

Sensitivity of Birth Certificate Reporting of Birth Defects in North Carolina, 2011-2017

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Introduction

In North Carolina, about 4,000 infants (3% of all births) are born with a major birth defect each year. The North Carolina Birth Defects Monitoring Program (NCBDMP) collects information about all medically diagnosed cases of major birth defects among North Carolina residents and maintains a central registry with this information. Select birth defects are also reported on the birth certificate, but research suggests that birth certificates are not a reliable source for identifying birth defects.¹⁻⁶

The current revision of the US birth certificate, released in 2003 and launched in North Carolina in August 2010, was revised in an effort to improve birth defect reporting and data quality. The revised certificate only includes anomalies diagnosable within the first 24 hours after birth.⁷⁻⁸ Despite these changes, a recent study reported poor reliability of birth defect data reported on the revised certificate, and therefore recommended against the use of birth certificates alone as a source of birth defect data.⁴ This report examines the reliability of birth defects reported on the birth certificate by linking birth certificate data to cases from the NCBDMP, a complete and accurate source of data on birth defects in North Carolina.

Methods

For births occurring in 2011-2017, birth certificates were linked to data on birth defects obtained from the NCBDMP; 2011 was the first full year of revised birth certificate data collected in North Carolina, and 2017 is the most recent complete year of NCBDMP data available. NCBDMP is an active, population-based surveillance system, in which data are collected by trained field staff who systematically review and abstract medical records in order to verify suspected cases identified by hospitals. Information from administrative health databases such as hospital discharge records and vital records is utilized as well. This method provides the most complete and accurate data on the prevalence of birth defects.

The following birth defects captured on the 2003 birth certificate revision were examined: anencephaly, meningomyelocele/spina bifida, cyanotic congenital heart disease, congenital diaphragmatic hernia, omphalocele, gastroschisis, limb reduction defect, cleft lip with or without cleft palate, cleft palate alone, Down syndrome, and hypospadias. Cyanotic congenital heart disease is a broad grouping, and specific heart defects that this category encompasses are not specified on the birth certificate. For the purposes of this analysis, we defined cyanotic congenital heart disease as any one of the seven critical congenital heart defects most likely to be detected by pulse oximetry screening at birth.⁹

Sensitivity values were calculated for each birth defect and for all birth defects together (any reported birth defect), along with 95% confidence intervals (CIs). Sensitivity is the proportion of true cases (cases confirmed by the NCBDMP) that were also captured on the birth certificate. For specific birth defects reported on the birth certificate (i.e., each birth defect excluding broader categories of cyanotic congenital heart defects and limb reduction defects), positive predictive values (PPVs) were also calculated. PPV is the proportion of cases captured on the birth certificate that were true cases (as opposed to false positives).

For all birth defects together, sensitivity was also calculated by the following characteristics obtained from data recorded on the birth certificate: year of birth, maternal age (<20, 20-24, 25-29, 30-34, or 35+ years), maternal race/ethnicity (non-Hispanic white, non-Hispanic Black, Hispanic, or other), maternal nativity (US-born or foreign-born), maternal education (less than high school, high school, or greater than high school), plurality (singleton or multiple), birthweight category (<2500 grams or 2500+ grams), gestational age category (<37 weeks or 37+ weeks), Adequacy of Prenatal Care Utilization (Kotelchuck) Index (inadequate, intermediate, adequate, adequate plus), Perinatal Care Region (Region I: western, Region II: northwestern, Region III: southwestern, Region IV: northeastern, Region V: southeastern, Region VI: eastern), and average annual number of births in the infant's birth hospital (<500, 500-999, 1000-1999, 2000+).

Results

There were 6,921 cases of selected birth defects ascertained by the NCBDMP from birth years 2011-2017. Overall, 1,368 (19.8%) were also captured by the birth defect indicators on the birth certificate. Sensitivity varied by birth defect type, ranging from 7.4% for hypospadias to 62.7% for anencephaly (Table 1). PPVs for specific birth defects also varied, but were generally better, from 47.3% for hypospadias to 86.4% for gastroschisis (Table 2).

for non-Hispanic Black (15.3%) and other or unknown race (14.9%). Sensitivity was also lower among mothers with more than a high school education (18.4%) compared to those with less than a high school education (23.2%). Results differed by adequacy of prenatal care as well, with lower sensitivity for those with 'inadequate' (17.8%) and 'adequate plus' (18.4%) levels of the Kotelchuck Index than those with 'adequate' (23.6%) prenatal care. By region of residence, sensitivity was highest in the western region (29.2%) and lowest in the northeastern region (14.9%). Additionally, there were differences in sensitivity values by the average number of births in the infant's birth hospital, with the highest overall sensitivity among those born in the smallest hospitals (<500 births per year; 33.7%) and the lowest sensitivity among those born in the largest hospitals (2000+ births per year; 17.4%).

Table 1. Sensitivity of birth certificate indicators for capturing selected birth defects, North Carolina, 2011-2017

Birth Defect	Cases in the BDMP Registry		
	Total (N)	Cases Identified on the Birth Certificate (N)	Sensitivity (%) (95% CI)
Anencephaly	75	47	62.7 (51.7-73.6)
Meningomyelocele/spina bifida	260	70	26.9 (21.5-32.3)
Cyanotic congenital heart disease	1075	83	7.7 (6.1-9.3)
Congenital diaphragmatic hernia	237	58	24.5 (19.0-30.0)
Omphalocele	165	42	25.5 (18.8-32.1)
Gastroschisis	320	146	45.6 (40.2-51.1)
Limb reduction defect	330	42	12.7 (9.1-16.3)
Cleft lip +/- cleft palate	671	316	47.1 (43.3-50.9)
Cleft palate alone	456	78	17.1 (13.7-20.6)
Down syndrome	1002	252	25.2 (22.5-27.8)
Hypospadias	2586	192	7.4 (6.4-8.4)
Any included defect	6921	1368	19.8 (18.8-20.7)

Discussion

Among North Carolina resident infants born 2011-2017, birth defects reported on the birth certificate captured only about 20% of all true cases. Though predictive values were generally better, they were poor for some of the specific birth defects recorded – for example, less than 60% of cleft palate alone and hypospadias cases identified on the birth certificate were true cases subsequently confirmed by the NCBDMP.

These results are consistent with another recent study examining sensitivity and accuracy of birth defect indicators on the 2003 revision of the birth certificate in Florida, which found 19% of true cases were captured by the birth certificate, and PPVs ranging from 49%-97% for specific birth defects.⁴ As with our study, sensitivity was highest for anencephaly, a defect easily recognizable at birth and commonly diagnosed prenatally. Similar to our findings, the previous study also found differences in sensitivity by sociodemographic, clinical, and hospital characteristics, including lower sensitivity for infants of non-Hispanic Black mothers compared to non-Hispanic white and Hispanic mothers. This variability could be due to the ways in which different populations receive

prenatal care, the hospitals in which they give birth, or other factors. Sensitivity differed by the average number of births per year in an infant's birth hospital in both studies as well, with both studies reporting lower sensitivity for hospitals with the highest numbers of births.

There were differences in overall sensitivity by several of the sociodemographic, clinical, and hospital characteristics we examined (Table 3). For instance, among maternal age groups, sensitivity was lowest for infants of mothers age 30-34 (16.5%), and among maternal racial/ethnic groups, sensitivity was lowest

New birth defect fields were included in the 2003 revision of the U.S. birth certificate in an effort to improve reporting. However, the results of this study suggest that birth certificates alone remain an inaccurate source of information on birth defects in North Carolina. Information from this analysis will be used to improve North Carolina birth registration training and encourage hospitals to utilize National Center for Health Statistics best

practices for reporting birth defects on the birth certificate.¹⁰⁻¹¹ Until birth certificate reporting improvements are achieved, researchers should be advised that the Birth Defects Monitoring Program continues to provide the most comprehensive and accurate information for birth defects surveillance in North Carolina.

Table 3. Differences in the sensitivity of selected birth defects captured by the birth certificate across sociodemographic, clinical, and hospital characteristics, North Carolina, 2011-2017

Characteristic	Sensitivity (%) (95% CI)	Characteristic	Sensitivity (%) (95% CI)
Year of birth		Plurality	
2011	21.9 (19.3-24.5)	Singleton	20.0 (19.0-21.0)
2012	18.8 (16.3-21.3)	Multiple	15.5 (11.7-19.4)
2013	19.2 (16.6-21.7)	Birthweight	
2014	20.4 (18.0-22.9)	<2500 grams	21.4 (19.5-23.4)
2015	18.5 (16.2-20.9)	2500+ grams	19.2 (18.1-20.3)
2016	21.6 (19.0-24.2)	Gestational age	
2017	18.0 (15.6-20.3)	<37 weeks	21.5 (19.5-23.5)
Maternal age		37+ weeks	19.2 (18.1-20.2)
<20 years	22.4 (18.7-26.0)	Adequacy of Prenatal Care Utilization (Kotelchuck) Index	
20-24 years	22.5 (20.5-24.6)	Inadequate	17.8 (15.9-19.7)
25-29 years	19.1 (17.3-20.9)	Intermediate	20.9 (16.9-24.9)
30-34 years	16.5 (14.7-18.3)	Adequate	23.6 (21.4-25.7)
35+ years	20.4 (18.2-22.5)	Adequate Plus	18.4 (17.1-19.8)
Maternal race/ethnicity		Perinatal Care Region	
Non-Hispanic white	20.9 (19.7-22.1)	Region I: western	29.2 (25.2-33.3)
Non-Hispanic Black	15.3 (13.5-17.1)	Region II: northwestern	18.2 (16.3-20.2)
Hispanic	24.0 (21.2-26.9)	Region III: southwestern	17.7 (15.4-19.9)
Other/unknown	14.9 (11.1-18.7)	Region IV: northeastern	14.9 (13.1-16.6)
Maternal nativity		Region V: southeastern	24.8 (22.3-27.2)
U.S.-born	19.3 (18.3-20.3)	Region VI: eastern	21.7 (19.2-24.3)
Foreign-born	22.5 (19.9-25.2)	Average annual births in hospital	
Maternal education		<500	33.7 (29.0-38.4)
<High school	23.2 (20.7-25.7)	500-999	30.9 (27.1-34.8)
High school	21.3 (19.3-23.3)	1000-1999	19.3 (16.9-21.7)
>High school	18.4 (17.2-19.5)	2000+	17.4 (16.3-18.4)

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