

Certified cause of death in children and young adults with cerebral palsy

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Abstract

The status of 732 children suffering from cerebral palsy from the South East Thames region (births from 1970-9) was ascertained at the end of 1989, and copies of death certificates of the 73 children who have died, aged 4 weeks to nearly 16 years, were obtained. Infantile cerebral palsy (ICD Code 343-) was coded as the underlying cause of death in only 16 (22%) cases. On 28 (38%) certificates there was no mention of any form of cerebral palsy, the proportion in which it was not mentioned increasing with age. In 20 (28%) cases the coded underlying cause of death was respiratory, hence in published national statistics the number of deaths from respiratory causes is inflated. A postmortem examination was known to have been performed in 23 cases, but the recorded information was in some cases limited to a 'terminal event'. The importance of good data on the death certificate, and the significance of published national statistics, need to be communicated to all those involved in the certification process if cerebral palsy and other chronic conditions, which raise the relative risk of death, are not to be under-represented.

The under-representation of chronic 'non-fatal' diseases in mortality statistics has been documented.^{1 2} The life expectancy, the cause of death, and its antecedent causes in individuals suffering from cerebral palsy are of interest to those seeking to ensure that their long term needs are provided for. If cerebral palsy is similarly under-represented, however, published national statistics based upon death certificate data might lead to misleading conclusions.

The South East Thames region cerebral palsy register (births from 1970-9) has provided the cases for a population based view of survival of those suffering from the various types of cerebral palsy with different degrees of impairment. This paper presents the data obtained from death certificate copies relating to 73 children who have died.

Methods

The South East Thames cerebral palsy register (births from 1970-9) was assembled between 1978 and 1981 using multiple sources of ascertainment. A more detailed description of the methodology of this study may be found elsewhere.³ A total of 732 cases, of whom 420

were male and 312 were female, were traced again in 1988, mainly through the National Health Service Central Register (NHSCR) at Southport. By the end of 1989, 73 children (47 boys and 26 girls) were known to have died, at ages ranging from 4 weeks to 15.8 years. Survival analysis is published elsewhere.⁴

Copies of the death certificates have been received from NHSCR for the 73 cases who have died. These show the certified cause of death and any causes antecedent to it in part I of the certificate, contributory cause(s) in part II, and the coded underlying cause of death using the *International Classification of Disease (ICD)* 9th revision which is selected according to international coding procedures.

Results

Table 1 provides a full description of the cause of death information on the death certificates, plus the type of cerebral palsy as given to us by each child's paediatrician, and our explanatory comments where appropriate. In a number of cases minor spelling corrections have been made, but otherwise the data are recorded exactly as given to us, and include some obvious errors.

CEREBRAL PALSY ON DEATH CERTIFICATES

Except for deaths occurring in the years 1985 and 1986, when the Office of Population, Censuses and Surveys (OPCS) carried out multiple cause coding, only *underlying* cause of death is coded. The proportion of cases in whom some form of cerebral palsy appears somewhere on the death certificate declines with age, but the proportion in whom the underlying cause is coded as 343- follows a different pattern (see table 2).

The presentation of these figures is complicated by two factors: firstly, three cases (314, 540, and 740), all of whom died at ages less than 7 years (the diagnoses on the death certificate being spastic diplegia, spastic quadriplegia, and quadriparesis,) were allocated the underlying cause code 344- (other paralytic syndromes) for reasons that are not apparent to us; these cases are classed as having a mention of cerebral palsy on the death certificate. Secondly, two cases (964 and 965) who died aged 4 and 5 weeks were ascertained by means of a search by OPCS using underlying cause coding, but the cause was given as 'cerebral birth anoxia'; these two cases have been counted as having a mention of cerebral palsy in order to avoid confusion.

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Table 1 Survival. Certified cause of death and clinical diagnosis (73 cases)

Case No	Alive	Death certificate information				ICD code	Diagnosis given to us by paediatrician	Comment
		1a	1b	1c	11			
025	10-70-08-79	Acute lymphoblastic leukaemia	—	—	—	2040	Spastic quadriplegia	
041	07-71-04-72	Bronchopneumonia	—	—	—	485X	Cerebral palsy	
042	04-73-10-88	Cerebral failure	Microcephaly, epilepsy	Severe physical and mental subnormality	—	3181	Spastic quadriplegia	
075	08-77-05-83	Bronchopneumonia	Mental retardation	—	—	319X	Spastic quadriplegia	
076	09-71-05-86	Aspiration pneumonia	Cerebral palsy	—	—	3439	Cerebral palsy	
085	11-73-11-85	Bronchopneumonia	Quadriplegia	Previous meningitis	—	3229	Spastic	
119	11-76-04-85	Respiratory infection	Chronic obstructive airway disease	—	—	496X	Spastic quadriplegia	
140	08-71-12-78	Bronchopneumonia	—	—	—	485X	Dystonic spastic quadriplegia	
146	08-75-04-84	Chickenpox	—	—	—	052X	Double hemiplegia	
147	08-70-03-75	Bronchopneumonia	—	—	—	485X	Cerebral palsy	
148	07-78-05-82	Overwhelming measles infection	—	—	—	0559	Cerebral palsy	
169	02-74-01-81	Hypoxia	Chronic bronchitis	—	—	4919	Spastic quadriplegia	
191	10-71-11-80	Bronchopneumonia	—	—	—	485X	Spastic quadriplegia	
195	05-73-04-83	Cardiac arrest	Hypotonic cerebral palsy	—	—	3439	Athetoid	
205	12-72-02-81	Acute bronchitis	Acute bronchitis	—	—	4660	Athetoid	
211	01-74-01-76	Bilateral bronchopneumonia	Spasticity, mental retardation	—	—	319X	Spastic quadriplegia	
215	06-70-04-75	Bronchopneumonia	—	—	—	485X	Spastic quadriplegia	
239	10-73-01-78	Grand mal epilepsy	Cerebral palsy	—	—	3439	Ataxia—mixed	
245	02-70-10-76	Bronchopneumonia	—	—	—	485-	Spastic quadriplegia	
247	12-72-06-79	Pneumonia	—	—	—	486-	Spastic quadriplegia	
258	09-71-01-86	Lobar pneumonia	—	—	—	481-	Spastic quadriplegia	
264	12-70-01-76	Bronchopneumonia	Primary cerebral degeneration	—	—	3319	Dystonic spastic	
267	05-77-12-79	Haemolytic streptococcal pneumonia	—	—	—	4823	Severe quadriplegia	
287	08-71-01-75	Chest infection	Severe mixed cerebral palsy	—	—	3439	Dystonic mixed type	
292	02-79-01-82	Stevens-Johnson syndrome	—	—	—	6951	Choroathetoid	
293	01-71-08-84	A1: Primary alveolar hypoventilation syndrome	A2: Microcephaly (small brain)	—	—	7421	Spastic quadriplegia	
306	10-73-10-78	Pneumonia	Pneumony dysplax	Cerebral palsy	—	7485	Dystonic quadriplegia	
307	04-73-02-78	Bronchopneumonia	Spastic quadriplegia	Microcephaly	—	7421	Spastic quadriplegia	
314	01-74-04-77	Chronic renal failure	Renal tubular acidosis	Spastic diplegia, severe meckel retardation, microcephaly	—	3442	Spastic quadriplegia	'Meckel' counted as 'mental' in calculations
352	02-70-01-71	Gastroenteritis	Bronchopneumonia	—	—	0558	Athetoid	
353	08-76-07-87	Epilepsy	Congenital hydrocephalus	—	—	7423	Spastic quadriplegia	
370	07-76-08-83	Bronchopneumonia	Epilepsy	Cerebral atrophy	—	7428, 485, 3459	Athetoid	[Scottish death certificate]
371	02-74-05-75	Resp failure	Pneumonia	—	—	486X	Spastic left>right	
378	03-74-03-78	A1: Cardiorespiratory failure	A2: Congenital cerebral palsy ('spasticity')	A3: Epilepsy	—	3459	Spastic quadriplegia	
384	07-72-06-73	Inhalation of vomit in association with neuromuscular disease	—	—	—	3589	Hypotonic athetoid	
387	09-72-05-74	Bronchopneumonia	Cerebral palsy	—	—	343X	Severe asymmetrical dystonic quadriplegia	
392	07-70-12-85	Reye's syndrome	—	—	—	3318	Cerebral palsy	
396	01-76-09-81	Multiple injuries (accidental death)	—	—	—	E9289, 9598	Crural monoplegia	Inquest held
431	09-73-12-81	Status epilepticus	Hydrocephalus and cerebral palsy	Neonatal meningitis	—	3229	Spastic quadriplegia + ataxia	
439	12-73-07-86	Bronchopneumonia	—	—	—	485-	Dystonic quadriplegia + athetosis	
478	03-70-01-79	Viral pneumonitis	—	—	—	4809	[No diagnosis received]	[Notified as cerebral palsy]
504	09-70-03-86	Aspiration of vomitus	Cerebral palsy	Hydrocephalus	—	3439	Spastic quadriplegia	
508	05-70-10-80	Adrenal failure due to	Adrenal hypoplasia and bronchopneumonia	—	—	7591	Cerebral palsy	
525	06-77-07-88	Status epilepticus	Spastic quadriplegia (from birth)	—	—	3432	Spastic quadriplegia	
533	08-71-12-74	Bronchopneumonia	Congenital heart disease	Mental retardation	—	7469	Athetoid + ataxic	
540	03-78-04-84	Respiratory insufficiency	—	—	—	3440	Spastic quadriplegia	
563	01-78-01-80	Bronchopneumonia	—	—	—	485X	Spastic quadriplegia	
575	12-77-12-86	Gastrointestinal haemorrhage	—	—	—	5789	Spastic quadriplegia	
596	03-73-04-81	Ependymoma of fourth ventricle	—	—	—	1915	Spastic quadriplegia	
614	06-71-03-82	Hypostatic pneumonia	Congenital hydrocephalus	—	—	7423	Spastic quadriplegia	
632	10-70-11-78	Bronchopneumonia	Gastroenteritis	Severe mental handicap due to neonatal meningitis	—	3229	Spastic quadriplegia + athetoid	
659	04-79-06-80	Acute bronchiolitis	—	—	—	4661	Spastic quadriplegia	
661	04-78-11-80	Encephalitis	—	—	—	3239	Spastic quadriplegia	
686	06-72-10-73	Severe hypostatic bronchopneumonia	Septicaemia	—	—	0389	[No diagnosis received]	[Notified as cerebral palsy]
726	06-72-01-77	Bronchopneumonia	—	—	—	485-	Cerebral palsy	
727	10-70-02-71	Congestive cardiac failure	Bronchopneumonia	—	—	485X	Quadriplegia	
728	03-76-08-77	Epilepsy	Cerebral palsy	Microcephaly	—	7421	Cerebral palsy	
729	07-74-09-78	Bronchopneumonia	Whooping cough	—	—	0339	Spastic quadriplegia	
730	01-72-08-72	Bronchopneumonia	Cerebral palsy	Cerebral atrophy	—	3319	Cerebral palsy	
732	12-77-12-87	Asphyxia	Cerebral atrophy	—	—	3319	[No diagnosis received]	[Notified as cerebral palsy]
740	01-79-06-80	Cardiac arrest	Chest infection	Quadripareisis	Congenital infection	3440	Spastic quadriplegia	
742	09-74-06-80	Hypostatic pneumonia	Cerebral palsy	—	—	3439	Severely hypotonic	
905	12-71-10-87	Cardiorespiratory failure	Spastic quadriplegia	Cerebral palsy	—	3439	Spastic quadriplegia	
923	03-75-12-76	Meningitis (<i>Staphy albus</i>)	Chronic infection in a child with spina bifida and hydrocephalus	—	—	7410	Hydrocephalus, spina bifida, right hemiplegia	[Dubious case]
943	10-79-12-79	Bronchopneumonia	Porencephaly	—	—	7424	Porencephaly	[Notified as cerebral palsy]
959	12-70-11-71	Bronchopneumonia	—	—	—	485X	Cerebral palsy	
960	12-71-04-73	Inhalation of stomach contents due to cerebral palsy	—	—	—	343X	Cerebral palsy	
961	01-70-10-71	Respiratory arrest	Spastic CP	Septicaemia	—	343X	Spastic	
962	10-70-03-72	Bronchopneumonia	Internal hydrocephalus	Cerebral palsy	—	343X	[OPCS dead case]	
963	01-70-01-73	Bronchopneumonia	Cerebral palsy	—	—	343X	[OPCS dead case]	
964	02-74-03-74	Bronchopneumonia	Epilepsy	Cerebral birth anoxia	—	343X	[OPCS dead case]	
965	04-74-05-74	(Bronchopneumonia) Status epilepticus	Irreversible cerebral anoxia at birth	—	—	343X	[OPCS dead case]	() = cause on death certificate which was revised
966	04-74-07-74	(Pneumonia) Acute respiratory failure	—	Cerebral palsy	(Cerebral palsy)	343X	[OPCS dead case]	() = cause on death certificate which was revised

Table 2 Cerebral palsy on the death certificate

Age at death (years)	No of cases	No (%) with cerebral palsy (343-) as underlying cause	No (%) with mention of cerebral palsy on death certificate*
<1	9	3 (33)	7 (78)
1-<4	21	6 (29)	15 (71)
4-<7	16	2 (13)	10 (63)
7-<10	13	0	7 (54)
10-<13	7	2 (29)	3 (43)
13-16†	7	3 (43)	3 (43)
Total	73	16 (22)	45 (62)

*Includes three cases where underlying cause is coded 344-; also two cases where the cause was given as 'cerebral birth anoxia' that were coded 343-. The trend is significant (p=0.04).

†The highest age at death was 15.8 years.

OTHER CEREBRAL CONDITIONS

Of the 45 cases with a mention of some form of cerebral palsy on the death certificate, 12 also had another mention of a cerebral condition other than mental subnormality or epilepsy; of the 28 cases with no mention of cerebral palsy, 16 mentioned another cerebral condition; in 12 cases neither cerebral palsy nor any other cerebral condition was mentioned. Among the 'other cerebral' conditions were microcephaly (nine cases—of which five also mentioned cerebral palsy), hydrocephaly (eight cases—of which three also mentioned cerebral palsy), and cerebral atrophy (three cases—of which two also mentioned cerebral palsy).

Also included in this group are three cases in whom previous meningitis was mentioned (85, 247, and 632). In another child (923), with spina bifida and hydrocephalus, meningitis (described as a chronic infection) was by implication present at the time of death. In another case (661) encephalitis was given as the cause without any indication as to timing, although as it was not mentioned in the information originally supplied to use by the child's paediatrician we assume that this was a late event. In one case (632) the coding failed to reflect the chronology of the condition as recorded on the death certificate. A child who died at 8 years of age was certified as follows: 1a: bronchopneumonia, 1b: gastroenteritis, 1c: severe mental handicap due to neonatal meningitis. The coded underlying cause was 3229 (meningitis, unspecified), but we are advised that it should have been 326- (late effects of intracranial abscess or pyogenic infection).

MENTAL SUBNORMALITY AND EPILEPSY

Mental subnormality or retardation featured in 15 (21%) of the death certificates, and in five of these cases there was no mention of cerebral palsy or another cerebral condition. Epilepsy was mentioned in 14 cases (19%), including three in which status epilepticus was given under section 1a.

OTHER CERTIFIED CAUSES OF DEATH

In 57 cases (78%) a respiratory (or cardiorespiratory) cause of death appeared on the death certificate, the commonest being bronchopneumonia (29 cases). In 20 cases (28%) the coded

Table 3 Cases with respiratory underlying cause of death

ICD code	Condition	No of cases
4660	Acute bronchitis	1
4661	Acute bronchiolitis	1
4809	Viral pneumonia—unspecified	1
481-	Pneumococcal pneumonia	1
4823	Pneumonia due to streptococcus	1
485-	Bronchopneumonia, organism unspecified	11
486-	Pneumonia, organism unspecified	2
4919	Chronic bronchitis—unspecified	1
496-	Chronic airways obstruction	1
Total		20

underlying cause of death was respiratory, as shown in table 3.

Reye's syndrome, Stevens-Johnson syndrome, chronic renal failure due to renal tubular acidosis, acute lymphoblastic leukaemia, chicken pox, measles, and pertussis were mentioned in one case each.

In some cases, the information provided on the death certificate appears to conflict with data obtained from other sources. In one case, a 1 year old child said by the attendant clinician to be suffering from hypotonic cerebral palsy, the cause of death 'certified after postmortem without inquest' was given as inhalation of vomit in association with neuromuscular disease (coded 3589: myoneural disorders—unspecified). However, from another source we were told that at postmortem examination the doctor found 'no histological evidence of muscle disease'. One must assume that the results of the histological examination were not available at the time of certification.

POSTMORTEM EXAMINATIONS

In 23 of the 73 cases (32%) it was apparent from the copy of the death certificate supplied to us that a postmortem examination had taken place. This was usually because after the name of the certifier appeared the phrase 'after postmortem without inquest'. In one case (396), an accidental death, an inquest had taken place, but the death certificate was not particularly informative. In most cases the box containing the information about whether or not a postmortem examination had been performed had been obscured before the copy was sent to us, so we are not able to be certain that the remaining 49 cases had been certified without necropsy.

In eight (35%) of the 23 cases known to have had a postmortem examination the underlying cause of death was given as infantile cerebral palsy (343-), and there was a mention of some form of cerebral palsy in four additional cases, hence cerebral palsy appeared on 12 (52%) of certificates in this group. This contrasts with the 49 cases not known to have had a postmortem examination: only eight (16%) had the underlying cause coded as 343-, but a total of 33 (67%) had a mention of cerebral palsy on the death certificate.

In other respects also, the death certificates issued after postmortem examination are rather less informative than those where a postmortem examination is not mentioned. Particularly disappointing is the fact that in four cases a single

respiratory cause of death is given with no mention of any other condition. The sole certified causes and approximate age at death of these cases are as follows: lobar pneumonia (14 years), bronchopneumonia (12 years), viral pneumonitis (8 years), and acute bronchiolitis (14 months). We have no clinical data on the 8 year old child, owing to follow up difficulties caused by his mother's remarriage, but the other three cases are known to have been both mentally and physically handicapped.

Discussion

It is the inability to obtain from published data either an estimate of the mortality associated with cerebral palsy, or a true picture of the causes of death across the whole range of affected individuals, which highlights the need for an examination of deaths from population based studies.

The under-representation of chronic 'non-fatal' diseases in mortality statistics is well recognised,^{1 2} and many of the reasons given are relevant to cerebral palsy. The balance might be redressed in part by a change to multiple cause coding, as discussed by Israel *et al* who comment⁵: 'Although the underlying cause of death is conceptually easy to understand and is a well-accepted measure of mortality, often it does not convey the complexity of the reported medical conditions at the time of death. Because most deaths are the result of more than one disease entity, a single underlying cause excludes much useful information on intervening, contributory, and even concurrent conditions'.

The practitioners who complete the death certificates, however, may be unaware of the effect that apparently trivial differences in their mode of expression may have on the categorisation of underlying cause. This problem is discussed by Leadbetter, who concludes that death certificates are completed imprecisely or inaccurately 'because of ignorance of, or failure to apply, the principles of death certification and not because relevant information is lacking.'⁶

On 28 death certificates (38%) there was no mention of any form of cerebral palsy or cerebral birth anoxia, and hence even multiple cause coding would not allow these cases to be ascertained by means of death certificate data. Cerebral palsy is more likely to be mentioned on the death certificate if the child dies in the first few years of life; it is mentioned in less than half the cases dying aged 10 years or more. Most of the children in the study (90%) are still alive, and now aged between 10 and 20 years. It remains to be seen if the proportion of death certificates containing a mention of cerebral palsy continues to decline with age.

Underlying cause coding using ICD code 343- (infantile cerebral palsy) would identify only 22% of cases. One could improve the yield by searching using a greater variety of codes including ICD code 344- (other paralytic syndromes), which was unfortunately used for 7% of the cases where some form of cerebral palsy was mentioned. If cases coded under this and several other central nervous system categories (microcephaly, meningitis, encephalitis, and

cerebral degeneration) had been reviewed manually it would have been possible to pick up nine of the cases not coded 343- but with some sort of cerebral palsy mentioned on the death certificate. This would predict a yield of 25 cases (35%) using underlying cause coding enhanced by manual review, which is hardly encouraging.

The fact that in 78% of cases a respiratory (or cardiorespiratory) cause of death was mentioned on the death certificate will come as no surprise to those who are in day to day contact with the severely affected individuals who account for most of the 73 documented deaths. However, the number of cases in which a respiratory illness is coded as the underlying cause of death must be of some concern. While the very young and the very old may succumb to respiratory infections, deaths from such causes in adolescence are relatively uncommon, and the fact that certificates are considered adequate without additional information is surprising.

In January 1984 there was a significant change in the guidance to OPCS coders in the use of World Health Organisation rule 3.⁷ This was in order to prevent certain 'terminal events' (for example, bronchopneumonia, pneumonia, or cardiac arrest) recorded as the only cause of death in part I of the death certificate being coded as the 'underlying cause of death' if the presence of a major disease was recorded in part II. This is a logical way of preventing under-recording, especially of chronic conditions which raise the relative risk of death but which clinicians may be reluctant to cite as 'the' cause of death. However, this change will not achieve its desired effect if the only cause of death appearing on the death certificate is a 'terminal event' such as bronchopneumonia.

It is discouraging to find that this is more likely to happen in cases where the death certificate is stated to have been completed after a postmortem examination. It appears that those responsible for assigning a cause in some post-mortem cases are content to limit the expression of their findings to a 'terminal event', even in a few cases giving a detailed description of the nature and extent of the respiratory involvement while neglecting to record the frailty or distortion of the rest of the body associated with many years of immobility, which probably rendered the individual susceptible to a respiratory death. We would not wish to undervalue the use of a postmortem examination to shed light on conditions which had not been elucidated during life.⁸ However, if the pathologist seeks only to demonstrate the presence of bronchopneumonia, or omits relevant necropsy findings, the cause of death given may be more misleading than an informed guess from the attendant clinician.

The consequence of such inadequacy of information is that the number of deaths from respiratory causes in children and adolescents is being inflated by deaths that should be attributed to other causes; the corollary is that the number of deaths from conditions that cause major physical and/or mental handicap is likely to be an underestimate. Duley demonstrated, in a study of 590 stillbirths and neonatal deaths, that the

presence of congenital malformations was underestimated in death certificates completed without the benefit of necropsy information.⁹ Valuable data from necropsy on congenital malformations, in particular those in the brain which cause some cases of cerebral palsy, may be failing 'to see the light of day' because of the preoccupation with terminal events, particularly in coroners' cases.

Even if the quality of death certificate data were improved, the information obtained would often be insufficient to provide an adequate description of the cause of death, because of the interaction of numerous antecedents before the terminal event. The collection of more detailed information about the period before death poses serious problems, however, even for a population based study. Our experience in the South East Thames region has confirmed that it is difficult to keep track of affected individuals. In addition to normal population mobility, there are transfers away from the notifying paediatrician because individuals become too old to attend a paediatric clinic, or associated with the need for residential or other care. Even paediatric departments with above average record keeping systems have found it surprisingly difficult to inform us of the whereabouts of cases now followed up elsewhere. Family practitioner committees are only able to help with those registered with a general practitioner. Moreover, given that most of the affected children are surviving to adulthood, there are ethical considerations regarding their right to be consulted about being 'followed up': their parents may have consented to the release of medical information and their inclusion upon a register 10 years ago, but a young adult is entitled to take a different view if he or she wishes.

Improvements in quality of information during life, and after death, would lead to benefits

for those suffering from a wide range of conditions. It would also prevent misleading conclusions being drawn from inadequate national statistics. It is time for greater effort and, where necessary, finance, to be directed towards strengthening the weak points in the system. The 10th revision of the *International Classification of Diseases* with new coding rules and recommendations, scheduled to come into operation in 1993, may be regarded as an advance, but will only work if the aims and intentions are fully communicated to all those involved in the certification process. Meanwhile it is important to emphasise the distinction between 'certified' cause of death and 'the' cause, or more often causes, of death, in children and adults suffering from chronic conditions including cerebral palsy.

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