


Comparing emergency department presentations among children with cerebral palsy with general childhood presentations: a data linkage study

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ABBREVIATIONS

VCPR	Victorian Cerebral Palsy Register
VEMD	Victorian Emergency Minimum Dataset

AIM The aims of this study were to estimate the proportion of emergency department presentations attributable to children with cerebral palsy (CP), investigate the frequency of emergency department presentations in a CP cohort, and compare emergency department presentations among children with CP with those of other children.

METHOD This was a retrospective cohort study. The Victorian Cerebral Palsy Register was linked to the Victorian Emergency Minimum Dataset. Data on emergency department presentations for the CP cohort occurring between 2007 and 2014 and population control data were obtained.

RESULTS The CP cohort ($n=1748$) had 7015 emergency department presentations during the 7-year period, accounting for 0.4% of the 1.69 million age-specific presentations during that time. The number of annual presentations per 1000 children rose with increasing CP severity. Compared with presentations among the general population, higher proportions of presentations among the CP cohort were preceded by ambulance arrivals (27% vs 8%), triaged as urgent (66% vs 32%), and required hospital admission (38% vs 12%).

INTERPRETATION The marked differences in presentations between the CP cohort and the general population in the proportions that were urgent and required ambulance arrivals and hospital admissions was an important finding. Strategies to ensure appropriate use of services, including encouragement to seek earlier assistance from primary care providers, may prevent problems escalating to the need for urgent care.

Across the world, increasing numbers of emergency department presentations are resulting in overcrowding and associated treatment delays, and impaired access for those in genuine need of emergency care.¹ In the Australian state of Victoria, the group with the greatest number of emergency department presentations annually is children aged 0 to 4 years.² There is evidence that many paediatric emergency department presentations could be safely managed in primary care settings,³ and much discussion surrounds the need for strategies to encourage parents to use alternatives for urgent care when appropriate.^{4,5}

Children with medical complexity, such as those with neurodisabilities like cerebral palsy (CP), account for a disproportionate amount of paediatric health care expenditure in developed countries.^{6–8} Interest in the patterns of service use among this group is growing;^{8–10} however, there is a

paucity of published data on service use specifically in children with CP, the most common cause of childhood physical disability.¹¹

While the physical disability in CP can range from mild to severe, comorbidities are common. These include epilepsy and impairments of speech, vision, hearing, and intellect, medical device dependency, and increased susceptibility to frequent respiratory and gastrointestinal complications.^{12,13} All these factors increase the health care requirements of children with CP, compared with their typically developing peers.

Studying the patterns of emergency department use among children provides insight into the appropriateness of emergency service use and the accessibility of primary care in a region, thus having implications for public policy and clinical practice.¹⁴ Among children with CP, the complexity

of the condition can introduce a requirement for emergency care for illnesses or other acute events which, for other children, may be managed appropriately in primary care. Consequently, research on emergency department use among general populations of children may not be generalizable to children with CP; any recommendations arising from such research may not be applicable to this population.

A better understanding of the characteristics of emergency department presentations among children with CP and how these differ from those of other children from the same population would assist with the development of strategies to reduce unnecessary emergency department use in this group. Therefore, the aims of this study were to investigate the frequency of emergency department presentations among a CP population cohort, estimate the proportion of all emergency department presentations within a certain age range attributable to children with CP, and compare the characteristics of emergency department presentations among children with CP and those without the condition.

METHOD

Data sources

The Victorian Cerebral Palsy Register (VCPR), a database of individuals with CP born or living in Victoria since 1970, was linked to the Victorian Emergency Minimum Dataset (VEMD), which contains demographic, administrative, and clinical data detailing all emergency department presentations to Victorian public hospitals.¹⁵ The study was approved by the Human Research Ethics Committee of the Royal Children's Hospital, Melbourne.

The CP cohort comprised individuals born between 1 July 1995 and 30 June 2009 (aged 5–18y at the end of the study period on 30 June 2014) who were registered on the VCPR at the time of data extraction. Clinical data extracted on each case before linkage included Gross Motor Function Classification System (GMFCS) level, epilepsy status, and whether individuals had a gastrostomy tube or intrathecal baclofen pump in place. The GMFCS is a five-level scale that describes the gross motor function of children with CP on the basis of their self-initiated movement. Children who are functioning in GMFCS level I can generally walk without restrictions but may be limited in some more advanced motor skills. Children who are classified as functioning in GMFCS level V are very limited in their ability to move themselves around and require a manual wheelchair for transport.¹⁶

Data linkage

The VCPR and VEMD were linked using a deterministic linkage approach by Victorian Data Linkages, a dedicated data linkage unit situated within the Victorian Department of Health and Human Services. Linkage variables were identified as hospital codes, patient unit record numbers, date of birth, and sex. The completeness of these variables in both the VCPR and the VEMD was deemed to be high, hence why they were selected as linkage variables. As the VEMD is internally linked, once a patient was matched to one of their

What this paper adds

- Children with cerebral palsy (CP) account for 0.4% of childhood emergency department presentations.
- More emergency department presentations among children with CP require ambulance arrival.
- More CP emergency department presentations are urgent and require hospital admission.
- Traditional emergency department triage scales seem less accurate for this group.

emergency department encounters, all their other emergency department encounters (i.e. emergency department presentations to other hospitals) could be identified.

To allow comparisons to be made between CP emergency department presentations and those of the general childhood population, data on all emergency department presentations were also obtained for patients whose date of birth fell within the same range as the CP cohort. Data were obtained on presentations that took place between financial years 2007–08 and 2013–14 (1 July 2007–30 June 2014). Linked data were de-identified before being released to the research team.

Each emergency department presentation was triaged using the Australian Triage Scale, a five-level classification system describing the urgency with which a patient should be treated.¹⁷ For this study, presentations triaged as 1, 2, or 3 according to the Australian Triage Scale were categorized as higher-urgency presentations, and presentations in categories 4 and 5 as lower urgency. Other data obtained included referral source, arrival mode, departure disposition, and principal diagnosis. The principal diagnosis, established at the end of the patient's emergency department presentation, should describe the reason for attendance at the emergency department. For each presentation, it was classified according to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems.¹⁸

Statistical analysis

For the CP cohort, odds ratios and 95% confidence intervals were calculated using a contingency table approach to compare the odds of having at least one emergency department presentation across groups of GMFCS, epilepsy, gastrostomy tube, and intrathecal baclofen pump. After adjusting the denominator to take into account children who were not alive for the entire study period (some members of the cohort were born after 2007 and some died over the 7-year period), the number of annual emergency department presentations per 1000 children was calculated, and comparisons were made across GMFCS levels. This was done by subtracting the number of deaths each year from the denominator for the following year.

Numbers and percentages are reported for the most common diagnosis groups, which were diseases of the respiratory (J00–J99), neurological (G00–G99), and digestive (K00–K93) systems, injuries or poisonings (S00–T98), and symptoms, signs, and abnormal clinical and laboratory findings not elsewhere classified (R00–R99). Other diagnosis groups that were reported less frequently were grouped

together as an 'Other' category, which is defined in the relevant table legends.

Emergency department presentations were categorized according to age, triage category, referral source, arrival mode, departure status, and principal diagnosis category, and comparisons made between the general population and CP presentations, as well as across subgroups of GMFCS level (I–II, independently ambulant; III, ambulates with aids; IV–V, non-ambulant). χ^2 analysis was used to test for differences between groups; *p*-values are provided. All analysis was performed using Stata 14.1 (StataCorp, College Station, TX, USA).

RESULTS

The CP cohort

The CP cohort comprised 1748 individuals (58% male, 42% female) who ranged in age from 5 to 18 years (median 12y) at the end of the study period. One thousand five hundred and thirty-five were born before 1 July 2007 and were followed up for the entire study period. Two hundred and thirteen were born between 1 July 2007 and 30 June 2009 so were followed up, and data on their emergency department presentations were obtained from their day of birth until the end of the study period. Fifty-four children died over the study period.

Sixty-two per cent (*n*=1091) were classified as having a mild motor impairment, namely functioning in GMFCS levels I or II (36% and 26% respectively), 10% (*n*=172) were functioning in GMFCS level III, and 25% (*n*=445) were functioning in GMFCS levels IV or V (12% and 13%

respectively). Overall, 28% (*n*=493) had a co-diagnosis of epilepsy, 13% (*n*=221) had a gastrostomy feeding tube in place, and 2% (*n*=30) had an intrathecal baclofen pump inserted (Table I). Compared with children who were classified as functioning in GMFCS levels I to III, higher proportions of children classified as functioning in GMFCS level IV or V had epilepsy (58% vs 19%; χ^2 *p*<0.001), gastrostomy feeding tubes (43% vs 2%; χ^2 *p*<0.001), and intrathecal baclofen pumps (6% vs 0.2%; χ^2 *p*<0.001).

Overall, 64% (*n*=1116) of the CP cohort could be successfully matched with the VEMD; that is, 64% were known to have had an emergency department presentations during their lifetime. A total of 956 (55%) had at least one emergency department presentation to one of 39 Victorian public hospital emergency departments during the 7-year study period. The frequency of individuals having at least one emergency department presentation rose with increasing GMFCS level. It was also higher for those with epilepsy, gastrostomy tubes, and intrathecal baclofen pumps (Table I). These 956 individuals accounted for a total of 7015 presentations during this time, representing approximately 0.4% of the 1.69 million emergency department presentations during this time that involved a child in their age range (Table II).

Frequency of presentations in the CP cohort

Among the 956 children who had at least one emergency department presentation, the median number of presentations was 4 (interquartile range 2–9); however, this ranged from 1 to 84. Sixty children had at least 22 presentations

Table I: Characteristics of the cerebral palsy (CP) cohort, proportions to have ≥ 1 emergency department (ED) presentation over the study period, and associated odds ratios

	CP cohort		≥ 1 ED presentation over the study period		Odds ratio (95% confidence interval)	<i>p</i>
	<i>n</i>	%	<i>n</i>	%		
Entire cohort	1748	100.0	956	54.7		
GMFCS level						
I	629	36.0	274	43.6	Reference	
II	462	26.4	229	49.6	1.27 (1.00–1.62)	0.049
III	172	9.8	102	59.3	1.89 (0.34–2.66)	<0.001
IV	213	12.2	149	70.0	3.02 (2.16–4.21)	<0.001
V	232	13.3	185	79.7	5.10 (3.57–7.29)	<0.001
Unknown	40	2.3	17	42.5		
Epilepsy						
No	1190	68.1	576	48.4	Reference	
Yes	493	28.2	359	72.8	2.86 (2.27–3.59)	<0.001
Unknown	65	3.7				
Gastrostomy tube						
No	1522	87.1	773	50.8	Reference	
Yes	221	12.6	182	82.4	4.52 (3.15–6.48)	<0.001
Unknown	5	0.3				
ITB pump						
No	1712	97.9	930	54.3	Reference	
Yes	30	1.7	25	83.3	4.20 (1.60–11.03)	0.004
Unknown	6	0.3				

Percentages relating to the 'CP cohort' column are computed on the total number of children included in the cohort (*n*=1748). Percentages relating to the ' ≥ 1 ED presentation over the study period' column represent the proportion of children belonging to the specific subgroups of Gross Motor Function Classification System (GMFCS), epilepsy, gastrostomy tube, and intrathecal baclofen (ITB) pump that accessed the emergency department over the study period. Victorian hospital data source: Victorian Emergency Minimum Dataset.

Table II: Characteristics of emergency department presentations 2007–08 to 2013–14: a comparison between cerebral palsy (CP) and general childhood presentations and across three subgroups of Gross Motor Function Classification System (GMFCS)

	General population presentations		All CP presentations		<i>p</i> ^a	GMFCS levels I–II presentations		GMFCS level III presentations		GMFCS levels IV–V presentations		<i>p</i> ^b
	<i>n</i>	%	<i>n</i>	%		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Age at presentation (y)	1 692 748	99.6	7015	0.4		2568	36.6	549	7.8	3782	53.9	
0–4	654 672	38.7	2622	37.4	<0.001	980	38.2	188	34.2	1362	36.0	0.002
5–9	449 334	29.5	2310	32.9		792	30.8	183	33.3	1322	35.0	
10–14	407 122	24.1	1692	24.1		662	25.8	133	24.2	891	23.6	
15–19	131 640	7.8	391	5.6		134	5.2	45	8.2	207	5.5	
Referral source												
Self/family	1 524 900	90.1	6447	91.9	<0.001	2328	90.9	515	93.8	3503	92.7	<0.001
Health professional	138 609	8.2	392	5.6		181	7.1	25	4.6	180	4.8	
Other	28 757	1.7	168	2.4		53	2.1	9	1.6	97	2.6	
Unknown	482	0.02	8	0.1								
Arrival mode												
Ambulance	132 613	7.8	1907	27.2	<0.001	525	20.4	111	20.2	1248	33.0	<0.001
Walk-in and other ^c	1 560 135	92.2	5108	72.8		2043	79.6	438	79.8	2534	67.0	
Triage category												
1–3 (highest urgency)	535 770	31.7	4635	66.1	<0.001	1414	55.1	319	58.1	2835	75.0	<0.001
4–5 (lowest urgency)	1 156 769	68.3	2373	33.8		1154	44.9	230	41.9	940	25.0	
Dead on arrival	209	0.01	7	0.1		0		0		7	0.2	
Primary diagnosis category (ICD-10 codes)												
Respiratory (J00–J99)	237 970	14.1	1444	20.6	<0.001	367	14.3	68	12.4	994	26.3	<0.001
Injury or poisoning (S00–T98)	577 049	34.1	1258	17.9		575	22.4	147	26.8	517	13.6	
Neurological (G00–G99)	13 430	0.8	480	6.8		165	6.4	27	4.9	283	7.5	
Digestive (K00–K93)	66 423	3.9	285	4.1		91	3.5	23	4.2	167	4.3	
Symptoms, signs, and abnormal clinical and laboratory findings NEC (R00–R99)	196 597	11.6	1805	25.7		627	24.4	125	22.8	1012	26.8	
Other ^d	457 872	27.1	1464	20.9		589	22.9	127	23.1	723	19.1	
Unknown	143 407	8.5	279	4.0		154	6.0	32	5.8	89	2.4	
Departure status												
Home	1 311 321	77.5	3872	55.2	<0.001	1621	63.1	344	62.7	1828	48.3	<0.001
Admitted	203 055	12.0	2680	38.2		724	28.2	152	27.7	1774	46.9	
Other	178 225	10.5	462	6.6		223	8.7	53	9.7	180	4.8	

^a*p*-value from χ^2 test for equality of percentages between general population and CP presentations; ^b*p*-value from χ^2 test for equality of percentages across the three subgroups of GMFCS; missing/unknown values excluded from analysis. ^cIncludes arrival by foot, private vehicle, or community service. ^dIncludes infectious and parasitic diseases (A00–B99); neoplasms (C00–D48); diseases of the blood (D50–89); endocrine, nutritional, and metabolic diseases (E00–E90); mental and behavioural disorders (F00–F99); diseases of the eye (H00–H59), ear (H60–H95), circulatory system (I00–I99), skin (L00–L99), genitourinary system (N00–N99); and O00–O99, P00–P96, Q00–Q99, V01–Y98, Z00–Z99. Victorian hospital data source: Victorian Emergency Minimum Dataset. NEC, not elsewhere classified.

over the 7-year period, of whom 44 (73%) were classified as functioning in GMFCS levels IV or V, and 42 (70%) had epilepsy.

The number of emergency department presentations annually per 1000 children with CP rose steadily with increasing GMFCS level. Among children functioning in GMFCS level V, the annual number of emergency department presentations over the 7-year study period ranged from 1259 to 2186 per 1000 children per year. This compares with a range of 215 to 391 annual emergency department presentations per 1000 children functioning in GMFCS level I (Fig. 1).

Emergency department presentation characteristics: a comparison between groups

Most emergency department presentations were self- or family-initiated (92% of the CP emergency department presentations and 90% of the general population presentations). Diagnoses classified as ‘symptoms, signs and abnormal

clinical and laboratory findings, not elsewhere classified’ and diseases of the respiratory system were the most common presenting complaints among children with CP (26% and 21% respectively). Children functioning in GMFCS levels IV and V had the highest proportion of presentations that were due to respiratory illnesses (26%). Injuries and poisonings were the most common complaints among the general population of children (34%, compared with 18% of CP presentations) (Table II).

Compared with the general childhood presentations, emergency department presentations among the CP cohort were more likely to have been preceded by an ambulance arrival (27% vs 8%; *p*<0.001), triaged as being of higher urgency (66% vs 32%; *p*<0.001), and to have resulted in a hospital admission (38% vs 12%; *p*<0.001) (Table II). This was observed both for lower- and for higher-urgency emergency department presentations. For lower-urgency presentations in the CP cohort, over 8% were preceded by an ambulance arrival (compared with 3% of lower-urgency

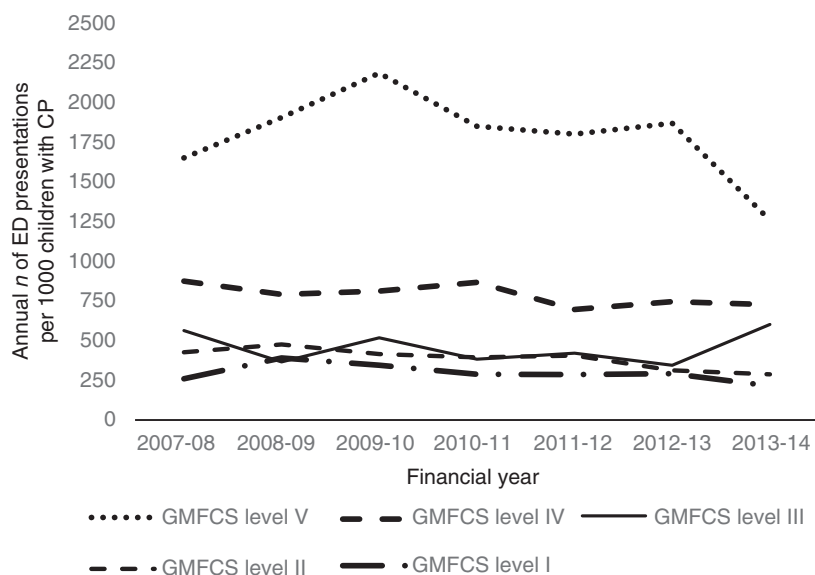


Figure 1: Annual number of emergency department presentations per 1000 children with cerebral palsy (CP) by Gross Motor Function Classification System (GMFCS) level. ED, emergency department.

presentations in the general population; $p < 0.001$), and 12% resulted in a hospital admission (compared with 5% of lower-urgency presentations in the general population; $p < 0.001$) (Table III).

Of the three GMFCS subcategories (levels I–II, levels III, and levels IV–V), presentations among children functioning in levels IV or V differed most from the general population presentations across the categories of arrival mode, triage category, and departure status. However, even those children with CP who were classified as having a mild gross motor impairment (GMFCS level I or II) had comparatively higher proportions of emergency department presentations that were preceded by an ambulance arrival (20% vs 8%; $p < 0.001$); triaged as urgent (55% vs 32%; $p < 0.001$), and required a hospital admission (28% vs 12%; $p < 0.001$) (Table III).

DISCUSSION

Although children with CP accounted for less than 1% of emergency department presentations among children of the same age, there was a marked difference in the use of health care resources between children with CP presenting to the emergency department and children without CP. Specifically, children with CP were more likely to have arrived by ambulance, have their presentation triaged as urgent, and require a hospital admission. For each of these factors, the group that differed most from the general childhood population were children classified as functioning at GMFCS levels IV or V. Within the CP cohort, it was this group with severe gross motor impairment that, per 1000 children, had more emergency department presentations annually.

Using publicly available data from the Australian Bureau of Statistics, we estimate that there were 981 232 children

and young people residing in the state of Victoria on 30 June 2014 who were aged 5 to 18 years, which was the age criterion used for the CP cohort.¹⁹ Subtracting the 1748 children in the CP cohort from this figure, there remain 979 484 children and young people who may have accounted for the 1 692 748 emergency department presentations from the general population over the 7-year study period. From this, we estimate an average annual number of emergency department presentations of 246.9 per 1000 individuals. These figures are estimates and should be interpreted with caution; nevertheless, they do suggest that the average annual number of emergency department presentations among the general childhood population is similar to that of children with CP who are classified as functioning at GMFCS levels I or II, but substantially lower than that of children with CP who have a moderate or severe gross motor impairment.

Arrival mode, triage, and departure disposition data from the current study would suggest that a higher proportion of CP emergency department presentations are ‘appropriate’ compared with those of other children. However, it is unclear from these data whether the relatively higher proportions arriving by ambulance, being triaged as urgent, and proceeding to admission reflect the severity of the underlying disability or other non-medical needs (e.g. more frequent carer crises) among the CP cohort, rather than the presenting complaints.

A pattern of increased use of ambulance services has also been reported for elderly people (compared with younger people),³ and the reasons for this are multifactorial. Most likely, in the case of children with complex disabilities, a perception of greater severity of the child’s problem due to the presence of comorbidities and non-ambulant and/or

Table III: Characteristics of emergency department presentations by triage category: a comparison between referral source, arrival mode, diagnosis, and departure disposition

	Higher-urgency presentations (ATS 1–3) (n=540 635)					Lower-urgency presentations (ATS 4–5) (n=1 159 142)				
	General population presentations (n=535 770)		CP presentations (n=4635)		<i>p</i> ^a	General population presentations (n=1 156 769)		CP presentations (n=2373)		<i>p</i> ^a
	<i>n</i>	%	<i>n</i>	%		<i>n</i>	%	<i>n</i>	%	
Referral source										
Self/family	473 319	88.3	4257	91.8	<0.001	1 051 469	90.9	2186	92.1	0.002
Health professional	49 869	9.3	250	5.4		88 736	7.7	142	6.0	
Other	12 436	2.3	122	2.6		16 230	1.4	43	1.8	
Unknown	146	0.03	6	0.1		334	0.03	2	0.1	
Arrival mode										
Ambulance	93 211	17.4	1707	36.8	<0.001	39 337	3.4	197	8.3	<0.001
Walk-in and other ^b	442 559	82.6	2928	63.2		1 117 432	96.6	2176	91.7	
Primary diagnostic category (ICD-10 codes)										
Respiratory (J00–J99)	125 434	23.4	1211	26.1	<0.001	112 536	9.7	233	9.8	<0.001
Injury or poisoning (S00–T98)	147 852	27.6	565	12.2		429 197	37.1	693	29.2	
Neurological (G00–G99)	8253	1.5	414	8.9		5177	0.5	66	2.8	
Digestive (K00–K93)	26 213	4.9	177	3.8		40 210	3.5	108	4.6	
Symptoms, signs, and abnormal clinical and laboratory findings NEC (R00–R99)	86 418	16.1	1424	30.7		109 970	9.5	374	15.8	
Other ^c	129 811	24.2	803	17.3		328 061	28.4	661	27.9	
Unknown	11 789	2.2	41	0.9		131 618	11.4	238	10.0	
Departure status										
Home	359 421	67.1	2071	44.7	<0.001	951 900	82.3	1801	75.9	<0.001
Admitted	146 144	27.3	2386	51.5		56 911	4.9	294	12.4	
Other	30 205	5.6	178	3.8		147 958	12.8	278	11.7	

^a*p*-value from χ^2 test for equality of percentages between general population and CP presentations; missing/unknown values excluded from analysis. ^bIncludes arrival by foot, private vehicle, or community service. ^cIncludes infectious and parasitic diseases (A00–B99); neoplasms (C00–D48); diseases of the blood (D50–89); endocrine, nutritional, and metabolic diseases (E00–E90); mental and behavioural disorders (F00–F99); diseases of the eye (H00–H59), ear (H60–H95), circulatory system (I00–I99), skin (L00–L99), genitourinary system (N00–N99); and O00–O99, P00–P96, Q00–Q99, V01–Y98, Z00–Z99. Victorian hospital data source: Victorian Emergency Minimum Dataset. ATS, Australasian Triage Scale; CP, cerebral palsy; NEC, not elsewhere classified.

non-verbal status plays a role. Practical issues, including difficulties with transporting an acutely unwell child with a severe physical disability, may also be implicated.

A perception of greater severity due the child's underlying disability may also influence triage category allocation upon presentation to the emergency department and decision-making around whether a child requires a hospital admission. In the current study, the increased use of ambulance services and the higher proportion requiring admission among children with CP compared with other children presenting to the emergency department existed for both higher- and lower-urgency presentations. This suggests that traditional triage scales may have lower accuracy and reliability when used for children with disabilities. Alternatively, it may be the case that factors other than medical urgency frequently influence the need for hospital admissions from the emergency department among children with CP.

Regardless, it seems that children with CP, particularly those classified as functioning at GMFCS levels IV and V, are significant users of emergency medical services, including ambulance services. Increasing numbers of patients presenting to emergency departments and greater use of ambulance services are two issues that have received attention in recent years in the research literature,^{20,21} as well as in mainstream

media. Internationally, various strategies have been used to identify patient groups for which improved primary care management could reduce emergency medical service use.²² Children with complex disabilities such as CP may be a group for which improved primary care management could reduce their use of emergency medical services.

However, those factors that make it difficult for health care professionals and parents to judge the real urgency of a child's condition, such as non-ambulant and/or non-verbal status and medical device dependency, may also be barriers to accessing appropriate and effective primary care. It has been proposed that increased paediatric training and exposure for general practitioners may encourage more parents to use primary care services when appropriate instead of attending the emergency department with their child.^{23,24} For this strategy to work for children with complex care needs, additional professional development related to assessing and managing acutely ill, medically complex children with multiple comorbidities would be required, alongside ready access to tertiary care colleagues.

In the shorter term, readily available data could be used to increase our understanding of the health care needs of this group, and to find out what is effective in reducing their health care encounters. Linkage of large clinical registries

and administrative data sets is more time efficient and cost effective than prospective cohort studies.²⁵ Analysis of data collected by existing programmes such as complex care coordination programmes and hospitals in the home may indicate if they are effective at reducing unnecessary hospital visits. Data from the US and Canada suggest that such programmes are successful,²⁶ and similar findings have been reported from Western Australia;²⁷ however, studies of a larger scale are required, with linkage to administrative health service data sets incorporated. This would enable researchers to assess the effect of these programmes on the use of medical services outside the centres in which they are based.

Limitations

Limitations of this study include the lack of patient-level data on the non-CP presentations which limited the inability to investigate the frequency of presentations among the general population of children and to make comparisons with the CP cohort. It would be particularly informative to further explore differences in emergency department presentation frequency between those with mild CP and the general childhood population. If repeated measures in the control presentations could be accounted for, it is likely that some *p*-values would be higher. As such, the *p*-values in Tables II and III in particular should be interpreted with this limitation in mind.

It is possible that some members of the CP cohort were not linked to their emergency department records, which would have led to some children with CP being in the non-CP presentations; if this were the case, real differences between both groups may have in fact been slightly diluted. In addition, because of the study design, the length of follow-up for children in the CP cohort varied by birth year. This may have introduced a potential bias as health service use is influenced by age.

Finally, without information on non-medical factors that could contribute to health care utilization, we were limited in our ability to make further conclusions about the ‘appropriateness’ of emergency department presentations in this group.

CONCLUSIONS

By including a large population cohort of 1748 children with CP, representing all age groups and GMFCS levels, the findings are generalizable to other populations of children with CP. In particular, they are generalizable to those from countries that have similar health care structures as Australia and emergency department services that are free at the point of access.

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This study benefited from the use of data linkage techniques to ascertain emergency department data on a population cohort of children with CP. It confirms that, compared with other children in the emergency department, children with CP used more resources. It is unclear whether this is a result of the greater severity of their presenting complaints or a perception of greater severity due to their underlying disability.

This has several implications. If emergency services are being overutilized in this group because of a perception of greater severity, strategies to address this are warranted. In addition to having financial implications for health services, unnecessary ambulance use, emergency department presentations, and hospital admissions impact negatively (both emotionally and financially) on children and their families. Given the differences that exist in the patterns of emergency department use among children with CP compared with the general childhood population, strategies to reduce unnecessary emergency department use must be specifically tailored for this group. Such strategies may include encouragement to seek earlier assistance from primary care providers, which may prevent problems escalating to the need for urgent care.

Addressing structural barriers, namely access to primary care and community-based secondary care physicians who are familiar with the medical management of children with medical complexity, and assessing further the role of complex care coordination programmes and alternative models of care delivery should also be prioritized.

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