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Trends in the Prevalence of Cerebral Palsy in a Population-Based Study

Sarah Winter, MD*; Andrew Autry, PhD‡; Coleen Boyle, PhD‡; and Marshalyn Yeargin-Allsopp, MD‡

ABSTRACT. *Objective.* To determine trends in the prevalence of congenital cerebral palsy (CP) over a 16-year period for 1-year survivors using a large, population-based surveillance program.

Methods. We determined birth weight-specific trends in the prevalence of CP in live birth and 1-year survivor cohorts of children in a 5-county metropolitan Atlanta area for the periods from 1975–1977, 1981–1985, and 1986–1991. We ascertained children with CP in metropolitan Atlanta by record review as part of an ongoing developmental disability surveillance program conducted by the Centers for Disease Control and Prevention and the Georgia Department of Human Resources. A total of 110, 262, and 443 cases of congenital CP were identified for the birth years 1975–1977, 1981–1985, and 1986–1991, respectively. Data were analyzed by birth weight, race, subtypes of CP, and whether the CP existed as an isolated disability or was accompanied by another disability.

Results. There was a modest increase in the overall prevalence of congenital CP from 1.7 to 2.0 per 1000 1-year survivors during the period from 1975–1991. This trend was primarily attributable to a slight increase in CP in infants of normal birth weight—CP rates in moderately low and very low birth weight infants did not show consistent trends. There was an increase in the proportion of children who had CP and no other disabilities that was most apparent in infants of normal birth weight from 17% in 1975–1977 to 39% in 1986–1991. For children weighing <1500 g, the proportion of children with spastic diplegic CP increased over time (7% of cases in 1975–1977, 36% in 1985–1988, and 32% in 1986–1991).

Conclusions. In the only ongoing population-based study of CP in the United States, there has been a modest increase in the prevalence of CP in 1-year survivors born from 1975–1991. This increase however was seen only in infant survivors of normal birth weight. No change was seen in the trends in CP prevalence in low birth weight and very low birth weight infant based on infant survivors. *Pediatrics* 2002;110:1220–1225; cerebral palsy, epidemiology, trends, prevalence, developmental disability.

ABBREVIATIONS. CP, cerebral palsy; CDC, Centers for Disease Control and Prevention.

Understanding trends in the prevalence of cerebral palsy (CP) is important in evaluating primary prevention efforts and in estimating the medical care and supportive services needed for affected children and their families. Although most studies agree on the prevalence of CP at ~2 to 3 per 1000 live births,^{1–13} there is conflicting evidence regarding changes in rates over time. Data from CP registries outside the United States have followed trends in the prevalence of CP for decades. Data from Sweden show an increasing trend in the rate of CP from the late 1960s to the mid-1980s (1.3–2.5 per 1000 live births). This trend was most pronounced in those children born preterm with spastic/ataxic diplegia.^{6,14,15} However, data from western Australia show no significant change in the overall prevalence of CP for a similar period although the prevalence of CP in low birth weight children did increase (12.1–64.9 per 1000 live births),¹¹ primarily in the period from 1975–1985. An increase in the prevalence of CP was also seen in low birth weight survivors from the Mersey region of the United Kingdom for the same period.⁹

In the absence of data for the United States, Bhusan et al¹⁶ attempted to estimate trends in the prevalence of CP based on changes in the birth weight distribution, CP risk estimates by birth weight, and infant mortality risks. They concluded that the prevalence of CP in the United States may have risen 20% from 1960–1986 as a result of the increased survival of low and very low birth weight infants. However, subsequent US studies suggested that the prevalence of CP in low birth weight survivors may have declined in the early 1990s.^{17–19}

To evaluate trends in CP prevalence using a US population-based cohort of 1-year survivors, we analyzed data collected over a 16-year period as part of the Centers for Disease Control and Prevention's (CDC) developmental disabilities surveillance program conducted in metropolitan Atlanta. We describe CP prevalence for 1-year survivors by birth weight, race, and gender. We also analyzed trends in the types of CP and whether CP exists in isolation or is present as 1 of multiple developmental disabilities in children with CP.

METHODS

CP Database

Numerator Data

For the surveillance system, CP is defined as a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising at any time during brain development.⁸ For these analyses, only congenital

From the *Department of Pediatrics, Emory University, Atlanta, Georgia; and the †National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia.
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Reprint requests to (S.W.) Ohio State University, Columbus Children's Hospital, Division of Behavioral-Developmental Pediatrics, 700 Children's Dr, Columbus, OH 43205. E-mail: swinter@chi.osu.edu
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cases of CP are included; ie, CP cases judged to be acquired after 28 days of postnatal life were excluded. Children with CP were identified through 2 related prevalence studies over 3 birth year periods, 1975–1977, 1981–1985, and 1986–1991.^{1,7} In the first study, children born in 1975–1977 were identified in 1985–1987 at 10 years of age; in the second study children born in 1981–1991 were identified in 1990–1994 at 3 to 10 years of age. Three periods of comparison were chosen to provide the longest period for examining trends in the prevalence of CP.

Data collected on children born from 1975–1977 were part of an initial prevalence study conducted by the CDC and the Georgia Department of Human Resources. This study developed the methodology for identifying all children in the community with 1 or more of 5 developmental disabilities: CP, mental retardation, visual impairment, hearing impairment, and epilepsy, who were living in the 5-county metropolitan Atlanta area in 1985–1987. Data for the 1981–1991 birth cohorts were obtained from an ongoing developmental disabilities surveillance program initiated by the CDC in 1991, which was modeled after the 1975–1977 study. In both efforts, children were identified by record review at multiple sources including hospitals, selected physicians offices, clinics, early intervention programs, private social service agencies, the Department of Education, which included 9 school systems, the Department of Human Resources, and the CDC's Metropolitan Atlanta Congenital Defects Program. The same developmental pediatrician determined confirmation of CP case status for all periods. The records of children who were born in Atlanta were electronically linked to their birth certificate data to obtain information on birth weight. Detailed descriptions of the methods for both studies are provided elsewhere.^{1,7}

Denominator Data

The number of births and infant deaths for the 5-county metropolitan Atlanta area for the periods of interest were obtained from the Georgia Department of Human Resources. One-year survivors, defined as born alive and surviving the first birthday in the state of Georgia, for the 1981–1985 and 1986–1991 birth cohorts were determined by subtracting the number of infant deaths from the number of live births, stratified by race, gender, and birth weight. For the 1975–1977 cohort, the number of 1-year survivors was not available by birth weight. Therefore, linear regression

analysis of national infant mortality rates by race, gender, and birth weight for the single years 1960, 1980, and 1983–1988 were used to estimate infant mortality rates for the period from 1975–1977.²⁰ The estimated rates were then applied to the live birth count for this period to estimate the number of 1-year survivors, stratified by race and birth weight.

The large percentage of black children (34.6%, 36.7%, and 39.4% for each cohort under consideration) in the Atlanta area allows for analysis by race, which has been reported in few other studies.^{4,21,22} Non-white and non-black children were excluded from analysis (<2% of case children), as were children without a recorded birth weight or gender. Birth weight groups were defined as follows: normal birth weight, ≥ 2500 g; moderately low birth weight, 1500 to 2499 g; and very low birth weight, <1500 g.

Data were also analyzed by 1) presence of CP as an isolated disability versus CP in the presence of 1 or more other disabilities including mental retardation, vision impairment, hearing impairment, or epilepsy and 2) trends in the type of CP. The types of CP include spastic types (spastic diplegia, spastic hemiplegia, and spastic quadriplegia), extrapyramidal types (hypotonic, ataxic, athetotic, choreoathetotic, dyskinetic), mixed types, and CP, not otherwise specified.

The significance of apparent trends in the prevalence rates of CP across time by various factors (gender, race, and birth weight group) was assessed using the Cochran-Armitage trend test.²³

RESULTS

Overall, there was a modest increase in the prevalence of CP from 1975–1991, from 1.7 to 2.0 per 1000 1-year survivors—a similar trend was noted when live births were used as the denominator (Table 1). This suggestive trend was driven primarily by a small increase in CP rates in normal birth weight infants. Importantly, no change in the prevalence of CP over time was found for infants survivors born moderately low and very low birth weight, although there was an upward trend in the lowest birth weight category when live births was used as the denominator (Fig. 1).

TABLE 1. Prevalence of CP in Live Births and Infant Survivors by Birth Weight: A Comparison Between 1975–1977, 1981–1985, and 1986–1991

Birth Weight (Grams)	Parameter	Birth Cohort			Cochran-Armitage Trend Test P Value \ddagger
		1975–1977*	1981–1985 \dagger	1986–1991 \dagger	
<1500	Number of children with CP	27	84	144	
	CP prevalence rate per 1000 infant survivors (95% CI) \S	65.2 (43.4, 93.5)	58.6 (47.0, 72.0)	59.5 (50.3, 69.6)	.377
	CP prevalence rate per 1000 live births (95% CI) \S	28.5 (18.9, 41.1)	36.5 (29.2, 45.0)	39.7 (33.6, 46.6)	.054
1500–2499	Number of children with CP	30	70	87	
	CP prevalence rate per 1000 infant survivors (95% CI) \S	6.9 (4.6, 9.8)	7.6 (5.9, 9.6)	6.2 (5.0, 7.7)	.224
	CP prevalence rate per 1000 live births (95% CI) \S	6.4 (4.3, 9.1)	7.4 (5.8, 9.4)	6.1 (4.9, 7.5)	.297
>2500	Number of children with CP	53	108	212	
	CP prevalence rate per 1000 infant survivors (95% CI) \S	0.9 (0.6, 1.2)	0.8 (0.7, 1.0)	1.1 (0.9, 1.2)	.047
	CP prevalence rate per 1000 live births (95% CI) \S	0.9 (0.6, 1.2)	0.8 (0.7, 1.0)	1.1 (0.9, 1.2)	.045
Total	Number of children with CP	110	262	443	
	CP prevalence rate per 1000 infant survivors (95% CI) \S	1.7 (1.4, 2.0)	1.9 (1.6, 2.1)	2.0 (1.9, 2.2)	.028
	CP prevalence rate per 1000 live births (95% CI) \S	1.7 (1.4, 2.0)	1.8 (1.6, 2.1)	2.0 (1.9, 2.2)	.024

CI indicates confidence interval.

* CP cases identified at 10 years of age.

\dagger CP cases identified at 3 to 10 years of age.

\ddagger P value presented is an asymptotic P value for a 1-sided test.

\S Prevalence rate estimates include only children with recorded birth weight, race.

|| Number of 1-year survivors estimated by regression.

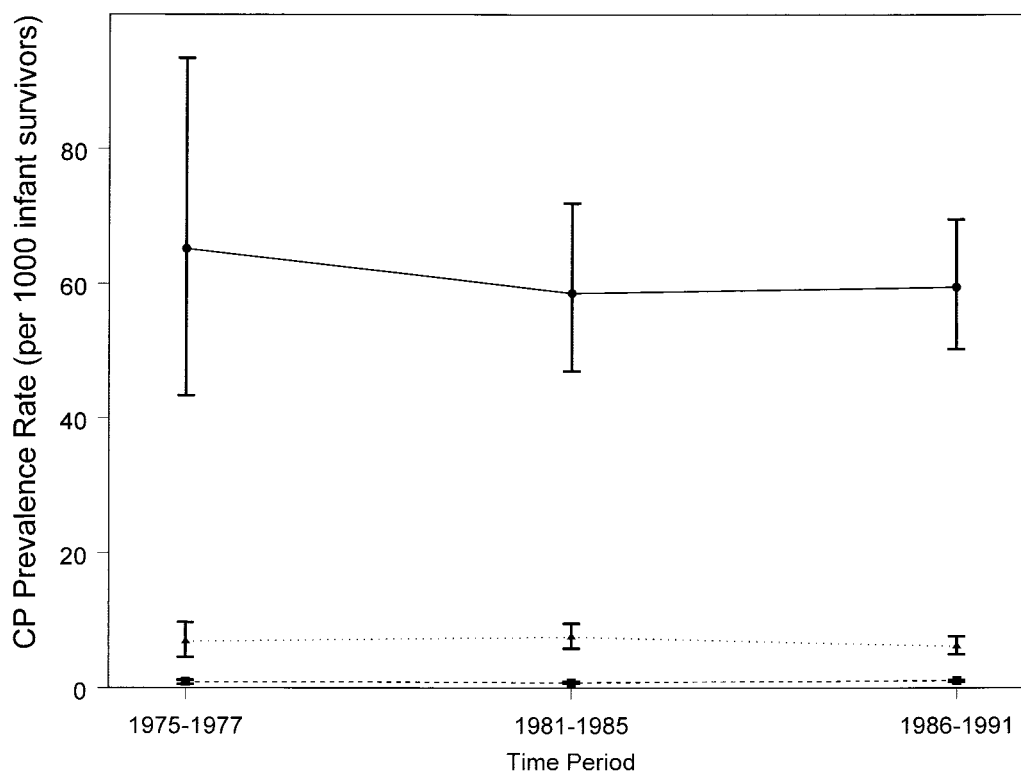


Fig 1. Filled circles indicate <1500 g; filled triangles indicate 1500–2499 g; filled squares indicate 2500+ g.

As shown in Table 2, the rates of CP were somewhat higher for whites than black infants in the low birth weight categories, but the reverse—higher black rates compared with white rates—in the normal birth weight categories. However, the birth weight/race-specific trends over the 16-year period were similar for white and black infants.

For children weighing <1500 g at birth, ~40% to 50% of CP occurred as an isolated disability; and this pattern remained relatively constant over time. In contrast, for children of normal birth weight, we observed an increase in the proportion of children with isolated CP over time, from 17% in 1975–1977 to 39% in 1986–1991 (Table 3).

The proportion of children with spastic diplegia who were born weighing <1500 g increased from 7% in 1975–1977 to 32% in 1986–1991 (Table 4). Spastic quadriplegia was the predominant type of CP overall in the majority of birth weight categories.

DISCUSSION

In our analysis of the only ongoing US CP surveillance program data, we found that the overall prevalence of CP in 1-year survivors increased from 1975–1991 by 18%. However, the increase was noted only in infant survivors who weighed 2500 g or more. Given that the magnitude of this change is relatively small and may be attributable to methodologic issues, such as changes in diagnostic procedures over time or ascertainment issues, continued monitoring of CP rates, especially into the 1990s, is warranted.

Because 25% to 35% of children with CP are born

with a birth weight of <1500 g, much attention has been paid to trends in the prevalence of CP in this group of children. Our finding that there was no change in the prevalence of CP in these infants differs from other studies. For the period from 1967 to the early to mid-1980s, data from England, western Australia, and Sweden showed an increase in the live birth prevalence of CP in children with low birth weight,^{6,9,10} with a leveling off thereafter.^{11,24} A recent hospital-based US study showed that the prevalence of CP among survivors was constant from 1982–1988 and decreased slowly through 1994.¹⁷

Additionally, a recent report from California documented a decrease in the infant survivor prevalence of CP in children born weighing <1500 g over 3 periods: 1983–1985, 1988–1989 and 1990–1994.¹⁹ CP prevalence trends based on live births in low and very low birth weight categories, as shown in this study, may be confounded by changes in infant mortality over time. Additionally, changes in medical practice such as the use of surfactant could explain some of the discordant findings. The North Carolina and California studies include in the most recent birth cohorts, children who may have been treated with surfactant. Surfactant has improved survival although its impact on disability is uncertain.²⁵ Finally, while the Metropolitan Atlanta Developmental Disabilities Surveillance Program attempts to ascertain all children with moderate to severe CP, it is likely that we have missed some children with mild CP. If some of the changes in the rates of CP observed in other studies are primarily among children

TABLE 2. Prevalence of CP in Infant Survivors by Birth Weight and Race: A Comparison Between 1975–1977, 1981–1985, and 1986–1991

Birth Weight (Grams)	Race	Birth Cohort						Cochran-Armitage Trend Test <i>P</i> Values			
		1975–1977		1981–1985		1986–1991		Infant Survivor-Based Prevalence Rates	Live Birth Based-Prevalence Rates		
		Number of Children With CP*†	CP Prevalence Rate (per 1000 Live Births)	Number of Children With CP†‡	CP Prevalence Rate (per 1000 Infant Survivors)	Number of Children With CP†‡	CP Prevalence Rate (per 1000 Infant Survivors)				
<1500	White	10	70.4	30.0	74.7	45.7	53	63.8	42.0	.280	.241
	Black	17	60.9	27.9	50.2	32.0	91	58.2	39.2	.416	.062
1500–2499	White	16	-7.7	7.1	8.8	8.5	36	8.0	7.8	.486	.419
	Black	14	6.2	5.8	6.9	6.7	34	5.2	5.1	.201	.236
>2500	White	34	0.9	0.9	0.7 [§]	0.7 [§]	55	1.0	1.0	.078	.076
	Black	19	0.9	0.9	1.1	1.1	51	1.2	1.2	.187	.180
Total¶	White	60	1.5	1.4	1.5	1.5	130	1.7	1.7	.070	.064
	Black	50	2.2	2.1	2.5	2.5	130	2.6	2.6	.145	.124

* CP cases identified at 10 years of age.

† Includes only children with recorded birth weight and race

‡ CP cases identified at 3 to 10 years of age.

§ *P* value presented is an asymptotic *P* value for a 1-sided test.

|| Prevalence rate ratios indicated a significant difference between white and black children.

¶ Totals do not add to those in Table 1 because of the non-white, non-black children excluded from this analysis.

with milder disability, our data would not be sensitive to this.

Historically, many studies have not provided enough racial heterogeneity to examine differences in trends in the prevalence of CP by race. Our study is unique in that the racial composition of metropolitan Atlanta allows us to compare differences in trends in the prevalence of CP among white and black infants. Such differences might suggest variable prenatal or antenatal medical care of high-risk infants or differential infant mortality experiences. Interestingly, we did not find that the CP prevalence patterns over time differed between these groups.

An important strength of our developmental disability data collection systems is that they allow analysis of information regarding other disabilities including vision and hearing impairment, mental retardation, and epilepsy. Understanding trends in the prevalence of CP as an isolated disability versus CP with other coexisting disabilities is important, as children who experience >1 disability may require more and varied services. Also, the presence of isolated CP as compared with CP with other developmental disabilities may reflect different causal mechanisms and timing of injury affecting the brain. Our data suggest a trend toward fewer coexisting serious developmental disabilities in children with CP. This finding may be attributable to changes in perinatal and postnatal medical care and may suggest that such children require less long-term intervention.

To make meaningful comparisons over time, a stable case definition and subtype classification must be applied. Our system has the unique advantage in that 1 expert medical epidemiologist applied the case definition and classification over the entire 16-year period. A limitation of our data are that the children identified as cases for these analyses were from 2 studies that used different age criteria, ie, 10 years of age and 3 to 10 years of age. For both age criteria, underascertainment may have occurred resulting in lower prevalence rates. For the 3- to 10-year-old age group, there may have been some underascertainment in younger children who had not yet come to the attention of a medical subspecialist or enrolled in special education services. This is more likely to occur in cases of mild CP. In the group of 10-year-old children, there may also be underascertainment attributable to deaths or children who moved out of the study area. A second limitation is the need to estimate the number of infant survivors in the earliest period resulting from the lack of regional or national birth weight-specific data. The data based on live births showed an increased in CP rates over time, but the data based on the estimated denominator for infant survivors indicated that that increase may be an artifact of higher infant mortality rates in the earlier periods. However, because this trend is based on an estimated denominator, our conclusions may be somewhat tentative.

Data presented reflect infants born before 1992. Overall, these data suggest that, contrary to initial expectations with improvements in perinatal medicine including the use of fetal monitoring and cesarean section, the prevalence of CP has not decreased.

TABLE 3. Prevalence of CP Prevalence as an Isolated Disability and With Other Disabilities: A Comparison Between 1975–1977, 1981–1985, and 1986–1991

Birth Weight (Grams)	CP Type	Birth Cohort					
		1975–1977*		1981–1985†		1986–1991‡	
		Number of Cases	Percent	Number of Cases	Percent	Number of Cases	Percent
<1500	Isolated CP	11	41	39	46	73	51
	CP and other disability‡	16	59	45	54	71	49
1500–2499	Isolated CP	8	27	31	45	39	45
	CP and other disability‡	22	73	39	55	48	55
>2500	Isolated CP	9	17	34	31	83	39
	CP and other disability‡	44	83	74	69	129	61

* CP cases identified at 10 years of age.

† CP cases identified at 3 to 10 years of age.

‡ Presence of 1 or more disabilities including mental retardation, hearing impairment, vision impairment, or epilepsy.

TABLE 4. Difference in the Types of Spastic CP at Different Birth Weights: A Comparison Between 1975–1977, 1981–1985, and 1986–1991

Birth Weight (Grams)	Type of CP	Birth Cohort					
		1975–1977*		1981–1985†		1986–1991‡	
		Number of Cases	Percent	Number of Cases	Percent	Number of Cases	Percent
<1500	SD	2	7	30	36	46	32
	SH	7	26	23	27	27	19
	SQ	13	48	25	30	51	35
	Nonspastic	5	19	6	7	20	14
	Total	27	100	84	100	144	100
1500–2499	SD	5	17	19	27	17	20
	SH	7	23	11	16	16	18
	SQ	14	47	30	43	33	38
	Nonspastic	4	13	10	14	21	24
	Total	30	100	70	100	87	100
>2500	SD	10	19	19	18	22	10
	SH	12	23	31	29	58	27
	SQ	15	28	39	36	64	31
	Nonspastic	16	30	19	17	68	32
	Total	53	100	108	100	212	100

SD indicates spastic diplegia; SH, spastic hemiplegia; SQ, spastic quadriplegia.

* CP cases identified at 10 years of age.

† CP cases identified at 3–10 years of age.

In fact, the prevalence may have increased slightly among heavier birth weight infants. The reason for this increase in heavier infants is not known. As monitoring of the prevalence of CP successive years continues via the ongoing CDC surveillance system, additional trends in CP prevalence rates may emerge, including a more current evaluation of the impact of recent medical care interventions on the risk of CP and other disabilities.

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THE GENE FOR EARWAX?!

“Japanese researchers, led by Norio Niikawa at the Nagasaki University School of Medicine, are zeroing in on the gene that makes earwax; the question is: Who cares?”

Well, it turns out earwax says a lot about a person. It comes in 2 varieties: moist and gloppy, or dry and flaky. (The wet kind is more common in Americans, Europeans, and Africans; the dry type more frequently found in Asians and Native Americans; both types are also found in chimpanzees.) A few years ago, epidemiologist Nicholas Petrakis at the University of California, San Francisco found evidence suggesting earwax contains hints of a woman’s risk for contracting breast cancer. Ears and breasts both contain apocrine glands, and women with too much apocrine tissue—and moist earwax—have a tendency to form breast cysts. Finding the gene that orchestrates apocrine development might one day help doctors predict a woman’s risk of developing the disease.”

Sinha G. *Popular Science.* September 2002:31

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