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Recording of Neonatal Seizures in Birth Certificates, Maternal Interviews, and Hospital Discharge Abstracts in a Cerebral Palsy Case-Control Study in Michigan

Qing Li, M.D., Dr.P.H.^{1,2}, Madeleine Lenski, M.S.P.H.¹, Glenn Copeland, M.B.A.³, Stephen L. Kinsman, M.D.⁴, Matthew Francis, Ph.D.¹, Russell S. Kirby, Ph.D., M.S.⁵, and Nigel Paneth, M.D., M.P.H.^{1,6}

¹Department of Epidemiology & Biostatistics, Michigan State University, East Lansing, Michigan

²Departments of Obstetrics and Gynecology and Public Health Sciences, Medical University of South Carolina, Charleston, South Carolina

³Michigan Department of Community Health, Division for Vital Records and Health Statistics, Lansing, Michigan

⁴Department of Pediatrics, Division of Pediatric Neurology, Medical University of South Carolina, Charleston, South Carolina

⁵University of South Florida, College of Public Health, Department of Community and Family Health, Tampa, Florida

⁶Department of Pediatrics and Human Development, Michigan State University, East Lansing, Michigan

Abstract

We evaluated the recording of neonatal seizures in birth certificates, hospital discharge abstracts, and maternal interviews in 372 children, 198 of them with cerebral palsy, born in Michigan hospitals from 1993 to 2010. In birth certificates, we examined checkbox items “seizures” or “seizure or serious neurologic dysfunction”; in hospital discharge abstracts ICD-9-CM codes 779.0, 345.X, and 780.3; and in maternal interviews a history of seizures or convulsions on day one of life recalled 2–16 years later. In 27 neonates, 38 neonatal seizures were recorded in one or more sources; 17 in discharge abstracts, 20 in maternal interviews, but just one on a birth certificate. The Kappa coefficient (K) between interviews and discharge abstracts was moderate (K

Corresponding author: Qing Li, MD, DrPH, Medical University of South Carolina, Departments of Obstetrics and Gynecology and Public Health Sciences, Center for Women’s Health Research, Charleston, SC 29425, PH: 205-4277556, liqi@musc.edu;youliqing08@gmail.com.

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= 0.55), and substantial ($K = 0.63$) if mothers noted use of anti-epileptics. Agreement was higher ($K=0.71$ vs $K=0.29$) in term births than in preterm births. Birth certificates significantly under-reported neonatal seizures.

Keywords

Neonatal Seizures; United States Standard Certificate of Live Birth; Hospital Discharge Abstracts; Cerebral Palsy

Introduction

Neonatal seizures (seizures in the first 28 days of life) are an important indicator of newborn neurological dysfunction,^{1, 2} and have been suggested as a measure of the quality of perinatal care.^{3, 4} The condition requires immediate medical attention, and is linked to an elevated risk of mortality and adverse neurologic outcomes, such as epilepsy and cerebral palsy.^{5–8} Neonatal seizures commonly occur soon after birth. In two population-based studies, 20–33% of seizures began in the first 24 hours of life, and 50% had onset in the first three days.^{9, 10} While neonatal seizures can be caused by metabolic disorders such as hypoglycemia and hypocalcemia, they often reflect underlying brain injury such as hypoxic-ischemic injury, perinatal ischemic stroke, and rarely, intracranial infection.^{7, 11} In the United States, neonatal seizures affect 4,000 to 14,000 newborns each year, based on an estimated prevalence of 1 to 3.5 per 1000 live births.^{9, 10, 12, 13} Seizures often overlap with neonatal encephalopathy, which was estimated to account for 2.0% of global disability-adjusted life years in 2010¹⁴ and which can now be treated in some term infants with head or body cooling, leading to reductions in mortality and cerebral palsy outcomes.^{15–17} These important markers of newborn neurological dysfunction require accurate medical record documentation, as emphasized in the second edition of Neonatal Encephalopathy and Neurologic Outcome by the American College of Obstetricians and Gynecologists' Task Force.^{18, 19}

Seizures were first added as a specific code to the United States Standard Certificate of Live Birth in the 1989 revision,²⁰ and the term was expanded to “seizure or serious neurologic dysfunction” in the 2003 revision.^{21–22} United States vital registration areas based their birth certificates on one or the other of these two revisions before 2015.^{23, 24} While neonatal seizures were thus recorded on both versions of the birth certificate in circulation, the validity of this recording is uncertain, since reporting analyses of the new certificate have not yet been performed.^{9, 25–29}

Although the validity of many birth certificate items is uncertain,³⁰ and conditions occurring after birth certificate filing (generally within three days of birth) cannot be recorded, birth certificates have nonetheless been relied upon as the sole data source in studies of safety measures including neonatal seizures in home births compared to hospital births.^{31–33}

To investigate the recording of neonatal seizures more broadly than has been done so far, we investigated three sources of information – birth certificates, hospital discharge abstracts, and maternal interviews undertaken as part of a case-control investigation of cerebral palsy.

Materials and Methods

Study design and sample selection procedure

We used data collected in the Origins, Wellness, and Life-history in Cerebral Palsy case-control study that enrolled children ages 2–16 and born 1993–2010 from specialty clinics in Michigan hospitals serving children with cerebral palsy and matched controls (see Figure). Cases had a physician's diagnosis of disabling cerebral palsy, which was not post-natally acquired, nor a component of a major malformation syndrome or recognized genetic syndrome. Controls, free of major brain disorders, were recruited from area primary care practices, and, for cases < 32 weeks, newborn follow-up programs, and were matched on birth year, gender, and gestational age to cases. Although we enrolled a total of 639 children (cases, matched controls and siblings of cases) in the main study, after exclusion of subjects without complete records or access to all three information sources, our data set consisted of 372 children, 198 of them cases, and 174 controls (Figure). This study was approved by the Institutional Review Boards of the Michigan Department of Community Health and Michigan State University.

We compared the recording of seizures in all three data sources, and also examined whether seizures for which the mother recollected use of anti-seizure medication before the newborn's hospital discharge were more likely to be confirmed by discharge abstracts than when mothers did not report such use. We further assessed whether seizure recording was more reliable in term or preterm infants.

Three data sources and seizure diagnoses

Birth certificates—Data from birth certificates were provided by the Michigan Department of Community Health. The recording of neonatal seizures on birth certificates was based on the entry “seizures” in the 1989 revision, and “seizure or serious neurologic dysfunction” in the 2003 revision.

Maternal Interviews—Maternal interviews were conducted by trained research assistants by telephone when children entered the study, from ages 2 to 16 years. In our phone interviews, we asked mothers for a history of seizures or convulsions *in the first 24 hours of life*.

Discharge Abstracts—The discharge summaries were abstracted by hospital coders; automated records of discharges including diagnoses based on International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes containing 1 principal diagnosis code and up to 30 secondary diagnosis codes are compiled from participating hospitals by the Michigan Health and Hospital Association, and provided to the study team by the Michigan Department of Community Health. In our analyses of newborn discharge abstracts, we recorded neonatal seizures and followed Lanska et al²⁵ and Wu et al³⁴ in employing three ICD-9-CM codes: 779.0 (convulsions in newborn); among those with length of hospital stay within 28 days, 345.X (epilepsy), and 780.3 (convulsions).

Statistical analysis and evaluation

Descriptive statistics were computed for study variables. T-test was performed for maternal age at delivery; Chi-square tests were used for all other variables. Using the Kappa (K) option of PROC FREQ procedure in SAS version 9.4 (SAS Institute Inc, Cary, NC), we calculated the Kappa statistic to measure the agreement between recording methods compared to the agreement expected by chance alone.^{35–37} In a fourfold table with a, b, c, and d cells and a sum of these counts N, one type of Kappa paradox can present as a low K value but a high percentage recorded total agreement $(a+d)/N$.^{38, 39} This paradox can occur with a large count in d cell but small counts in other 3 cells in our data, where the marginal totals are highly symmetrically unbalanced.^{38, 39} To better understand findings and show the proportionate agreement in the recorder's positive and negative results, positive agreement (PA) and negative agreement (NA) were reported to accompany K.^{38, 39} Because the number of seizures recorded on birth certificates was so low ($n = 1$), we restricted our attention to comparisons of abstracts to interviews. We further calculated the sensitivity of the birth certificate using 1) discharge abstract or 2) either discharge abstract or maternal interview as a gold standard.

Results

Twenty three children (6.2%) were born in 2008 or later, and their births were recorded using the 2003 revision of the birth certificate; the remaining births were recorded on the 1989 revision of the birth certificate. The average age of child at maternal interview was 8 years. Compared to children excluded from the overall case-control study, subjects in this study of neonatal seizures were more likely to be born preterm, to have cerebral palsy, and to be born since 2000 (Table 1). These features likely indicate more complete recording in children in intensive care, and better availability of more recent records.

We identified 38 records (in 27 newborns) of neonatal seizures recorded in at least one of the three sources (Table 2). Seventeen seizures were reported in discharge abstracts, 20 in maternal interviews, but just one seizure was noted on a birth certificate, which was the 1989 version. The sensitivity of the birth certificate was 5.9% (1/17) using discharge abstract and 3.7% (1/27) using either discharge abstract or maternal interview as a gold standard. Term birth ($15/27 = 56\%$) was over-represented among subjects with seizures, compared to subjects without seizures ($127/345 = 38\%$).

After excluding 14 responses of "Don't know", 358 children had maternal interview responses of "yes or no" to the question on neonatal seizures. Table 3, section 1, compares the recording of seizures in interviews and hospital discharge abstracts. Ten seizures were recorded only in interviews, and five only in discharge abstracts, while 10 were recorded in both sources. This yielded a moderate^{35, 36} Kappa coefficient of 0.55 ($P < 0.001$; PA, 0.57; NA, 0.98).

After excluding 31 responses of "Don't know", 341 children had maternal interview response "yes or no" to the question on use of anti-seizure medication before the newborn's hospital discharge. Mothers reported 14 children with both neonatal seizures and anti-seizure medication. Nine of these seizures were also recorded in discharge abstracts (Table 3,

section 2). For this sub-group, the Kappa coefficient between interview and abstract was substantial 0.63 ($P<0.001$; PA, 0.64; NA, 0.98).

Table 4 shows that agreement was considerably better in children who had been born at term ($K=0.71$; $P<0.001$; PA, 0.73; NA, 0.98) than born preterm ($K=0.29$; $P<0.001$; PA, 0.31; NA, 0.98), likely reflecting the greater ease of seizure diagnosis in the term infant.

Kappa coefficients, surprisingly, were slightly higher among mothers with longer recall time: 0.48 (PA, 0.50; NA, 0.98) for 2–5 years, 0.55 (PA, 0.57; NA, 0.98) for 6–10 years, and 0.59 (PA, 0.62; NA, 0.98) for 11–16 years (all $P<0.001$, not tabulated).

Comment

Compared to discharge abstracts and maternal interviews, Michigan birth certificates significantly under-recorded neonatal seizures among a sample of births born in hospitals. Among 38 neonatal seizures recorded in 3 sources, only one was found on the child's birth certificate. Maternal interviews were of value in ascertaining neonatal seizures, even many years after the event, correlating moderately with discharge abstracts, especially if mother recollected anti-seizure medication use, and even more so if the infant was born at term. Maternal recollection of first-day seizures did not become less reliable with time over a span of 2–16 years, in these data.

Our finding of low sensitivity of the birth certificate in recording neonatal seizures (3.7%–5.9% depending on seizure denominator used) is similar to the findings of other studies. A population-based study in Kentucky reported a 37% sensitivity of birth certificate seizure diagnosis.²⁵ The gold standard for seizure diagnosis in that study was a consensus of the diagnosis of seizures ascertained from hospital discharge diagnoses, death certificates and medical record review. A case-control study in Tennessee in 1989 also found poor recording of seizures on birth certificates. Sensitivity was 4.6% compared to hospital medical records, and false positives were also common. The positive predictive value was only 37.5%.²⁹ In a population-based study in Harris County, Texas, birth certificates from 1992 to 1994 recorded only 14 of 207 cases ascertained through discharge diagnoses, birth and death certificates, and the concurrent study of neonatal seizures.⁹

The recording of neonatal seizures is affected by several factors. Neonatal seizures are difficult to accurately diagnose,⁴⁰ particularly in premature infants, a significant fraction of our study population. The cortex of preterm births may not be developed enough to show the usual clinical motor manifestations of seizure activity seen in term births; seizures in these infants are also less likely to be assessed by electroencephalography.⁴¹ This diagnostic difficulty may explain the lower Kappa for seizures in premature infants.

Neonatal seizures are recorded by hospital discharge abstractors primarily for administrative purposes, relying upon regulations and practice standards in the ICD-9-CM Official Guidelines for Coding and Reporting,⁴² which can prioritize the recording of events that prolong hospital stay or increase the requirement for nursing care. Other institutional factors that may affect recording of seizures include the nature of the personnel assigned reporting responsibility, and birth setting (e.g., hospital, birthing center or home) as well as the total

number of diagnoses reported in the dataset. Timing is also an issue, because most birth certificate reports are prepared within a day or two of the birth. Although Michigan law allows up to five days for reporting a birth, the requirement for parental signature on the birth certificate makes it likely that most certificates are completed prior to maternal discharge from hospital, generally in the first 48–72 hours. Therefore, the full five days are rarely available for data entry.

Our evaluation is distinctive in drawing data from three sources: birth certificates, hospital discharge abstracts, and maternal interviews, and in studying a population at high risk for newborn seizures, because it is composed of cases of cerebral palsy and controls weighted towards lower gestational ages (because of matching to cases on that variable). The prevalence of reported seizures in our study sample was at least 3% (counting only the 11 cases agreed upon by abstract and interview), or as high as 7.3% (counting the 27 total cases reported in either source), which is about 8 to 20 times higher than found in the general population.

However, this study has several limitations. First, we did not have full medical records to review. Second, neonatal seizures by definition are seizures in the first 28 days, but most children are discharged well before that age, and such late or post-discharge neonatal seizures cannot be recorded in either birth certificate or birth hospital discharge abstract. Although a sizeable fraction of neonatal seizures occur in the first three days of life,^{9, 10} recording of neonatal seizures in our study is affected by the variable time period of observation covered by each of our data sources. The error introduced by the non-overlapping time frames of neonatal seizure occurrence may lead to ascertainment differences that could reduce the extent of agreement in seizure recording in our study, and thus the level of agreement we measured could be an underestimate of true agreement. Third, comparison of our study with other studies may be complicated by differences in characteristics of the underlying populations, seizure definitions, and variable periods of observation and/or recording and recall in the newborn period.

Birth certificate data quality improvement efforts might best focus on leveraging the dramatic growth in the development and standardization of electronic medical records. This invites developing procedures to populate medical items within the birth certificate data directly from the hospital electronic medical records, something that the National Center for Health Statistics and the National Association for Public Health Statistics and Information Systems are already working to devise and test. This may be the shortest path to addressing longstanding issues with the data quality of selected birth certificate items. Initiatives in this area include developing standardized electronic messaging of newborn information to facilitate birth reporting.⁴³ Such approaches hold the promise of significantly improving birth certificate data while reducing the “double entry” of medical data by hospital staff, as well as providing the potential for longer periods of data checking and integration of medical professionals through electronic access to certificates prior to signature verification. Meanwhile, maternal interviews were of value in ascertaining neonatal seizures even many years after the event in this small study; the durability of maternal recall deserves further investigation.

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Figure.
Flow diagram of participants in this study

Table 1

Characteristics of included and excluded children for this study

Variable	Included (n=372)	Excluded (n=212)	P-value
	Mean (SD, range) or N (%)	Mean (SD, range) or N (%)	
Born since 2000	248 (66.7 %)	124 (58.5%)	0.048
Maternal age at delivery	29.4 (5.9, 15–50)	29.8 (5.7, 15–44)	0.44 *
Less than high school education	101 (27.1%)	57 (26.9%)	0.25
White mothers	326 (87.6%)	193 (91.5%)	0.21
Boy	211 (56.7%)	121 (57.1%)	0.93
Cerebral palsy case	198 (53.2%)	52 (24.5%)	<0.001
Gestational weeks	33.4 (5.3, 23–42)	36.1 (5.2, 23–42)	<0.001
Less than 37 weeks gestation	230 (61.8%)	76 (35.9%)	<0.001

Note:

* T-test was performed for maternal age at delivery; Chi-square tests were used for all other variables.

Table 2

Terminology used in recording neonatal seizures in three sources in this study

Neonatal Seizure Measure	Data Source and Location	Number of Reports
Abnormal Conditions of the Newborn: Seizure or serious neurologic dysfunction	Birth certificate NEW 43.6	0
Abnormal Conditions of the Newborn: Seizures	Birth certificate OLD 36.8	1
Convulsions in newborn	Infant hospital discharge file 779.0	17
Epilepsy *	Infant hospital discharge file 345.X	0
Convulsions *	Infant hospital discharge file 780.3	0
Seizures or convulsions in the first day **	Maternal Interview	20
Total		38
Medications for seizure treatment **	Maternal Interview	14

* Events were counted if the neonate had a hospital stay of 28 days or less

** Wording in the maternal interview when children were 2 to 16 years old:

Do you recall if [CHILD'S NAME] experienced any seizures or convulsions within the first 24 hours of life? _ No _ Yes _ Don't know _ Refused

Did [CHILD'S NAME] receive any medications for seizure treatment before being discharged from the hospital? _ No _ Yes _ Don't know _ Refused

Table 3

Agreement of seizure recording

1. Between maternal interviews and discharge abstracts
2. Between maternal interviews and discharge abstracts when seizures were accompanied by maternally recollected anti-seizure medication use

1) Kappa=0.55 ($P<0.001$) PA, 0.57; NA, 0.98		Seizures in discharge abstract		Total
Seizures in maternal interview		Yes	No	
Yes		10	10	20
No		5	333	338
Total		15	343	358 *
2) Kappa=0.63 ($P<0.001$) PA, 0.64; NA, 0.98		Seizures in discharge abstract		Total
Seizures reported with medication use		Yes	No	
Yes		9	5	14
No		5	322	327
Total		14	327	341 *

* Excludes 14 mothers who responded "Don't know" to newborn seizure questions

Note: Positive agreement (PA) and negative agreement (NA)

Table 4

Agreement of neonatal seizure recording between maternal interviews and discharge abstracts among children who had been born term or preterm

Children born at 37 weeks of gestation or more			
1) Kappa=0.71 ($P<0.001$) PA, 0.73; NA, 0.98	Seizures in discharge abstract		Total
Seizures in maternal interview	Yes	No	
Yes	8	4	12
No	2	136	138
Total	10	140	150 *
Children born before 37 weeks of gestation			
2) Kappa=0.29 ($P<0.001$) PA, 0.31; NA, 0.98	Seizures in discharge abstract		Total
Seizures in maternal interview	Yes	No	
Yes	2	6	8
No	3	197	200
Total	5	203	208 *

Note: Positive agreement (PA) and negative agreement (NA)

* Excludes 14 mothers who responded “Don’t know” to newborn seizure questions