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[CP Register Supplement: eighth paper after Forewords; 2 tables; 2 figures]

Profile of associated impairments at age 5 years in Australia by cerebral palsy subtype and Gross Motor Function Classification System level for birth years 1996 to 2005

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ABBREVIATIONS

ACPR	Australian Cerebral Palsy Register
SCPE	Surveillance of Cerebral Palsy in Europe
UKCP	UK cerebral palsy database

[Abstract]

AIM To describe the distribution of impairments among persons with cerebral palsy (CP) in a large Australian cohort.

METHOD Records of persons on the Australian Cerebral Palsy Register (ACPR) (*n*=3466) born from 1996 to 2005 were reviewed to extract year of birth, sex, CP subtype, Gross Motor Function Classification System (GMFCS) level, and impairments in vision, hearing, speech, intellect, and epilepsy. The distributions of GMFCS levels and CP subtype were plotted, and

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the proportions of each level of impairment were tabulated and presented as stacked graphs within the GMFCS and CP subtype distributions.

RESULTS The proportions of persons with CP with each associated impairment increased with increasing GMFCS level. Compared with other spastic CP subtypes, individuals with spastic quadriplegia had higher frequencies of all associated impairments. Other than epilepsy, which was most prevalent in persons with spastic quadriplegia (53%), all impairments were most frequent in non-spastic CP subtypes. Hearing impairment was recorded for 21% of persons with dyskinesia whereas the hypotonic subtype had the highest prevalence of visual impairment (57%), intellectual impairment (90%), and speech impairment (95%).

INTERPRETATION Distributions of associated impairments across all GMFCS levels and CP subtypes in a large cohort are presented in formats suitable for clinical use and discussion with families.

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Australian CP Profile 1996–2005 *Michael J deLacy and Susan M Reid*

[Boxed text to appear on page 2]

What this paper adds

- Proportions of persons CP with associated impairments by GMFCS level and all CP subtypes.
- Graphical presentation of data suitable for discussion with families of persons with CP.

[Main text]

Population-based cerebral palsy (CP) registers can be used to describe the clinical characteristics of persons with CP and the relationships between them. Traditionally, CP has

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been described by the type of motor disorder and its topographical distribution (CP subtype), and more recently by the level of gross motor function using the Gross Motor Function Classification System (GMFCS).[1,2] Derived from scores on the Gross Motor Function Measure (GMFM-66),[3] the GMFCS classifies the ability to perform functional tasks into five levels within five age brackets. Since the GMFCS is quite stable over time,[4] it is possible to predict, up to 18 years, which functional tasks a person is likely to be able to complete. There is a strong relationship between CP subtype and ambulatory status as classified by the GMFCS.[5]

CP registers usually collect additional data about impairments that are commonly seen in association with the motor disorder. The Australian Cerebral Palsy Register (ACPR) collaboration, comprising representatives from all Australian states and territories, has adopted an agreed set of definitions for CP subtype and a minimum dataset that includes information on intellectual status, epilepsy, speech, hearing, and vision. Each specific and number of associated impairments add to the overall severity of CP and may have substantial impact on participation, quality of life, and life expectancy.[6]

The aims of this study were (1) to describe the frequency of selected associated impairments, pertaining to children at approximately 5 years of age, in a large Australian CP cohort and (2) to explore their distributions across CP subtypes and GMFCS levels. No previously published reports have presented the frequency of associated impairments across all levels of the GMFCS and all CP subtypes, and categorized impairments into at least three levels. The more detailed information arising from this research was expected to be useful when counselling families in a clinical context.

METHOD

The CP cohort

Australian state and territory data submitted to the ACPR for inclusion in the 2013 triennial report[7] were available for analysis, but only data from the three jurisdictions that had reached an agreed minimum ascertainment level of 1.5 per 1000 live births were included from the available ACPR dataset (Western Australia, Victoria, and South Australia). Additional updated data from Queensland for birth years 1996 to 2005 (Queensland Cerebral Palsy Register[8]) were included as the minimum ascertainment criterion was satisfied in these birth years. Thus this study included data from four of eight Australian jurisdictions, covering approximately 63% of the Australian population. There was no minimum age for inclusion as a case. Brain injuries acquired after 28 days of life and up to the age of 2 years in a

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previously neurologically intact infant were included and all cases were analysed as a single cohort.

Data and definitions

Data included from the ACPR comprised year of birth, sex, CP subtype, GMFCS level, and associated impairments of epilepsy, intellectual status, vision, hearing, and speech. Clinical data were collected at approximately 5 years of age either from the child's medical record or from clinical assessment for their register.

CP subtype definitions were agreed by the contributing jurisdictions before the start of the ACPR so no further harmonization was needed. Categories for CP subtypes were based on the predominant subtype and comprised spastic hemiplegia (including monoplegia), spastic diplegia, spastic quadriplegia (including triplegia), ataxia, dyskinesia (including dystonic and choreo-athetotic forms), and hypotonia. The subtypes conform to the definitions proposed by the Surveillance of Cerebral Palsy in Europe (SCPE),[9] except the ACPR differentiates between spastic quadriplegia, where the spasticity in the upper limbs is equal to or greater than the spasticity in the lower limbs and spastic diplegia where the lower limbs are more affected. Hypotonic CP was defined as a combination of low muscle tone, out of proportion to that expected by intellectual impairment, and hyper-reflexia. In all subtypes, trunk tone and bulbar signs vary but their presence, characteristics, or severities are not part of the definitions.

Intellectual status was classified either by a formal IQ test or clinical assessment. Three categories were used: known moderate/severe impairment, corresponding to a tested IQ <50 (severe, IQ <35 plus moderate, IQ 35–49); mild or probable impairment, corresponding to a tested IQ of 50 to 69 and including persons whose level of impairment was unable to be estimated; and no known impairment, corresponding to a tested IQ ≥70 and including persons whose intellectual function was not formally tested but not clinically questioned.

Epilepsy was defined as a history of at least two afebrile seizures before the age of 5 years, excluding neonatal seizures, irrespective of seizure control. Epilepsy status included a category for resolved epilepsy for persons who had been seizure free for 2 or more years without medication.

Vision status was based on clinical or formal assessment before any correction. Functional blindness was defined as a tested visual acuity of 6/60 or worse in the better eye and included those who clinically had light or colour perception but were unable to use their

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vision in a functional way. Some visual impairment described children who, at age 5, required corrective lenses to achieve normal visual acuity. No impairment indicated normal uncorrected visual acuity on formal testing or visual status that was not clinically questioned.

Speech status was classified by clinical assessment. Non-verbal referred to no or severely limited verbal expressive communication at 5 years (only a very limited number of words, e.g. mum/dad/yes/no). Some impairment referred to any speech impairment or delay regardless of cause or the presence of intellectual impairment. No impairment indicated age appropriate speech and language or speech status that was not clinically questioned.

Hearing status was based on behavioural and/or physiological audiological testing or clinical assessment. Bilateral deafness was defined as unaided loss of >70 decibels (dB) in the better ear, or inability to hear a shouted human voice. Some impairment was defined as unaided loss of 25 to 70dB in the better ear or inability to hear whispers but with retained ability to hear a shouted voice. No impairment was defined as <25dB loss, the ability to hear whispers, or hearing status that was not clinically questioned.

Data analysis

For each associated impairment, the proportions within each category, and the 95% confidence interval around the mean of individual birth year proportions, were calculated using Stata/SE 14.0 (StataCorp, College Station, TX, USA) and tabulated for the entire cohort across all 10 birth years. The distributions were also tabulated within subgroups stratified on GMFCS level and CP subtype. The distributions of GMFCS levels and CP subtypes were plotted and the proportions of each associated impairment level were presented as stacked bar graphs within the GMFCS and CP subtype distributions. For each individual, the number of severe associated impairments (comprising moderate/severe intellectual impairment [IQ<50], epilepsy, lack of speech, functional blindness, and bilateral deafness) was calculated, and the frequency distributions were plotted by GMFCS level and CP subtype.

RESULTS

Data collected at age 5 years were included for 3466 persons with CP who were born between 1996 and 2005; 2022 (58%) were male. The distribution of GMFCS levels was (I) 34%, (II) 25%. (III) 12%, (IV) 13%, and (V) 16%. Postneonatally acquired CP accounted for 6.1% of the cohort (*n*=211) but all cases of children with CP, postneonatally and non-postneonatally acquired, were analysed together.

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Intellect

Intellectual status was known for 2982 (86%) individuals, nearly half (48%) of whom had some degree of intellectual impairment (Table I). Intellectual status and GMFCS level were both known for 2749 (79%) persons; CP subtype and intellectual status were known for 2798 (81%) persons (Table II and Fig. 1a, b). Intellectual impairment (IQ<70) and moderate/severe impairment (IQ<50) were both more common in children classified to higher GMFCS levels and in those with hypotonic CP or spastic quadriplegia.

Epilepsy

Epilepsy status was known for 3173 (91%) individuals, 28% of whom had epilepsy at 5 years of age. An additional 4% had a history of seizures which had 'resolved' by the age of 5 (Table I). GMFCS level and epilepsy status were known for 2895 (83%) persons; CP subtype and epilepsy status were known for 2959 (85%; Table II and Fig. 1c, d). The prevalence of epilepsy rose with increasing GMFCS level and was highest in persons with spastic quadriplegia, hypotonia, or dyskinesia.

Speech

Speech status was known for 3070 (89%) persons. Speech impairment was present in 61% of the CP cohort and almost 24% were essentially non-verbal at 5 years of age (Table I). GMFCS level and speech status were known for 2843 (82%) persons; CP subtype and speech status were known for 2886 (83%; Table II and Fig. 1e, f). Increasing proportions of both speech impairment and non-verbal status were seen with increasing GMFCS level. The CP subtypes of hypotonia (95%), dyskinesia (94%), and spastic quadriplegia (89%) showed the highest proportions of speech impairment.

Hearing

Table I presents data for 3069 (89%) persons with known hearing status and shows that 12% of the overall cohort had some degree of hearing impairment and 3.5% were deaf bilaterally. This was the least common of the associated impairments presented. GMFCS level and hearing status were known for 2807 (81%) persons; CP subtype and hearing status were known for 2863 (83%) records (Table II and Fig. 1g, h). The proportion of persons with hearing impairment increased with increasing GMFCS level, as did the proportion of persons with bilateral deafness. The dyskinetic subtype had the highest prevalence of hearing

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impairment at 21%.

Vision

Table I presents known visual status data for 2953 (85%) persons and indicates that 36% had some degree of visual impairment and 6% had functional blindness. GMFCS level and vision status were known for 2712 (78%) individuals while CP subtype and vision status were known for 2768 (80%; Table II and Fig. 1i, j). The proportions of children with any degree of visual impairment and the proportions with functional blindness rose with increasing GMFCS level. Children with spastic quadriplegia had the highest frequency of functional blindness (16%).

Number of severe associated impairments

Figure 2 presents frequency distributions for the number of severe associated impairments present in persons where CP subtype (*n*=3175) and GMFCS level (*n*=3021) were known. More than 90% of those with spastic hemiplegia and diplegia and 86% of the group with ataxia had none, or only one, severe associated impairment, whereas half of the quadriplegic and hypotonic groups had two or more (Fig. 2b). The proportion of children with two or more severe associated impairments increased with increasing GMFCS level from 3% in GMFCS level I to 73% in GMFCS level V (Fig. 2a).

DISCUSSION

This study provides comprehensive data about the frequency of associated impairments at age 5 years in a population-based, 10-year CP cohort comprising 3466 individuals from jurisdictions with good case ascertainment of CP, covering 63% of the Australian population. For clinical use, the frequency distribution for each of the associated impairments is presented in tabulated format stratified by GMFCS level and CP subtype. Graphical presentations of the data are expected to be particularly useful for clinicians engaged in discussion with families about the functional outcomes for their child, taking into account the impacts both of motor and associated impairments.[10]

The proportion of CP cases in Australia with intellectual impairment (48%) was similar to the proportion reported from UKCP (51%)[11] using comparable definitions (IQ<70 or equivalent). The proportion of cases with moderate/severe intellectual impairment in the ACPR was 22%, less than SCPE (31%).[12]

Two previous studies have demonstrated that 20% to 30% of children with CP have

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difficulty in responding to general intelligence tests[13,14] because most of the subtests are dependent upon verbal responses, motor coordination, or a written or point response.[15] Assessments using such measures, even when performed, will not always reflect the true cognitive abilities of the child.[16,17] As a consequence, the categories of 'probably no impairment' and 'probable impairment, severity unknown' are included to reflect the reality that many families will not know if or how severe any intellectual impairment may be, particularly by age 5. Despite difficulties assessing IQ[13] the smaller moderate/severe proportion in the ACPR data is most likely due to the non-inclusion of individuals with probable impairment severity unknown, some of whom are likely to have moderate/severe impairment. When these cases were included the Australian cohort was 37%.

The frequency of epilepsy was 35% for SCPE and 32% for ACPR. Both cohorts included CP acquired postneonatally and included those with a history of seizures which may have 'resolved'. In publications reporting SCPE data, an additional term 'active seizures' was used to describe children on medication at the time of registration.[18] Active seizures were reported in 21% of the SCPE cohort[12] and 25% in a later SCPE publication on epilepsy.[18] The age at which data is collected by individual CP registers may affect estimates of the frequency of epilepsy as the onset can sometimes be in later childhood.[19] In addition, there is evidence to suggest that in some cohorts the prevalence of epilepsy in CP has been decreasing over time,[18] so the different birth years included in the ACPR and SCPE cohorts may not necessarily be directly comparable.

Speech impairment was the most prevalent of all the impairments collected by the ACPR with 61% of the total cohort having some degree of speech impairment and 24% identified as non-verbal. No other large datasets were found for comparison although some data have been published from individual registers. The proportion of 38% with speech impairment based on data from Norway was lower, however their definition only included indistinct speech rather than any reported problems with speech and language.[20] The proportion of children who were essentially non-verbal was similar in Australia (24%) and Québec (23%).[21]

Hearing impairment was the least common impairment in the Australian CP cohort with 12% having any degree of impairment and 3.5% bilaterally deaf. The proportion with hearing impairment was higher than 8% reported from UKCP,[11] despite the definitions being similarly broad and inclusive. On the other hand, frequencies of severe hearing impairment from individual CP registers[22–25] were between 2% and 4%, despite some variability in definitions. The frequencies from ACPR (3.5%) and UKCP (2.4%)[11] fell within this range.

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The ACPR proportion of 36% for visual impairment was a little lower than the 40% obtained from UKCP.[11] Both combined datasets used a similar definition that encompassed any type or degree of visual impairment. Severe visual impairment was less common in the ACPR cohort (5.5%) compared with the SCPE (11%)[12] but different criteria were used. The ACPR included only those with uncorrected acuity of 6/60 or worse in the better eye or with little functional vision, while SCPE included persons whose visual acuity was less than 0.3 in the better eye after correction (corresponding to 6/12 on the Snellen scale) or blind.

An important finding from our study was that the frequency of all 5 documented impairments increased with increasing GMFCS level. This general pattern was also seen in western Sweden for epilepsy, intellect and vision,[26] in Norway for epilepsy, lack of speech, severe hearing impairment, and severe vision impairment,[20] and in the Québec cohort for severe auditory impairment, seizures, and non-verbal status.[21]

When CP subtypes are grouped similarly, the distribution for the Australian cohort was generally consistent with those reported from SCPE[12] and the UK CP database (UKCP).[11] However, because CP subtypes are not always reported the same way,[27,28] precise comparisons of associated impairments stratified by CP subtype are impractical. Of spastic subtypes, quadriplegia had relatively higher frequencies of all impairments in Australian data. When spastic and non-spastic CP subtypes were considered, spastic quadriplegia had the highest frequency of epilepsy whereas other impairments occurred more frequently in the non-spastic subgroups.

The cumulative number of severe impairments places additional limitations on function and greater risk of early death, beyond those imposed by the motor disorder and the specific associated impairments present. People functioning in GMFCS level V or with spastic quadriplegia and hypotonia subtypes not only have to deal with higher levels of motor impairment and higher levels of severe associated impairments but at least 50% have two or more severe associated impairments further compounding functional and life outcomes.

A limitation of studies of associated impairments in CP is the difficulty of applying the definitions and categorizing data in a consistent way, particularly in a population where an individual's motor impairment or medical complexity may limit quantitative testing, and where CP registers have access to different sources of data. Definitions of the ACPR take these factors into account by allowing both clinical assessment and measured criteria for each level of associated impairment. This in turn allows more participants to be correctly categorized although variability still exists.

There are no published measures of consistency in assigning categories of impairment

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between jurisdictions using the ACPR definitions. However, combining prenatally acquired data published in the 2013 ACPR report[7] (birth years 1993–2006) for Western Australia, Victoria, and South Australia with the 2012 Queensland Cerebral Palsy Register report[8] (birth years 1996–2005) for all associated impairments excluding unknown values provides an estimate of consistency. It shows that, when a value is known, for any level of impairment some variation still exists between registers but the ranges are typically smaller than 10% and are as low as 1.1% for bilateral deafness. Intellectual impairment shows greater variability than the other associated impairments, which is probably because of the difficulties with assessment, but continued focus on consistency of definitions and assigning categories of impairment is necessary.

CP registers are often limited by the necessity to adopt quite broad categories for associated impairments. The ACPR cannot currently separate out use of antiepileptic medication or degree of seizure control, nor can it differentiate between vision and hearing impairment that can and cannot be corrected, or identify children with IQ ≥70 with specific learning difficulties that may affect their academic capacity.

A further limitation is the lack of capacity for most registers to follow up children into later childhood, adolescence, and adulthood and account for associated impairments with an onset after age 5. Nevertheless, large datasets, such as those of the SCPE and ACPR, can give a useful overview of the CP population and provide researchers with a data-sampling framework to investigate more nuanced questions about specific impairments.

In summary, our Australian data are similar to internationally reported proportions of associated impairments in CP samples, allowing for differences in definitions and stratification of impairments. Importantly, this is the first study to present a systematic graphical representation of stratified associated impairments across all GMFCS levels and CP subtypes in a very large population-based cohort. We believe the graphical representations will assist clinicians explaining to families their child's abilities and impairments in the broader context.

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Table I: Distribution of associated impairments for all children with cerebral palsy

	Total *n*	Mean, % (95% CI)[a]
Intellectual status		
No/probably no impairment	1551	50.9 (48.0–53.7)
Mild/probable impairment	780	26.5 (24.0–28.9)
Known moderate/severe impairment	651	22.7 (19.2–26.2)
Total known	2982	
Unknown	484	
Epilepsy status		
None	2174	68.5 (65.1–72.0)
Resolved by age 5y	116	3.6 (3.0–4.3)
Epilepsy	883	27.8 (24.8–30.9)
Total known	3173	
Unknown	293	
Speech status		
No impairment	1204	39.3 (36.3–42.2)
Some impairment	1133	36.9 (34.6–39.3)
Non-verbal	733	23.8 (21.5–26.1)
Total known	3070	
Unknown	396	
Hearing status		
No impairment	2689	87.7 (86.1–89.3)
Some impairment	274	8.9 (7.9–9.9)
Bilateral deafness	106	3.4 (2.6–4.3)
Total known	3069	
Unknown	397	
Vision status		
No impairment	1894	64.1 (59.8–68.5)

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Some impairment	897	30.3 (26.4–34.3)
Functionally blind	162	5.5 (4.8–6.3)
Total known	2953	
Unknown	513	

[a]Mean and 95% confidence intervals for individual birth year (1996–2005) percentages.

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Table II: Distribution of associated impairment level and total number of known values, stratified by known Gross Motor Function Classification System (GMFCS) level and cerebral palsy subtype

	GMFCS level (%)					Cerebral palsy subtype (%)					
Intellectual status	I	II	III	IV	V	Mono/hemiplegia	Diplegia	Tri/quadriplegia	Dyskinesia	Ataxia	Hypotonia
No/probably no	74	54	47	33	15	68	61	26	45	51	10
Mild/probable	19	30	27	34	30	22	24	32	28	33	35
Moderate/severe	7	15	25	33	55	11	15	42	27	17	54
Total known *n*	953	705	321	359	411	958	842	631	139	132	96
Epilepsy status											
None	84	75	74	53	31	74	84	43	61	74	52
Resolved by 5y	3	3	4	5	4	4	2	5	4	4	5
Epilepsy	13	22	22	42	65	22	14	53	35	21	43
Total known *n*	982	738	339	386	450	1000	882	696	147	137	97
Speech status											
No impairment	61	46	35	13	2	59	52	11	6	17	5
Some impairment	37	46	46	43	10	36	39	28	40	64	37
Non-verbal	2	8	19	45	87	4	9	61	54	19	58
Total known *n*	975	711	339	377	441	976	869	663	146	135	97
Hearing status											
No impairment	93	89	87	86	75	92	90	82	79	84	82

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Some impairment	5	9	10	11	16	6	8	13	11	8	12
Bilateral deafness	2	2	3	4	9	2	2	5	10	8	6
Total known *n*	974	718	334	373	408	905	836	595	136	130	83
Vision status											
No impairment	79	70	58	51	32	74	70	45	64	65	43
Some impairment	21	28	39	42	44	25	28	39	30	34	47
Functionally blind	0	2	2	7	24	1	2	16	6	1	10
Total known *n*	927	691	325	361	408	941	829	644	138	127	89

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Figure 1: Distributions of Gross Motor Function Classification System (GMFCS) levels and cerebral palsy (CP) subtypes and percentage of all CP within these distributions with each level of impairment (1996–2005). Data labels represent no (and probably no) impairment.

Figure 2: Distributions of the number of severe associated impairments present in each individual stratified by cerebral palsy (CP) subtype and Gross Motor Function Classification System (GMFCS) level.

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