

Problems in Using Birth Certificate Files in the Capture-Recapture Model to Estimate the Completeness of Case Ascertainment in a Population-Based Birth Defects Registry in New York State

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BACKGROUND: The limitations and underlying assumptions of the capture-recapture methods have hindered their application in epidemiological settings, especially in evaluating the completeness of birth defects registries. This study explored the possibility of using birth certificates as the secondary data source in a simple two-source capture-recapture model to estimate the completeness of case ascertainment of the Congenital Malformations Registry (CMR) for selected major birth defects. **METHODS:** The CMR and the birth certificates were used as the primary and secondary sources, respectively. Children who were born in 1996–2001 and had selected major birth defects were identified from the two sources. The accuracy of the diagnoses was examined by comparing the individual birth defect categories of the children from the two sources. **RESULTS:** Discrepancies in birth defect categories in the two data sources and false positives in the birth certificates were the major problems encountered in estimating the completeness of the CMR using the simple two-source capture-recapture method. The estimated completeness for selected major birth defects was only about 71%. Stratified analyses resulted in relatively high estimated completeness for oral clefts (90%) and Down syndrome (88%). **CONCLUSIONS:** Although the birth certificate data was not a good source for estimating the completeness of case ascertainment of the CMR using capture-recapture methods, the analyses provided reasonable estimates for some conditions that were relatively easy to identify and diagnose at birth, such as oral clefts and Down syndrome. *Birth Defects Research (Part A) 76:772–777, 2006.* © 2006 Wiley-Liss, Inc.

Key words: birth defects; congenital malformations registry; capture-recapture; completeness; hospital discharge data; birth certificates

INTRODUCTION

Evaluating the completeness of registration of birth defect cases has been an especially important concern and a priority activity for birth defects registries. The completeness of a registry, that is, the ability to identify and register all new cases diagnosed within a population, is essential to produce accurate statistics and conduct valid studies on birth defects in a population. In the past decades, a number of studies were conducted to assess the completeness of birth defects registries' data (Boyed et al., 2005; Czeizel, 1997; Honein and Paulozzi, 1999; Larsen et al., 2003; Wang et al., 2001; Wen et al., 2000; Berghold et al., 2001; Cronk et al., 2003; Knox et al., 1984). Interestingly, only a few of these studies used the capture-recapture methods (Honein and Paulozzi, 1999; Berghold et al., 2001).

Capture-recapture methods, originally developed to estimate the size of a closed animal population (Cormack, 1968), have been used increasingly in epidemiological studies to assess the completeness of cancer registries (McClish and Penberthy, 2004; Silcocks and Robinson, 2004;

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Crocetti et al., 2001; Ballivet et al., 2000; Kim et al., 1999; Dockerty et al., 1997; Brenner et al., 1994, 1995; Brenner, 1994; Schouten et al., 1994; Robles et al., 1988) and birth defect registries (Honein and Paulozzi, 1999; Berghold et al., 2001), and to estimate the prevalence of some specific birth defects (Campbell et al., 2002; Orton et al., 2001; Rahi and Dezateux, 2000; Egeland et al., 1995; Bobo et al., 1994). This methodology attempts to estimate or adjust for the extent of incomplete ascertainment using information from overlapping lists of cases from distinct, independent sources. However, some limitations and underlying assumptions of the capture-recapture methods have hindered their application in most epidemiological settings (Hook and Regal, 1995, 1999; Papoz et al., 1996; Cormack, 1999; Tilling, 2001; Brenner, 1995), especially in evaluating the completeness of birth defects registries.

The two fundamental assumptions of the simple two-source capture-recapture method are the independence of the sources and the equal probability of individual cases being captured within any source (Hook and Regal, 1995). These assumptions may not hold in most epidemiological settings. For instance, some cases identified by one source have a higher (or lower) chance of being included in another source, leading to source dependence and violating the first assumption. Severe cases are more likely than mild cases to be captured within any source, violating the second assumption. Moreover, it is often difficult to find reliable data sources for comparison in the capture-recapture models, mostly due to differences in case definition or coding, such as including different birth defects in ICD-9 code groups.

The Congenital Malformations Registry (CMR) of the New York State Department of Health (NYSDOH) was established and began operation in late 1982. It is one of the largest statewide, population-based birth defects registries in the nation, and relies on reports from physicians and hospitals regarding new cases of structural birth defects. In the past decade, efforts have been made by the CMR staff to improve the completeness of the registry (Olsen et al., 1996; Druschel et al., 2001; Forand et al., 2002), including a monitoring system used since 1995 to audit all reporting hospitals using hospital discharge data from the Statewide Planning and Research Cooperative System (SPARCS). A previous study has shown that using hospital discharge data to improve the CMR's case ascertainment was a valuable and effective method of enhancing birth defect surveillance in New York State; new reports resulting from hospital discharge audits comprised about 21% of all CMR reports (Wang et al., 2005).

Because it is impossible to ascertain all cases for a population-based birth defects registry like the CMR, it is important and necessary to explore, develop, and validate methods for estimating the completeness of case ascertainment of the registry and, therefore, to provide an accurate and unbiased estimate of the number of birth defects in the population. The objective of this study was to explore the possibility of using birth certificates as the secondary data source in the two-source capture-recapture model to estimate the completeness of case ascertainment for selected major birth defects that are relatively easy to identify and diagnose at birth. The birth certificate files were used as the comparison data source in this study because no other data sources that collect birth defect information independently were available.

MATERIALS AND METHODS

Data Sources

CMR database. Hospitals and physicians are required to report to the CMR all children 2 years of age or younger who were born or reside in New York State and were diagnosed with major birth defects. Annually, the CMR receives birth defect reports for more than 10,000 children of New York State residents, which comprise about 4% of live births. CMR case ascertainment consists of: (1) mandatory reporting from hospitals and physicians; and (2) supplementary hospital audits by the CMR staff using SPARCS hospital discharge files (Wang et al., 2005).

Birth certificate files. The birth certificate files are maintained in the Vital Records Bureau of the NYSDOH, which annually records more than 255,000 live births in the State of New York. If a baby is diagnosed with birth defects at the time of birth, the birth certificate should indicate these malformations. One or more birth defects from a list of 27 conditions could be recorded on a newborn infant's birth certificate (New York State Department of Health, 2001).

Birth Defects Selected for the Study

Not all major birth defect categories were recorded in the birth certificate files. Moreover, some of the birth defect codes indicated on the birth certificates were not specific enough for classification. Thus, a list of selected major birth defects, which were in both sources and were relatively easy to identify and correctly diagnose at birth, was constructed for identifying cases in this study. This list, which accounted for about 13% of all cases in the CMR, included major congenital malformations in the central nervous, digestive, and musculoskeletal systems, oral clefts, and chromosomal anomalies. The selected major birth defects were then grouped into 11 categories. Children (not the defects) with one or more of these defects were counted because not all major malformations of a newborn were available in the birth certificate files.

Birth defects such as congenital anomalies of the cardiovascular system, which comprised about 30% of all cases in the CMR, were excluded from the study because some categories of these defects in the birth certificate files were not specific and some were less likely to be identified and diagnosed accurately at birth. The purpose of this exclusion was to remove the source dependency so that cases identified by one source should not have a higher (or lower) chance of being included in another source.

Data Matching

Matching cases in the CMR to the birth certificate files has been a routine procedure to obtain various birth variables including parents' demographic information, potential risk factors, and birth certificate number. The identifying variables such as the hospital's Permanent Facility Identifier (PFI), both infant's and mother's name, date of birth, medical record number, and mother's social security number and residential information are used as matching variables. Extensive matching with multiple matching variables results in more than 95% of all CMR cases and 99.5% of CMR cases of New York State residents matched to the birth records.

Table 1
Simple Two-Source Capture-Recapture Model for Estimating the Total Number of Birth Defects Cases

	Cases ascertained by secondary source		Total	
	Yes	No		
Cases ascertained by primary source	Yes	A	B	$n_1 = A + B$
	No	C	D	$n = A + B + C + D$
	Total	$n_2 = A + C$		

A: Cases captured by both sources.
 B: Cases captured only by the primary source.
 C: Cases captured only by the secondary source.
 D: Cases missed by both sources, estimate based on the assumption that the probability of ascertainment from both sources is equal, that is, $A \times D = B \times C$. Thus, $D = (B \times C)/A = (n_1 - A)(n_2 - A)/A$.
 n_1 : The total number of cases captured by the primary source.
 n_2 : The total number of cases captured by the secondary source.
 n : The estimated total number of cases in a population, $n = A + B + C + D = (n_1 \times n_2)/A$.

For this study, a dataset containing information about children who were born in 1996–2001 to New York State residents and had selected major birth defects noted on

Table 2
Results from the Simple Two-Source Capture-Recapture Analysis Using Birth Certificate Files as the Secondary Source

	Cases ascertained by secondary source: birth certificate		Total	
	Yes	No		
Cases ascertained by primary source: CMR	Yes	2,824	4,855	7,679 (70.6%)*
	No	1,178	2,025	
	Total	4,002		10,882

Results are from birth years 1996–2001.
 *Estimated completeness of the data source.

their birth certificates was abstracted from the birth certificate files. This dataset, used as the secondary source in the capture-recapture analysis, was linked to the primary source, the CMR records of children who had the same selected major birth defects and were born to New York State residents, by birth year and birth certificate number. The matched cases from the linkage were identified as the cases captured by both sources. The accuracy of the diag-

Table 3
Comparison of the Birth Defects of the Children Captured by Both Source

		Agreement of the birth defects						
		Total	Completely agree*		Partially agree†		Completely disagree‡	
			<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Birth year	1996	487	411	84.4	52	10.7	24	4.9
	1997	489	412	84.3	53	10.8	24	4.9
	1998	488	417	85.5	41	8.4	30	6.1
	1999	475	400	84.2	44	9.3	31	6.5
	2000	434	359	82.7	43	9.9	32	7.4
	2001	451	408	90.5	23	5.1	20	4.4
Hospital location	Upstate New York§	2,054	1,767	86.0	180	8.8	107	5.2
	New York City	770	640	83.1	76	9.9	54	7.0
Children with birth defects in CMR	Multiple	204	56	27.5	136	66.7	12	5.9
	Single	2,620	2,351	89.7	120	4.6	149	5.7
Malformation categories in CMR	Neural tube defects	227	132	58.1	69	30.4	26	11.5
	Encephalus	37	18	48.6	9	24.3	10	27.0
	Hydrocephalus	242	192	79.3	37	15.3	13	5.4
	Oral clefts	968	908	93.8	49	5.1	11	1.1
	Rectal atresia/stenosis	131	97	74.0	27	20.6	7	5.3
	Tracheoesophageal fistula/esophageal atresia	84	71	84.5	10	11.9	3	3.6
	Limb reduction	52	47	90.4	1	1.9	4	7.7
	Diaphragmatic hernia	104	94	90.4	5	4.8	5	4.8
	Omphalocele/gastroschisis	213	209	98.1	4	1.9	0	0.0
	Down syndrome	596	504	84.6	34	5.7	58	9.7
	Other chromosomal anomalies	170	135	79.4	11	6.5	24	14.1
	Total	2,824	2,407	85.2	256	9.1	161	5.7

Sources were CMR and birth certificates, birth years: 1996–2001.

*All defects agree.

†One or more but not all defects agree.

‡None of the defects agree.

§New York State excluding New York City.

||These 120 children had a single birth defect in the CMR but were identified as having multiple birth defects in the birth certificate files.

Table 4
Estimated Completeness of CMR for Selected Birth Defects and 95% Confidence Intervals from Stratified Analyses by Birth Defects Category, Using Simple Two-Source Capture-Recapture Model

		Total cases from primary source CMR (n_1)*	Total cases from secondary source birth certificates (n_2)*	Overlap cases in both (A)*	Estimated uncaptured cases (D)*	Estimated total cases (n)*	Estimated completeness of ascertainment†	95%CI‡	
Children with birth defects									
Multiple		401	230	204	25	452	88.7	85.9	91.6
Single		7,278	3,772	2,620	2,048	10,478	69.5	68.3	70.7
Birth defect category		ICD-9§							
Neural tube defects		740.0, 741.0, 741.9							
Encephalus		394	500	197	303	1,000	39.4	36.6	42.7
Hydrocephalus		80	106	25	178	339	23.6	18.6	32.1
Oral clefts		742.3	1,021	326	195	1,707	59.8	55.4	65.0
Tracheoesophageal		749	1,808	1,012	98	2,006	90.1	88.8	91.4
Rectal atresia/stenosis		750.3	482	132	102	624	77.3	71.5	84.1
Limb reduction		751.2, 755.2, 755.3, 755.4							
Diaphragmatic hernia		280	100	70	90	400	70.0	63.1	78.5
Omphalocele/gastroschisis		401	84	50	239	674	59.5	51.3	70.8
Down syndrome		756.6	254	135	99	346	73.3	68.0	79.6
Other chromosomal		756.70, 760.71, 758.0							
All		1,607	673	593	137	1,824	88.1	86.2	90.1
		617	306	170	358	1,111	55.6	51.2	60.7
		7,278	3,772	2,620	2,243	10,673	68.2	67.1	69.3

Birth cohort: 1996–2001.

*The notations n_1 , n_2 , A , D , and n were defined in the simple two-source capture-recapture model as illustrated in Table 1.

†Calculated by n_1/n .

‡Assuming the estimated total cases (n) are normally distributed, the 95% confidence interval for n is: $n_{lower} = n - 1.96[\text{Var}(n)]^{1/2}$, $n_{upper} = n + 1.96[\text{Var}(n)]^{1/2}$, $\text{Var}(n) = (n_1 + 1)(n_2 + 1)(n_1 - A)(n_2 - A)/[(A + 1)^2(A + 2)]$. Then, the 95% CI for the ratio is: $(n_1/n_{upper}, n_1/n_{lower})$.

§International Classification of Disease, 9th revision.

noses of these matched cases was examined by comparing the individual birth defects of the children from the two sources.

Two-Source Capture-Recapture Analysis

A simple two-source capture-recapture model was used for estimating the total number of cases (Brenner, 1994). The number of cases captured by both sources was determined by linking the two data sources. The number of cases missed by both sources was estimated based on the assumption that the probability of ascertainment from both sources was equal. The estimated completeness of the case ascertainment for the primary source can be calculated by dividing the number of cases captured by the total number of cases estimated from the model. The 95% CI of the estimated completeness was calculated using the normal distribution-based CI of the estimated total number of cases that occurred during the study period (Pollack et al., 1990).

RESULTS

Crude Analyses Using the Two-Source Capture-Recapture Model

Table 1 illustrates the simple two-source capture-recapture model for estimating the total number of selected

major birth defects. The analysis was performed using the CMR and the birth certificate data as the primary and the secondary sources, respectively. The results are shown in Table 2. Among live births for the years of 1996 through 2001, 2,824 cases with selected major birth defects were captured by both sources. There were 1,178 cases that were captured by the birth certificate files but not by the CMR. According to the model, 2,025 cases were missed by both sources. The estimated total number of cases was 10,882. The estimated completeness of case ascertainment of the CMR for selected major birth defects was 70.6%.

Discrepancies of the Birth Defects in the Two Sources

To compare the birth defects of the children captured by both sources (the CMR and the birth certificates) and to examine factors that affect the discrepancies in birth defect categories defined in the two sources, analyses were performed by birth year, geographic location of the reporting hospitals, the number of birth defects (single or multiple), and birth defect category. The results are shown in Table 3. Out of 2,824 children captured by both sources, 85.2% had birth defect categories that completely agreed in both sources, 9.1% partially agreed (one or more but not all malformations agreed), and 5.7% completely disagreed. Children with a single birth defect had much higher per-

cent agreement (89.7%) in the birth defect category defined in the two sources compared to children with multiple defects (27.5%). Among the individual birth defect categories, defects that were visible, such as oral clefts, gastroschisis, and omphalocele combined were more likely to be diagnosed correctly on both sources. The overall agreement (completely and partially agreed) of the birth defect categories in the two sources did not change significantly over the study years, 1996–2001.

Stratified Analyses Using the Capture-Recapture Method

Stratified analyses were performed by the number of birth defects (single or multiple) and by birth defect categories for the children with a single birth defect, using the simple two-source capture-recapture model. The birth defect categories defined by the CMR were used for the children who were captured by both sources but had birth defect categories that disagreed in the two sources. The results are presented in Table 4. The estimated completeness of case ascertainment for children with multiple defects was significantly higher (88.7%, 95% CI 85.9–91.6%) than that for children with a single defect (69.5%, 95% CI 68.3–70.7%). Moreover, results from stratified analysis among children with a single birth defect by birth defect category showed that the estimates of completeness strongly depend on the specific birth defect. The highest estimates were 90.1 and 88.1% for oral clefts and Down syndrome, respectively, and the lowest estimate was 23.6% for encephalus. The estimate for omphalocele and gastroschisis was surprisingly low (52%), even though these defects are relatively easy to identify and correctly diagnose at birth.

DISCUSSION

Using birth certificate files as the comparison source in a simple two-source capture-recapture model, the estimated completeness of case ascertainment of the CMR for selected birth defects was about 71%. This relatively low estimate was most likely attributable to the false-positive reports in the birth certificate files (Olsen et al., 1996; Pollock et al., 1990). A previous study conducted by our CMR staff to determine whether birth certificates could be used to ascertain unreported cases to the CMR found that about 45% of the children with one or more birth defects noted on their birth certificates were normal, that is, there was no mention of a malformation in their medical records (Olsen et al., 1996).

In order to evaluate the effect of false positives on the results of the capture-recapture analysis, we matched the cases that were found in the birth certificate files but not in the CMR to SPARCS hospital discharge data to verify the cases. When we assumed that the unmatched cases were false positives and removed them from the analysis, the estimated completeness was approximately 82% (data not shown). Although the use of SPARCS data to filter the false positives sacrifices the independence of data sources because the SPARCS data were used as a supplementary data source to the CMR, the finding demonstrates that the quality of the comparison data source is critical for evaluating the completeness of case ascertainment using the capture-recapture analysis. In order to identify false positive cases from the birth certificate files and ascertain

unreported cases, we would need to request individual medical records from reporting hospitals. This would add an extra burden to the reporting hospitals and the CMR staff. The CMR staff has been actively seeking more practical and less expensive measures to identify unreported cases from other sources.

The current study found that although false positives in the birth certificate files lead to an overestimate of the total number of cases and thus, the completeness of the case ascertainment for the birth defects of interest was underestimated, they did not significantly affect the estimates for some birth defects that were relatively easy to identify and diagnose at birth, such as oral clefts and Down syndrome. The estimated completeness for oral clefts and Down syndrome was 90 and 88%, respectively. Our estimate for Down syndrome was consistent with that reported by Berghold et al. (2001) for the Styrian Malformation registry. They estimated that Down syndrome cases reported to the registry between 1985–1992 were 88% complete, using the two-source capture-recapture method allowing for time-varying parameters (Berghold et al., 2001).

The discrepancy in the case definition of data sources has been shown to be one of the major problems encountered in estimating the completeness of case ascertainment using the capture-recapture methods (Hook and Regal, 1999). The results from our study show that among children captured by both sources, about 6% had birth defects that totally failed to agree. In this study, hospitals reported birth defect cases to the CMR using a standard reporting card to provide ICD-9-CM codes and narratives, as well as the information about the child and parents. On the other hand, there were only 27 one-digit fields (with the value of 1 or 0) used for recording major anomalies (New York State Department of Health, 2001) in the birth certificate files and there were no narratives available, resulting in discrepancies in birth defect categories in the two data sources. Because we do not confirm all of the diagnosed cases reported to the CMR due to limited resources, the CMR staff has initiated an on-site auditing program to focus on improving the accuracy of diagnoses by visiting hospitals that have an unreasonably low number of case reports and/or insufficient diagnostic information for the reported cases.

There was no strong evidence of dependence between the two sources in the current study. Our study selected only children with major birth defects that were relatively easy to identify and diagnose correctly at birth, because the CMR receives case reports of children up to 2 years of age whereas the birth certificate files collect birth defects information at birth. This exclusion greatly reduced (if not eliminated) the chance of positive source dependency, that is, cases identified by one source (the CMR) having a higher chance of being included in another source (the birth certificates). It should also be noted that our estimate of completeness of case ascertainment for selected birth defects might not be generalized to all the birth defects in the CMR, because only a portion of birth defects in the CMR, which comprised 13% of all CMR cases, was included in the study.

In conclusion, discrepancies in birth defect categories defined in the two sources (the CMR and the birth certificates) and false positives in the birth certificate files were the major problems encountered in estimating the completeness of case ascertainment using the simple two-source capture-recapture method. False positives in the birth certificate files lead to the overestimation of the total number of

cases and thus, the underestimation of CMR's completeness of case ascertainment for selected birth defects. Although the birth certificate data were not a good source for estimating the completeness of case ascertainment of the CMR using the capture-recapture methods, our results from the capture-recapture analyses provided reasonable estimates for some birth defects that are relatively easy to identify and correctly diagnose at birth, such as oral clefts and Down syndrome. The exploratory analysis and the findings of the current study should be helpful to the registries and researchers in the birth defects research community; our study has shown the importance of the quality of the data sources and has suggested that the two-source capture-recapture model should be used with caution in estimating the completeness of case ascertainment of birth defects if the quality of the comparison data source, such as the birth certificates, is in question.

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