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Estimating the Burden of Prematurity on Infant Mortality: A Comparison of Death Certificates and Child Fatality Review in Ohio, 2009–2013

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Abstract

Introduction—Infant mortality is a key population health indicator, and accurate cause of death reporting is necessary to design infant mortality prevention strategies. Death certificates and child fatality review (CFR) both track leading infant causes of death in Ohio but produce different results. Our aim was to determine the frequency and characteristics of differences between the two systems to understand both cause of death ranking systems for Ohio.

Methods—We linked and analyzed data from death certificates and CFR records for all infant deaths (aged < 1 year) in Ohio during 2009–2013. Death certificate and CFR cause of death assignments were compared. Kappa statistic was used to measure concordance. Death certificate-CFR cause of death pairs were plotted to identify common concordant and discordant pairs.

Results—A total of 5030 infant deaths with death certificate and CFR records were analyzed. The most common discordant cause of death pair was other perinatal condition on the death certificate and prematurity by CFR (1119). Specific injury categories had higher concordance (kappa 0.71–1.00) than medical categories (kappa 0.00–0.78). Among 456 deaths categorized as sudden infant death syndrome on death certificates, approximately 50% (230) were categorized as missing, unknown, or undetermined by CFR.

Discussion—Linking death certificate and CFR causes of death provided a more robust understanding of infant causes of death in Ohio. Separately, each system serves distinct and valuable purposes that should be reviewed before selecting one system for ranking leading causes of infant mortality.

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Conflict of interest The authors declare that they have no conflict of interest.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Keywords

Cause of death; Child death review; Death certificates; Infant mortality; Surveillance

Introduction

In 2015, Ohio had the 12th highest state infant mortality rate in the nation (US DHHS n.d.). Infant mortality is an important maternal and child health indicator of overall population health (Reidpath and Allotey 2003). Accurate infant cause of death reporting provides crucial data for focused strategy development to reduce infant mortality. In Ohio, two infant cause of death reporting systems exist—death certificates and child fatality review (CFR).

Death certificates are a primary source of infant mortality statistics and are used to rank leading causes of infant death nationally using the 71 rankable causes of infant death (Heron 2016). Since 1908, Ohio death certificates have consistently tracked infant mortality changes for public health purposes. Mortality statistics rely on the underlying cause of death, defined by the World Health Organization (WHO) as, “the disease or injury which initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury” (WHO 2011). Death certificates collect basic demographics but not detailed circumstances of the death.

In contrast, CFR was developed to document and understand circumstances related to fatal child abuse deaths (Durfee et al. 2009), and different CFR versions have developed nationally and internationally. Today, CFR scope has broadened to include other injury and medical causes of death, but the purpose remains to identify preventable causes of death. In 2000, Ohio mandated a CFR modeled after the National Center for Fatality Review and Prevention (NCFRP) process (Covington et al. 2005) to more fully understand and prevent child deaths. All deaths for persons aged < 18 years are reviewed, including all infant deaths. Local and state public health officials use CFR findings to develop infant mortality prevention initiatives that address safe sleep, child abuse, and infant home visiting programs (ODH n.d.).

In 2013, Ohio Department of Health (ODH) began publishing an annual infant mortality report to raise awareness of slowing improvements in the state’s infant mortality compared with national trends (ODH n.d.). Differences in leading causes of death between the two classification systems used by ODH at the time—71 rankable causes from death certificates and cause of death categories reported through CFR—were identified while preparing the report. Previous studies have noted limitations of death certificates in accurately reporting cause of death; however, few studies have examined infant deaths specifically and no previous studies have directly compared death certificates with CFR (Percy et al. 1981; Pritt et al. 2005; Seske et al. 2017). We investigated to compare the two systems directly and delineate the utility of each system. The primary objective was to examine the frequency, characteristics, similarities, and differences in cause of death classification between death certificates and CFR to enable selection of the most appropriate cause of death ranking system for Ohio.

Methods

During 2016 we conducted a cross-sectional, secondary data analysis. We reviewed all deaths among live-born Ohio residents aged < 1 year during 2009–2013. Fetal deaths and deaths outside Ohio were excluded.

Death Certificate Data

The ODH Bureau of Vital Statistics routinely links birth and death certificates for infant deaths. Birth and death certificates collect demographics including age, sex, race, ethnicity, gestational age (based on obstetric estimate), and county of residence. Cause of death is determined by a physician or coroner and entered into four open text fields: the immediate cause and up to three conditions that sequentially led to the immediate cause. In Ohio, all coroners are licensed physicians. Completed death certificates are sent to the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC) where each cause of death field is reviewed and assigned an *International Classification of Diseases, Tenth Revision* (ICD-10) code. An underlying cause of death is selected based on a defined set of rules (NCHS n.d.), which allow consistent selection across states, even when causes are not listed in a causal sequence.

Child Fatality Review Data

Each of Ohio's 88 counties has one CFR board. Boards are composed of the following: county coroner; chief of police or sheriff; executive director of a board of alcohol, drug addiction, and mental health service; executive director of a public children services agency; public health official; and pediatrician or family practice physician. Each board reviews a decedent's medical, law enforcement, social work, and death scene investigation records. Boards usually have access to the death certificate during their review but not the NCHS-assigned ICD-10 code for underlying cause of death. The board determines the cause of death, its circumstances, and whether it was preventable and reports the event to ODH electronically using a standardized case report form (NCFRP 2016). ODH provides training to new board directors and NCFRP maintains a data dictionary to improve standardized reporting.

CFR causes of death on the case report form are divided into 10 injury and 15 medical categories plus two additional categories, "unknown" and "undetermined if injury or medical cause" (Table 3 in Appendix 1). For this analysis, causes that were missing or listed as unknown or undetermined if injury or medical cause were considered missing/unknown/undetermined.

Data Linkage

Death certificate and CFR records were linked using iterative deterministic matching. Personal identifiers from death certificates and CFR were used to link infant records that included name, date of birth, date of death, sex, and address of residence. First, each record was linked on a set of personal identifiers (e.g. name, date of birth, date of death, and sex). Exact matches were identified and manually verified using an additional variable (e.g. residential zip code). Next, for remaining unmatched records, the process was repeated using

a new set of personal identifiers (e.g. last name, year of death). This process was repeated three additional times until > 95% of decedent records were linked.

Because death certificates and CFR classify cause of death differently, we aligned cause of death categories by assigning all possible underlying death certificate ICD-10 codes to a CFR cause of death category (Table 3 in Appendix 1). For example, the CFR category *congenital anomalies* included ICD-10 codes Q00-Q99, which relates to congenital malformations, deformations, and chromosomal abnormalities.

Data Analysis

Statistical analyses were performed with SAS© version 9.4 (SAS Institute Inc., Cary, North Carolina). Demographics were obtained from death certificates, and gestational age was obtained from birth certificates. If missing from the birth certificates, gestational age was obtained from CFR. Urban and rural designations were determined from 2013 NCHS urban–rural classification scheme (Ingram and Franco 2014). Cause of death concordance between the two systems was measured by Cohen's kappa statistic, which ranges from 0 (lowest concordance) to 1 (highest concordance).

To visualize the frequency of concordant and discordant causes of death, we created a matrix containing every death certificate-CFR cause of death pair. The matrix table was transformed into a circular plot using Circos, a software for visualizing relationships (Krzywinski et al. 2009). Each death certificate-CFR pair is displayed as a ribbon with the death certificate category at one end and the CFR category at the other. Ribbon width is proportional to the number of infants. Ribbon color corresponds to the death certificate category.

Research Ethics

This analysis was reviewed by ODH's Institutional Review Board (Protocol Number 2016–58). CDC reviewed this study for human subjects protection and deemed it to be non-research.

Results

For infants who died during 2009–2013, death certificates totaled 5192, CFR reviewed 5198 deaths, and 5030 records (96.9% death certificates; 96.8% CFR) were linked. More CFR reviews were conducted than death certificates because some infant deaths were reviewed by more than one board. Unlinked records occurred when CFR boards submitted insufficient personal identifiers. Population demographics are described in Table 1. Most infants died during the neonatal period (0– < 28 days) (68%), were boys (56%), were white, non-Hispanic (60%), resided in an urban county (82%), and were born early preterm (< 34 weeks) (59%).

Underlying Cause of Death

Death certificate and CFR causes of death using common cause of death categories are shown in Fig. 1. The three most common causes on death certificates were other perinatal

condition (1477), congenital anomaly (1000), and prematurity (951). The three most common causes according to CFR were prematurity (2356), congenital anomaly (725), and other medical condition (444). CFR selected prematurity more than twice as often as death certificates (2356 versus 951). Lastly, no infants were missing a cause of death from death certificates, but 362 were not assigned a cause by CFR.

Concordance Between Death Certificates and CFR

Three cause of death categories had a kappa statistic ≥ 0.9— drowning, motor vehicle and other transportation, and asphyxia (Table 2). Most injury categories had higher concordance than medical categories with six of the seven injury categories having a kappa statistic ≥ 0.7. Most "other" categories (other medical condition, other perinatal condition, and other external injury) had a kappa statistic of ≤ 0.1.

Death certificate-CFR cause of death pairs for 4873 (97%) of the 5030 infants are shown in Fig. 2 and Table 4 in Appendix 2. Ribbons that remain in the same category (e.g. asphyxia) indicate concordance while ribbons that cross categories indicate discordance. For example, for infant deaths listed as congenital anomaly on the death certificate (yellow ribbons), the most common CFR causes of death selected were congenital anomaly (604, concordant), other medical (154, discordant), and prematurity (103, discordant). The most common discordant pair (1119 infants, blue ribbon) categorized cause as other perinatal condition on the death certificate and prematurity by CFR. The second most common discordant pair (230 infants) classified as sudden infant death syndrome (SIDS) by death certificates and missing/unknown/undetermined by CFR.

Discussion

This is the first study to systematically compare infant cause of death between death certificates and CFR. We found notable differences in leading causes of death when each system was ranked separately, and we used linked data to explore the most common areas of discordance. Prematurity was more often selected by CFR than death certificates. Secondly, injury categories had higher concordance than medical categories. Lastly, half of SIDS deaths on death certificates (230 of 456) were categorized as missing/unknown/undetermined by CFR. We explore possible explanations as follows.

Prematurity ranks higher when using CFR rankings than death certificate because death certificates and CFR have different approaches to defining prematurity. For death certificates, ICD-10 coding instructions consider prematurity a mode of death rather than a cause of death and recommend that prematurity not be coded unless it was the only condition known (WHO 2004). National leading causes of infant death are based on 71 rankable causes (Heron 2016), with prematurity defined narrowly as, "disorders related to short gestation and low birth weight, not elsewhere classified (P07)." Other prematurity-related causes (e.g., neonatal hemorrhage, respiratory distress syndrome, or necrotizing enterocolitis) are ranked separately. Using this narrow definition for prematurity likely contributed to the low concordance for prematurity between death certificates and CFR. One solution is to classify prematurity-related causes together, as done by either NCHS (Mathews et al. 2015) or the modified Dollfus classification scheme (Nakamura et al. 2015).

The Dollfus prematurity category groups prematurity-related conditions together with short gestation and low birth weight (P07). By using a broader prematurity category, modified Dollfus more inclusively estimates prematurity burden on infant mortality (Nakamura et al. 2015).

In contrast to death certificates, CFR boards were more likely to record prematurity rather than a perinatal condition for infant decedents born prematurely. Perinatal conditions that contributed to or resulted from prematurity are recorded in a different section of the CFR data collection form. However, in Ohio these data are often not recorded, either because boards do not or cannot obtain detailed infant or maternal medical records. Because CFR focuses on preventability, some boards do not review medical deaths as closely as injury deaths. For example, one Ohio county partially reviewed two-thirds of all infant deaths because they were due to medical causes or prematurity. Consequently, the opportunity to collect information on perinatal and maternal conditions through CFR might be underutilized in Ohio. NCFRP has recognized the limitation of reviewing medical and premature deaths. National data quality initiatives, including online webinar training, have been developed to raise awareness that many medical infant deaths can be prevented, to make reviews more effective, and to improve recommendations for prevention activities (NCFRP 2016).

Our second finding of higher concordance for injury deaths than medical deaths might be attributed to injury deaths often occurring from a single event, whereas medical deaths are often multifactorial (Jacob et al. 2015). For example, bacterial meningitis (G00) can be categorized as a neurological condition or an infection. When NCHS selects the underlying cause from the death certificate and assigns an ICD-10 code, it follows a nosological system standardized nationally. In contrast, each CFR board in Ohio has independent methods for selecting cause of death. The high concordance for injury categories reveals that CFR collects reliable cause of death data for injury-related deaths, which are typically considered preventable. Other studies have reported that CFR is more effective than death certificates in identifying certain injury categories, especially child maltreatment (Schnitzer et al. 2008; Crume et al. 2002).

Finally, we revealed that most SIDS deaths on death certificates were not categorized as SIDS by CFR. In CFR, SIDS is subcategorized under medical causes, and most SIDS deaths were reported as undetermined if injury or medical cause. This is understandable as CDC defines SIDS as, “the sudden death of an infant under one year of age that cannot be explained after a thorough case investigation, including a complete autopsy, examination of the death scene, and review of the clinical history” (CDC n.d.). The difference in SIDS reporting between death certificates and CFR might reflect differences in interpretation of SIDS criteria. CFR has an additional section on deaths related to sleeping or the sleep environment, and Ohio avoids this confusion by reporting sleep-related deaths rather than SIDS. Before using this CFR measure, other states might consider evaluating the data quality of the SIDS cause of death variable.

In summary, both systems revealed limitations for tracking infant cause of death, particularly prematurity-related deaths. Death certificate underlying cause codes underestimated the

broader contribution of prematurity when ranked using the 71 rankable causes, while CFR missed opportunities to record perinatal and maternal medical conditions. Data completeness on death certificates and the standardized methodology used by NCHS are advantages to using death certificates for cause of death rankings. In response, Ohio now uses death certificate causes of death for annual infant mortality reporting (ODH n.d.). To more inclusively capture prematurity-related causes of death, Ohio groups causes using the modified Dollfus classification.

This analysis had several limitations. Each county conducts an independent review process, so data collection and determination of cause of death might vary by county. Additionally, no validated method of assigning ICD-10 codes to CFR cause of death categories exists. ICD-10 assignments to CFR injury categories are published in Ohio's annual CFR report (ODH n.d.), and assignments to CFR medical categories were determined by the authors. This analysis was restricted to underlying cause codes on death certificates rather than multiple cause codes because national rankings are based on the underlying cause (Heron 2016). Further-more, kappa statistic does not have universally accepted cut-offs for high or low concordance. Knowing this limitation, we used kappa statistic only to show relative levels of concordance among categories. Despite these limitations, Ohio provided a unique opportunity to conduct this assessment because Ohio CFR reviews all infant deaths, and by linking these datasets, we could quantitatively compare two widely used infant death reporting systems.

Conclusion

Differences in infant causes of death between death certificates and CFR were not attributable to inaccuracies or reporting errors but to an artifact of using different classification schemes. Each reporting system serves distinct, valuable purposes. Strengths of death certificates are in capturing higher degree of detail and in using a classification system consistent across counties, states, and years. Strengths of CFR are in identifying preventable causes of death and in examining circumstances surrounding a death. If CFR findings are used to rank causes of death, it should be stated that the purpose of CFR is to identify preventable causes of death, otherwise rankings could be misleading. Because the two systems complement each other, states could consider using linked death certificate-CFR records to better understand infant mortality.

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Appendix 1

See Table 3.

Appendix 2

See Table 4.

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Significance

What is already known on this subject?

Death certificates and child fatality review (CFR) both classify infant cause of death. Leading causes of infant mortality differ between the two systems.

What this study adds?

Most cause of death discordance occurred when perinatal condition was selected on death certificates and prematurity was selected by CFR. Death certificate cause of death rankings are preferable for understanding underlying causes of death, whereas CFR rankings are preferable for understanding preventable causes. The benefits of each system should be considered when selecting a system to rank causes of infant mortality. These findings resulted in Ohio's change from using CFR to death certificate data for cause of death rankings in annual reporting.

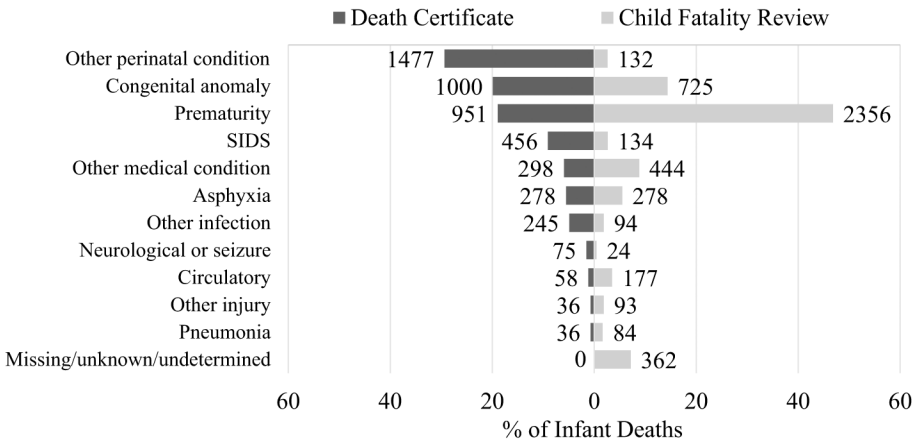

Fig. 1.

Number and proportion of infant deaths by cause of death category according to death certificates and Child Fatality Review, 2009–2013. Categories with small numbers (< 50 infants by both methods) are not shown: animal bite or attack, asthma, cancer, drowning, environmental exposure, fall or crush, fire, burn, electrocution, HIV/AIDS, influenza, low birth weight, malnutrition or dehydration, motor vehicle and other transportation, poisoning, overdose or acute intoxication, and weapon, including body part. *SIDS* sudden infant death syndrome

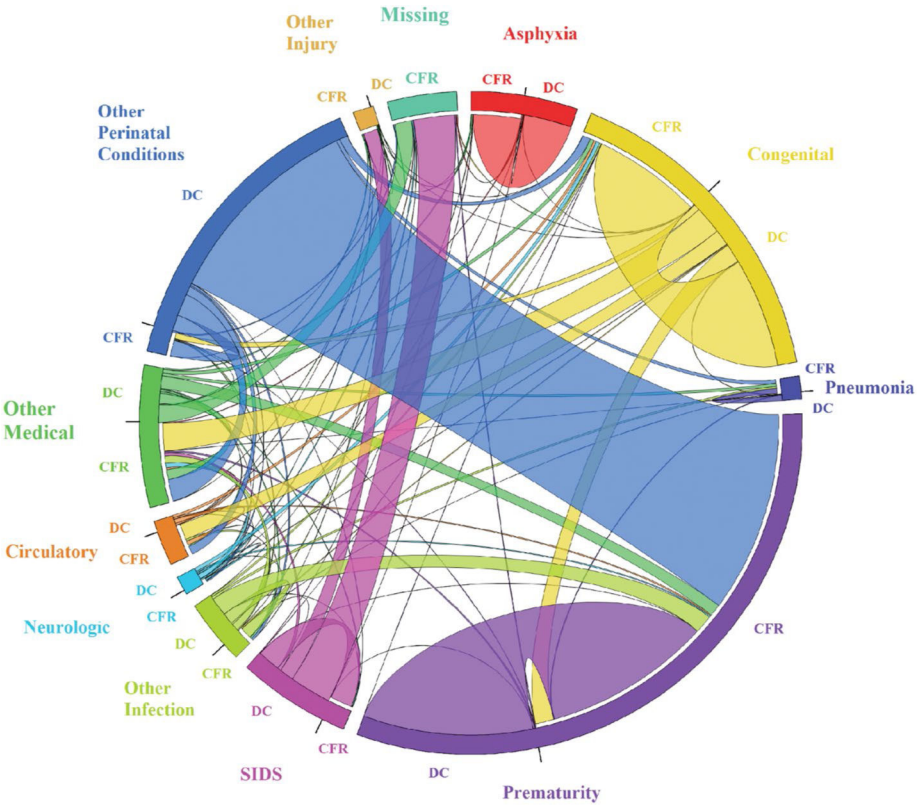

Fig. 2.

Concordance and discordance of infant cause of death categories, comparing death certificates (DC) and Ohio child fatality review (CFR), 2009–2013. For legibility, only categories with at least 50 deaths by either system are shown. Each ribbon connects the DC and CFR causes of death. Ribbon width is proportional to the number of infants represented. Ribbon color corresponds with DC category. Ribbons that stay within the same category (e.g. asphyxia) demonstrate higher concordance

Table 1

Demographic characteristics of 5030 deceased infants — Ohio, 2009–2013

	n	%
Age at death[a]		
Neonatal (0– < 28 days)	3430	68
Post-neonatal (28–365 days)	1597	32
Missing	3	0
Sex[a]		
Girls	2206	44
Boys	2820	56
Missing	4	0
Race and Ethnicity[a]		
Non-Hispanic white	2998	60
Non-Hispanic black	1690	34
Hispanic	205	4
Other non-Hispanic	61	1
Missing	44	1
County of residence size[b]		
Urban county	4143	82
Rural county	887	18
Missing	0	0
Gestational age[a]		
Early preterm (< 34 weeks)	2975	59
Late preterm (34–36 weeks)	417	8
Term (37–41 weeks)	1534	30
Postterm (> 41 weeks)	7	0
Missing	97	2

Source Ohio Department of Health, Office of Vital Statistics

[a]Age at death, sex, race and ethnicity were obtained from death certificates, and gestational age was obtained from birth certificates

[b]Urban defined as large central metro, large fringe metro, medium metro, or small metro according to 2013 NCHS urban–rural classification. Rural defined as micropolitan or noncore

Table 2

Infant cause of death categories by descending concordance between death certificates and Child Fatality Review in Ohio, 2009–2013[a]

Cause of death	Both	Death certificate only	Child fatality review only	Neither	Kappa
Drowning[a]	7	0	0	5023	1.00
Motor vehicle and other transportation[a]	15	0	1	5014	0.97
Asphyxia[a]	264	14	14	4738	0.95
Cancer	20	11	0	4999	0.78
Weapon, including body part[a]	32	1	17	4980	0.78
Poisoning, overdose or acute intoxication[a]	5	1	2	5022	0.77
Fire, burn, electrocution[a]	5	2	2	5021	0.71
Congenital anomaly	604	396	121	3909	0.64
Pneumonia	29	7	55	4939	0.48
Prematurity	932	19	1424	2655	0.40
Sudden infant death syndrome	124	332	10	4564	0.40
Other infection	61	184	33	4752	0.34
Malnutrition or dehydration	1	4	3	5022	0.22
Neurological or seizure disorder	9	66	15	4940	0.18
Circulatory	22	36	155	4817	0.17
Other medical condition	55	243	389	4343	0.08
Other perinatal condition	87	1390	45	3508	0.06
Other external injury[a]	4	32	89	4905	0.05
Low birth weight	0	10	8	5012	0.00

Categories with small numbers (< 5 infants) excluded: animal bite or attack, asthma, environmental exposure, fall or crush, HIV, and influenza

[a]Injury categories

Table 3

Assignment of ICD-10 underlying cause of death codes to child fatality review categories

Injury category	Child fatality review	ICD-10
1	Motor vehicle and other transport	V01-V99, X81, X82, Y03, Y32
2	Fire, burn, or electrocution	W85-W87, X00-X09, X33, X76, X77, X97, X98, Y26, Y27
3	Drowning	W65-W74, X71, X92, Y21
4	Asphyxia	W75-W84, X66, X67, X70, X88, X91, Y17, Y20
5	Weapon, including body part	W26, W32-W34, X72-X75, X78, X79, X93-X96, X99, Y00, Y04, Y05, Y08, Y09, Y22-Y25, Y28, Y29, Y35.0, Y35.3
6	Animal bite or attack	W53-W59, X20-X27, X29
7	Fall or crush	W00-W19, W23, X80, Y01, Y02, Y30, Y31
8	Poisoning, overdose or acute intoxication	X40-X49, X60-X65, X68, X69, X85, X87, X89, X90, Y10-Y16, Y18, Y19
9	Environmental exposure	W92, W93, W99, X30-X32
10	Other external injury	W20-W22, W24, W25, W27-W31, W35-W52, W60-W64, W88-W91, W94-W98, X10-X19, X28, X34-X39, X50-X59, X86, Y06-Y07, Y33, Y34, Y35.1, Y35.2, Y35.4, Y35.8, Y35.9, Y36, Y40-Y84
Medical category	**Child fatality review**	**ICD-10**
11	Asthma	J45-J46
12	Cancer	C00-C97, D00-D48
13	Cardiovascular	I00-I99 EXCEPT all of the following: I00-I02, I30.1, I32.0, I32.1, I33, I38, I40.0, I41.0- I41.2, I43.0, I52.0, I52.1, I60-I69, I98.0, I98.1
14	Congenital anomaly	Q00-Q99
15	HIV/AIDS	B20-B24
16	Influenza	J09-J11
17	Low birth weight	P07.0, P07.1
18	Malnutrition or dehydration	E40-E64, E86, E87
19	Neurological or seizure disorder	G04, G06-G12, G20-G72, G80-G93, G95-G98, I60-I69
20	Pneumonia	J12-J18
21	Prematurity	P07.2, P07.3
22	SIDS	R95
23	Other infection	A00-A09, A16-A33, A35-A99, B00-B19, B25-B99, G00, G03, I00-I02, I30.1, I32.0, I32.1, I33, I38, I40.0, I41.0-I41.2, I43.0, I52.0, I52.1, I98.0, I98.1, J00-J06, J20-J21, J40-J42, P35-P39
24	Other perinatal condition	P00-P05, P08, P10-P15, P20-P29, P50-P61, P70-P81, P83, P90-P96
25	Other medical condition	D50-D89, E00-E32, E34, E65-E85, E88, F01-F99, H00-H57, H60-H93, J22, J30-J39, J43-J44, J47-J98, K00-K38, K40-K46, K50-K92, L00-M99, N00-N15, N17-N23, N25-N95, R00-R53, R55-R94, R96-R99

SIDS sudden infant death syndrome

Table 4

Matrix of cause of death assignments, according to death certificates (rows) and child fatality review (columns) for 4873 infants in Ohio, 2009–2013

Death certificate	Child fatality review											
	Asphyxia	**Other external injury**	**Circulatory**	**Congenital**	**Neurologic**	**Pneumonia**	**Prematurity**	**SIDS**	**Other infection**	**Other perinatal condition**	**Other medical condition**	**Missing/ unknown/ undetermined**
Asphyxia	*264*	0	0	1	1	0	0	1	0	0	4	6
Other external injury	2	*4*	0	2	0	0	0	0	1	1	2	3
Circulatory	0	1	*22*	14	1	0	7	0	1	0	10	2
Congenital	0	1	87	*604*	3	5	103	0	5	32	154	4
Neurologic	0	2	2	20	*9*	0	7	0	2	1	26	6
Pneumonia	0	0	0	0	0	*29*	5	0	1	0	1	0
Prematurity	0	0	0	1	0	0	*932*	1	0	2	9	5
SIDS	2	79	0	1	0	0	1	*124*	1	0	18	230
Other infection	2	0	10	10	0	12	102	2	*61*	5	38	2
Other perinatal condition	1	0	47	46	7	20	1119	1	12	*87*	121	7
Other medical condition	6	6	9	21	2	16	69	5	10	3	*55*	94
Missing/ unknown/ undetermined	0	0	0	0	0	0	0	0	0	0	0	*0*

Categories with < 50 deaths by both methods are not shown

SIDS sudden infant death syndrome