the frequency of admissions in individual patients could be ascertained. It highlights the ability of CP registers to be used for health services research. To maximize the clinical impact of this type of research, CP registers should routinely collect information on comorbidities and medical device use which were shown to influence the risk of having a hospital admission in the current study.

In addition to demonstrating a potential new use for CP registers, findings from this study may also assist parents, medical professionals, and policy makers; despite the fact that CP is the most common childhood-onset physical disability, little is known about how and why children with the condition are admitted to hospitals, whether this differs greatly from the general childhood population, and how it is influenced by CP severity and complexity. Here we outline how CP admissions in Australia differ from, and are more costly than, general childhood admissions, and how even within the CP cohort, admission frequency and characteristics vary significantly.

The goal of health services research is to identify ways to organize, manage, finance, and deliver high quality care that will protect and improve the health of individuals and populations.[27] To achieve such a goal in the CP population, future research could focus on unnecessary or overuse of hospital inpatient services, preventable admissions, admissions before death, and re-admissions after surgical procedures, including the insertion of medical devices such as gastrostomy tubes. This type of research may identify priority areas for changes in current practice and facilitate education programmes for individuals with CP, their families, and care providers. This may reduce unnecessary hospital admissions and the associated negative impacts that they have on children and their families, ultimately improving patient care, outcomes, and health care experiences.

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SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1: WIES allocations for CP and general population multiday admissions – all diagnoses.

Figure S2: WIES allocations for CP and general population multiday admissions – respiratory diagnoses.

Figure S3: WIES allocations for CP and general population multiday admissions – neurological diagnoses.

Figure S4: WIES allocations for CP and general population multiday admissions – musculoskeletal diagnoses.

Figure S5: WIES allocations for CP and general population multiday admissions – digestive diagnoses.

Table SI: WIES (funding) allocation for multiday admissions, by disease category of the primary discharge diagnosis – comparison between cerebral palsy and general population admissions.

Table SII: Five (or more if multiple diagnoses had the same count) most common principal diagnoses for multiday admissions, by age group.

Table SIII: Five (or more if multiple diagnoses had the same count) most common principal diagnoses for multiday admissions, by GMFCS level.

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