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Epidemiology of Sudden Death in a Population-Based Study of Infants and Children

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Abstract

Objective—To describe epidemiologic data from the Sudden Death in the Young (SDY) Case Registry. Understanding the scope of SDY may optimize prevention efforts.

Study design—We analyzed sudden, unexpected deaths of infants (<365 days) and children (1–17 years) from a population-based registry of 8 states/jurisdictions in 2015 and 9 in 2016. Natural deaths and injury deaths from drowning, motor vehicle accident drivers, and infant suffocation were included; other injury deaths, homicide, suicide, intentional overdose, and terminal illness were excluded. Cases were categorized using a standardized algorithm. Descriptive statistics were used to characterize deaths, and mortality rates were calculated.

Results—Of 1319 cases identified, 92% had an autopsy. We removed incomplete cases, leaving 1132 analyzable deaths (889 infants, 243 children). The SDY rate for infants was 120/100 000 live

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births and for children was 1.9/100 000 children. *Explained Cardiac* rates were greater for infants (2.7/100 000 live births) than children (0.3/100 000 children). The pediatric *Sudden Unexpected Death in Epilepsy (SUDEP*) mortality rate was 0.2/100 000 live births and children. Blacks comprised 42% of infant and 43% of child deaths but only 23% of the population. In all ages, myocarditis/endocarditis was the most common *Explained Cardiac* cause; respiratory illness was the most common *Explained Other* cause. SDY occurred during activity in 13% of childhood cases.

Conclusions—Prevention strategies include optimizing identification and treatment of respiratory and cardiac diseases.

Understanding of sudden death in the young (SDY) in the US is hindered by a lack of standardized, systematic collection of epidemiologic data. Previous studies of sudden cardiac death in the young (SCDY) report wide ranges of mortality rates: 0.3 to 9.1/100 000 person-years internationally[1–11] and 0.7 to 10/100 000 person-years domestically.[12–18] Comparing these studies is challenging due to variable ages, inclusion criteria, and methodologies. Some studies include infants[8–11,14–17] and others exclude them[1–7,12,13] some include older ages, when coronary artery disease increases the rate of SCDY.[3,4,6,13,14] Some include trauma,[8,10] whereas others include resuscitated cardiac arrests.[8,9,14–17] Some are population-based,[7–11,15–18] whereas others use death certificates,[1–6,12,13] which may overestimate the SCDY rate due to errors in classification.[19] Notably, some studies presume that deaths without evidence of trauma or pathologic disease are due to arrhythmia.[6,9,12,14,17]

US data on pediatric sudden unexpected death in epilepsy (SUDEP) are limited,[20] with a reported rate of 0.11/100 000 population aged <20 years.[21] Sudden unexpected infant death (SUID), which includes unexplained infant deaths, sudden infant death syndrome (SIDS), and explained infant suffocations (also known as accidental suffocation and strangulation in bed), is better characterized, with a rate of 92/100 000 live births, but wide geographic variation: SUID rates range from 33/100 000 live births in Vermont to 202/100 000 live births in Alaska.[22] Genetic studies suggest that 4% of SIDS may be due to clinically actionable genetic cardiac causes.[23]

Improved understanding of the scope and causes of SDY may inform prevention strategies. The National Institutes of Health and the Centers for Disease Control and Prevention collaborated to address this epidemiologic knowledge gap by creating the SDY Case Registry.[24] This report describes sudden death mortality in the population-based SDY Case Registry of infants and children from multiple US states/jurisdictions in 2015 and 2016, characterizing these deaths by demographics, causes, and circumstances of death.

Methods

The SDY Case Registry methods have been published previously.[24] To summarize, the SDY Case Registry conducts population-based surveillance of SDY and facilitates research by compiling information and collecting biospecimens. The Registry attempts to identify all SDY cases from birth to 20 years among residents of multiple US states/jurisdictions, building on the methods, definitions, and protocols of the Centers for Disease Control and

Prevention's SUID Case Registry.[25,26] Cases are identified through Medical Examiner/Coroner systems in each state/jurisdiction. Detailed phenotyping is performed for cases of SCDY, unexplained infant and child death, and SUDEP, with more limited data gathered on other explained SDY cases. Data compilation began in 2015 in 9 states/jurisdictions, and an additional state started in 2016. Surveillance activities were classified as public health practice and did not require institutional review board approval. Registry activities involving biospecimen collection and consent of surviving family members for research were approved by the institutional review boards at the Data Coordinating Center and participating states/jurisdictions.

The Registry defines "sudden" as within 24 hours of the first symptom or death in the hospital after a resuscitated cardiac arrest and "unexpected" as death In someone who was believed to be in stable health or had an acute illness that would not be expected to cause death. Although some SCDY studies define "sudden" as within 1 hour from symptom onset, the SDY Case Registry uses a window of 24 hours due to the high number of pediatric deaths that occur during sleep and are often unwitnessed. Due to the rarity of sudden death in children, both witnessed and unwitnessed deaths are included in the Registry. Drowning and deaths of drivers in motor vehicle accidents are included because an arrhythmia or seizure could have precipitated the event, and infant suffocations are included as part of the definition of SUID; however, homicide, suicide, terminal illness, intentional overdose, and other obvious injury-related deaths are excluded. Acknowledging the variability in autopsy practices among states/jurisdictions, medical examiners and coroners are encouraged to use standardized autopsy guidance tools developed specifically for the Registry.[27] Cases undergo adjudication by state/local experts in a multidisciplinary Child Death Review[28,29] and an advanced clinically focused review, as well as central adjudication by SDY Case Registry staff. A case categorization algorithm[24] is used to promote standardization in the characterization of SDY in real-world settings and enable tracking of trends, and structured technical assistance promotes consistency across states/jurisdictions.

Cause-specific categories are divided into explained (*Infant Suffocation, Cardiac, Neurological*, and *Other)* and unexplained causes (*Possible Cardiac [only], SUDEP [only], Possible Cardiac/SUDEP, Unexplained Infant and Unexplained Child Deaths)*. Cases with insufficient data (eg, lack of autopsy, toxicology, or death scene investigation) are categorized as Incomplete Case Information and excluded from analysis. Cases that present as sudden and unexpected but are found during further investigation or review to be due to intentional overdose are excluded. All drownings and deaths of drivers in motor vehicle accidents are included and adjudicated, but if they are deemed after review to be truly accidental (without concern for underlying arrhythmia or seizure), they are also excluded from further analysis.

The standardized categorization algorithm dictates that *Explained Cardiac* and *Explained Neurological* cases have a definitive cause of death and an autopsy (or substantial medical evaluation for in-hospital deaths) to inform that determination. Cases categorized as *Possible Cardiac* do not have an apparent cause but have factors suspicious for a cardiac etiology, such as a family history of a heritable cardiac condition or sudden death before age 50 years, a personal history of cardiac disease, or clinical history suggestive of a cardiac cause, such

as death during exertion. In practice, review teams have chosen to categorize cases as *Possible Cardiac* if nonspecific cardiac findings were present at autopsy (eg, cardiomegaly). Suspected arrhythmia cases are categorized as *Possible Cardiac* only if they meet the aforementioned criteria; in the absence of *Possible Cardiac* criteria, cases without evidence of trauma or pathologic disease at autopsy are categorized as *Unexplained Infant* or *Unexplained Child* deaths.

SUDEP categorization requires a history of epilepsy, with or without evidence of seizure at the time of death (but excluding status epilepticus, which is categorized as *Explained Other). Possible Cardiac/SUDEP* cases meet *Possible Cardiac* criteria but also have a history of epilepsy. *Explained Infant Suffocation* categorization requires a complete and thorough death investigation, evidence of unsafe sleep factors, strong evidence of airway obstruction, appropriate developmental stage, and no other potentially fatal findings.

This analysis includes SDY cases among all residents 0–17 years of age in 8 states/jurisdictions in 2015 and 9 in 2016. Because age limits for each state/jurisdiction are mandated by Child Death Review statutes and only a few states/jurisdictions can review cases of those ≥18 years, this analysis was limited to cases involving those <18 years of age. The states were Delaware, Georgia, Minnesota, New Hampshire, Tennessee, and Nevada (2016 only); the jurisdictions were Virginia (Hampton, Newport News, Norfolk, and Virginia Beach Cities); Wisconsin (Fond du Lac, Forest, Kenosha, Milwaukee, Oneida, Racine, Vilas Waukesha, and Winnebago Counties); and California (San Francisco County). Data from New Jersey were excluded due to recurrent insufficient data collection.

Data from each case identified between January 1, 2015, and December 31, 2016, were used to calculate SDY category-specific mortality rates and describe the frequency and percentage of deaths by demographic characteristics, circumstances surrounding the death, medical and family histories, autopsy findings, and SDY category. Infants and children were analyzed separately, except for SUDEP cases, as described in the next paragraph. The authors grouped *Explained Other* cases by topic during analysis.

Category-specific mortality rates (per year) were calculated as the number of SDY deaths in 2015 and 2016 per 100 000 live births and child populations in 2015 and 2016 in participating states/jurisdictions. The infant population denominator was US live births; the child population denominator was derived from bridged race postcensal population estimates for children 1–17 years old. Due to the low frequency of infant SUDEP, infant and child SUDEP cases were considered together, and live birth and child populations were combined as the denominator to calculate a pediatric SUDEP mortality rate. The SUID mortality rate included *Unexplained Infant* and *Explained Infant Suffocation* cases. SIDS cases were captured within the *Unexplained Infant* category. To protect confidentiality, cells with fewer than 6 deaths were suppressed due to the Data Use Agreement with the National Center for Fatality Review and Prevention, which manages the Child Death Review database. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines were used for reporting.

Results

The population in participating states/jurisdictions during 2015 and 2016 included 743 741 live births (355 131 in 2015 and 388 610 in 2016) and 13 083 059 children aged 1–17 years (6 216 521 in 2015 and 6 866 538 in 2016),[30–32] representing 9% of the US pediatric population. The SDY Case Registry identified 1319 SDY cases in 2015 and 2016. Cases categorized as *Incomplete Case Information* (n = 122, 9%) and *Drownings or Motor Vehicle Accident Drivers* that were deemed after review to be truly accidental (n = 65, 5%) were omitted, leaving 1132 analyzable cases (889 infants, 243 children) (Figure 1). Sudden death mortality rates for all categories in the SDY Case Registry were greater for infants (120/100 000 live births) than children (1.9/100 000 children). The characteristics of the infants and children in the Registry are shown in Table I, and mortality rates are displayed in Table II.

Autopsy was performed in 92% (n = 1209) of identified cases, with more infants (98%) undergoing autopsy than children (74%). The reported reasons that autopsy was not performed were that the medical examiner/coroner declined the case (28%), the death occurred or was pronounced in the hospital (13%), chronic disease (13%), and family/religious objections (11%). There were no differences in the percentage of cases with autopsy by sex, race, or ethnicity (Table I). Unexplained (97%) cases had autopsies performed more often than explained (92%) cases. Autopsy completion was less common among cases categorized as *Explained Other* (82%) and *SUDEP* (69%). Among *Possible Cardiac* cases, autopsy was performed less often in those with a personal history of cardiac disease or arrhythmia (60%) than those with a positive family history (100%) or a clinical history suspicious for cardiac death (90%).

The mortality rate of infant SDY was 120/100 000 live births. Infant SDY was more common among males (56%, 130/100 000 live births) than females (44%, 108/100 000 live births). SDY disproportionately affected black infants (42%, 206/100 000 live births) compared with the black infant population in analyzed states/jurisdictions (23%). The median age of infant SDY was 94 days (range: 2–363 days), and cases peaked at 1 and 2 months of age (Figure 2, A). Most infant cases were unexplained (70%, 83/100 000 live births), with the majority categorized as *Unexplained Infant Death* (67%, 80/100 000 live births). The leading cause of explained infant SDY was *Explained Infant Suffocation* (22%, 26/100 000 live births). Taken together, 89% of infant SDY cases would be considered SUID (106/100 000 live births). The SUID mortality rate varied widely from 39 to 161/100 000 live births among analyzed states/jurisdictions. Other less common causes of infant SDY were *Explained Other* (6%, 6.9/100 000 live births) (primarily *Respiratory* [69% of infant *Explained Other* cases, 4.7/100 000 live births]), *Possible Cardiac* (3%, 3.1/100 000 live births), and *Explained Cardiac* (2%, 2.7/100 000 live births). In infants, 95% of SDYs occurred during sleep (114/100 000 live births).

The rate of SDY among children was 1.9/100 000 children (range 1.1–7/100 000 by age group; Table II). In children, SDY was also more common among males (58%, 2.1/100 000 children) than females (40%, 1.5/100 000 children). Among the 2- to 5-year-old and 14- to 17-year-old age groups, SDY frequency was notably greater in males than in females (66% −67%) as compared with the 1-year-old (54%), 6- to 9-year-old (42%), and 10- to 13-year-

old age groups (53%). As in infants, a greater proportion of black children experienced SDY (43%, 3.2/100 000 children) than the population distribution of black children in analyzed states/jurisdictions (23%). The median age of SDY in children was 8 years, 9 months (range 1.03–17.9 years). SDY was least common between 6- and 9-year-old children (1.1/100 000 children) and most common at age 1 year (7/100 000 children) and between 14 and 17 years (2.4/100 000 children) (Figure 2, B). Unlike infant SDY, childhood SDY was more commonly explained (57%, 1.1/100 000 children) than unexplained (43%, 0.8/100 000 children). *Explained Other* deaths were the most common category in children (37%, 0.7/100 000 children), particularly respiratory causes (50% of childhood *Explained Other* deaths, 0.3/100 000 children). Cardiac deaths were more prominent among children than infants, with *Explained Cardiac* cases making up 2% of infant SDY and 16% of childhood SDY. Unexplained childhood SDY cases were divided nearly evenly between the categories of *Unexplained Child* death (14%, 0.3/100 000 children), and *Possible Cardiac* (13%, 0.2/100 000 children). The majority of SDY cases in children occurred during nonexertional activities: 44% (0.8/100 000 children) during sleep/rest, and 21% (0.4/100 000 children) during other nonexertional activities (eg, bathing, riding in a vehicle, eating, receiving medical treatment, voiding, etc). SDY occurred during exertion in 13% (0.2/100 000 children) of childhood cases, and in one-quarter of all *Explained Cardiac* (n = 9, 24%) and *Possible Cardiac plus Possible Cardiac/SUDEP* (n = 11, 28%) cases. Exertional SDY was most common among those between 14 and 17 years of age (n = 19, 61%, 0.6/100 000 children).

In all ages, *Explained Cardiac* causes included myocarditis/endocarditis (45%), congenital heart disease (CHD) (17%), other cardiomyopathy (14%), hypertrophic cardiomyopathy (12%), and coronary artery anomalies (12%). The types of CHD included single ventricle anomalies, coarctation of the aorta, and tetralogy of Fallot. *Explained Cardiac* mortality rates were greater in infants (2.7/100 000 live births) than children (0.3/100 000 children). The frequency of *Explained and Possible Cardiac* cases was highest among the 14- to 17-year-old age group (44%) compared with other age groups and was greater in males than females (76% vs 24%). Although, 31 (3%) infants and children had a known cardiac diagnosis before death, in only 8 cases was the cardiac disease deemed significant enough to result in categorization as *Explained Cardiac* (eg, CHD, coronary anomaly, myocarditis, and another cardiomyopathy). All diagnoses of hypertrophic cardiomyopathy were identified post-mortem. In all ages, the most common *Possible Cardiac* criteria were personal history of cardiac disease/arrhythmia (32%) and family history of a heritable cardiac condition/ premature sudden death (21%).

The most common *Explained Other* cause overall was respiratory illness (n = 80; 57% *of Explained Other* deaths, 0.6/100 000 infants and children). Of those, 29% were attributed to asthma (0.2/100 000 infants and children), 83% of whom had a known diagnosis before death. Rarer causes of SDY categorized as *Explained Other* included infectious disease, hematological, and gastrointestinal conditions (Figure 3). Although *Explained Other* cases made up a much smaller proportion of infant SDY, mortality rates for *Explained Other* cases were still greater in infants (6.9/100 000 live births) than children (0.7/100 000 children). *Explained Neurological* cases were rare (n = 16, 1% of SDY cases in all ages).

The category of *SUDEP* was assigned to 32 (3%) SDY cases. An additional 9 (1%) cases were categorized as *Possible Cardiac/SUDEP*. Two-thirds of cases categorized as *SUDEP* occurred in those younger than 14 years of age. Most *SUDEP* cases occurred during sleep/rest (72%) and were not witnessed. The mortality rate of pediatric *SUDEP* was 0.2/100 000 live births and children.

Discussion

The epidemiologic data from the SDY Case Registry confirms the findings of previous studies, including great death rates among the youngest children,[14,33,34] increased SDY frequency among males[12–15,34,35] and blacks,[13,33,36] and a high proportion of unexplained cases.[2,34,35] However, this study builds on these previous findings by leveraging the SDY Case Registry's unique strengths.

Our analysis identified high-risk groups and etiologies that could be targeted to enhance prevention efforts. We found that 95% of infant deaths occurred during sleep and that SDY disproportionately affected black infants (206/100 000 live births). Public health outreach already focuses on infant's safe sleep campaigns, and efforts to reduce health disparities include developing culturally appropriate prevention tools and fostering partnerships with African American communities to enhance safe sleep outreach.[37,38] Phenotypic data from the SDY Case Registry could be used to explore additional risk factors among these high-risk groups to further optimize outreach efforts.

CHD represents another prevention target. It was a notable cause of *Explained Cardiac* SDY in our study as well as in the US death certificate study from 1999 to 2015 by El Assaad et al.[13] Newborn screening policies in the US for critical CHD (life-threatening heart defects present at birth that require intervention in the first year of life) have shown promise by resulting in a significant decline in infant critical CHD deaths between 2007 (11.1/100 000 live births) and 2013 (8/100 000 live births) after implementation of mandatory CCHD screening policies.[39] With widespread adoption of newborn critical CHD screening, optimization of the screening algorithm, and improvement of data collection and reporting, perhaps this rate could be decreased further. We also noted high rates of SDY due to respiratory illness, with 29% of those cases due to asthma (0.2/100 000 infants and children). The rates of pediatric asthma deaths in our study are comparable with those reported previously in the US (0.28/100 000 children).[40] Many of these deaths were likely preventable. Increasing education on recognition of asthma exacerbations and optimizing access to care and treatment represent additional modifiable targets for SDY prevention strategies.

A high proportion of our SDY cases had an autopsy (98% infants, 74% children). This rate is much greater than the 26%−40% rate of pediatric autopsies noted in some studies.[41,42] We noted lower autopsy rates for cases of *SUDEP* and *Possible Cardiac* cases with a personal history of cardiac disease or arrhythmia. Moreover, chronic illness was one of the reported reasons that autopsy was not performed in children. These factors suggest a tendency to attribute the cause of death to a pre-existing condition, which may or may not always be true. The importance of autopsy was highlighted in the study by Tseng et al in which

approximately one-half of the deaths attributed to adult cardiac arrest were found after autopsy to have nonarrhythmic causes.[43] Autopsy rates in our population may have been increased due to engagement with medical examiners and coroners in states/jurisdictions with the organizational capacity and institutional commitment to exploring SDY. In addition, the Registry's efforts to provide nominal financial support to under-resourced medical examiner and coroner offices and develop and disseminate tools and guidance[27] through the SDY Case Registry infrastructure may have contributed to the higher autopsy rates in our study.

Despite high rates of autopsy, we report a significant proportion of *Unexplained* cases (64%), similar to reports from Ontario (52%) and Australia/New Zealand (40%).[35] This high proportion of unexplained cases suggests that not only are we incompletely identifying known causes of SDY pre-and post-mortem (eg, genetic arrhythmia syndromes), but we also need to explore novel SDY mechanisms. To decrease the number of unexplained SDY cases further, research will need to parse out mechanistic differences in the causes of death between some subgroups identified in our population.

Our SDY mortality rate in children (1.9/100 000 children) is comparable with that reported by Chugh et al (1.7–3/100 000 children aged 1–14 years) in the prospective population-based Oregon SUDS cohort study.[16] But our rate cardiac SDY (0.3/100 000 children) is lower than that reported by El Assaad et al (0.42–0.52/100 000 children, 1–18 years) using US death certificates[13] and by Atkins et al and the Resuscitation Outcomes Consortium Epistry (3.76.4/100 000 children aged 1–19 years—including 9% cardiac arrest survivors).[15] In other studies, cases without an identifiable cause at autopsy were attributed to arrhythmia and included in the calculation of mortality rate.[6,9,12,14,17] The SDY Case Registry does not assume that SDY cases without evidence of trauma or pathologic disease at autopsy are due to arrhythmia, instead categorizing them as *Possible Cardiac* only if there is an accompanying factor suspicious for a cardiac cause. This approach results in lower mortality rates of SCDY reported in our study. By analyzing the phenotypic and genotypic data in the SDY Case Registry, future studies will explore in depth how many of the unexplained cases are truly due to arrhythmias, allowing for more reliable characterization of the arrhythmic SDY population. This conservative approach also prevents misguided application of targeted prevention strategies to a population that is not yet well defined. Genetic analyses and functional studies are ongoing for consented cases and will be the focus of a future analysis.

Although we demonstrated a similar proportion of infant deaths and used the same categorization algorithm as the SUID Case Registry, our SUID rate (106/100 000 live births), and our *Explained Infant Suffocation* rate in particular (26/100 000 live births), is greater than previously reported (SUID: 92/100 000 live births, *Explained Infant Suffocation*: 23/100 000 live births).[22,26] The range of SUID incidence rates by state/jurisdiction in our study varied from 39 to 161/100 000 live births, reflecting previously described geographic differences.[22] Accordingly, our SUID mortality rate was impacted by high rates in a few states/jurisdictions and the different geographic makeup of our states/jurisdictions compared with previous studies.[26] Such geographic variation underscores the importance of including multiple large catchment areas when studying low frequency events like SDY.

We noted greater rates of pediatric SUDEP than have been reported previously (0.2/100 000 infants and children vs 0.11/100 000 population aged <20 years).[21,44,45] This suggests that the use of population-based surveillance is an effective mechanism to identify SUDEP cases. The requirement that the state/local advanced clinical review teams include a neurologist may have helped to raise awareness of SUDEP as a possible cause of death in children.

SDY occurred with exertion in 13% of childhood cases. In previous reports, low rates of exertional SDY were noted in Pennsylvania (22%),[33] Washington State (24%),[14] and Australia/New Zealand (15%),[35] but not as low as those observed in our Registry. Although exercise has been described as a trigger for sudden death, only 1 in 8 SDY cases in our study occurred during exertion. However, the frequency of exertional SDY was noted to be higher among cases categorized as *Explained Cardiac* (24%), suggesting increased risk among children with heart disease. When considering exercise restriction, balancing the risk of obesity and cardio-metabolic disease with the risk of SDY is challenging. Future research is necessary to clarify the appropriate balance to mitigate risks and inform exercise prescription for children with known heart disease.

This analysis is subject to some limitations. The amount of missing data varied among states/jurisdictions despite monitoring, technical assistance, and feedback. Although the population analyzed was large and geographically diverse, it does not represent the diversity of the US population. Some SDY cases may have been missed (eg, hospital deaths). Adjudication of SDY category was subjective, though reviewers used standardized classification criteria to mitigate this. Despite recommending use of a standardized autopsy guidance tools, autopsy rates varied, and fewer autopsies were performed on children than infants, limiting the amount of data available on childhood SDYs. The quality of family history data on each case was variable and was not as comprehensive as would be gathered in a clinical encounter. Similarly, the *Possible Cardiac* criterion of “Family history of sudden death before age 50” is admittedly crude, but the Registry aims to be more inclusive and relies on the adjudication process to judge the likelihood of family history in influencing categorization of a case as *Possible Cardiac*. Data are not captured on survivors of resuscitated cardiac arrest, which limits our ability to understand resilience. Finally, some cells had small numbers, limiting our ability to draw conclusions and report on rarer causes of SDY.

Prevention strategies can be enhanced among high-risk groups (males, infants, and blacks) and target specific causes (respiratory and congenital heart diseases) by optimizing current strategies and exploring novel approaches. Future research using SDY Case Registry data may identify additional risk factors to inform prevention strategies. Finally, the SDY Case Registry methodology provides a model of a standard taxonomy for real-world application to facilitate comparisons among studies.

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Glossary

CHD	Congenital heart disease
SCDY	Sudden cardiac death in the young
SDY	Sudden death in the young
SIDS	Sudden infant death syndrome
SUDEP	Sudden unexpected death in epilepsy
SUID	Sudden unexpected infant death

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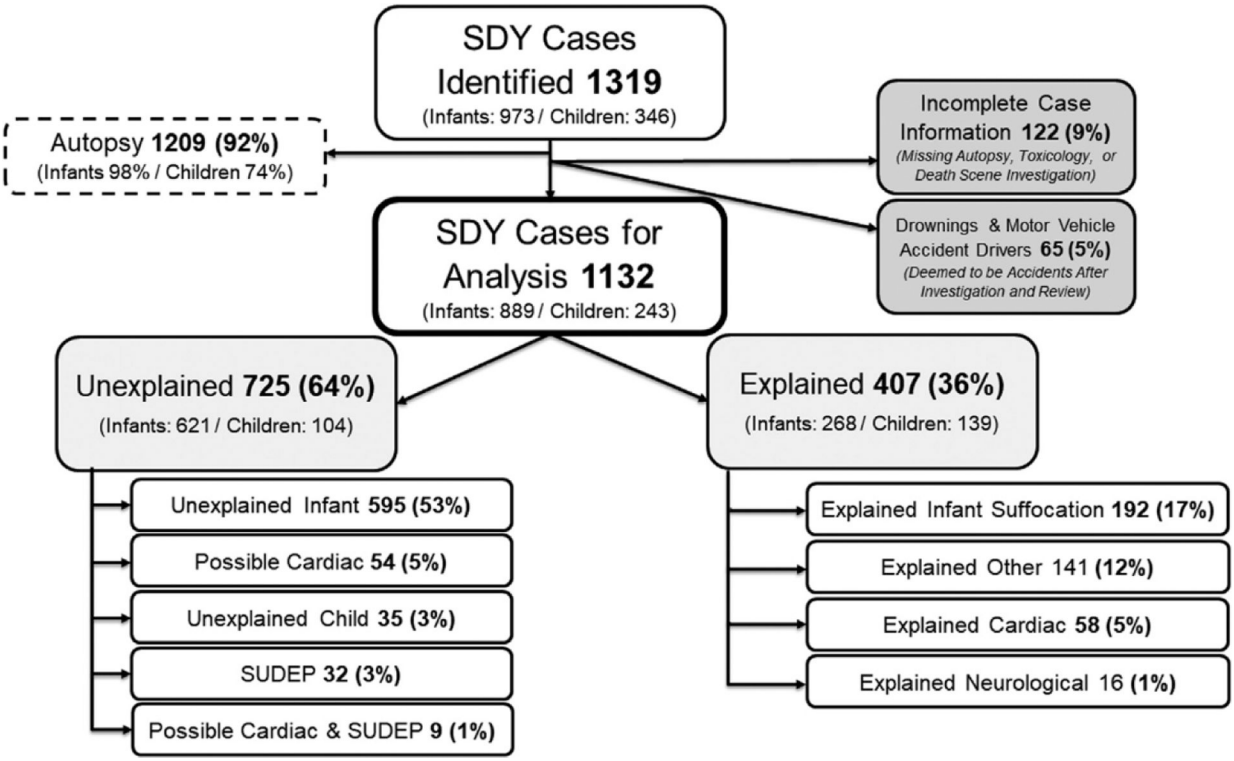

Figure 1.

Flow chart of SDY cases and cause-specific categories, SDY Case Registry, 2015–2016. The SDY Case Registry identified 1319 cases and analyzed 1132 of them. Autopsy rates were high. Most cases were unexplained.

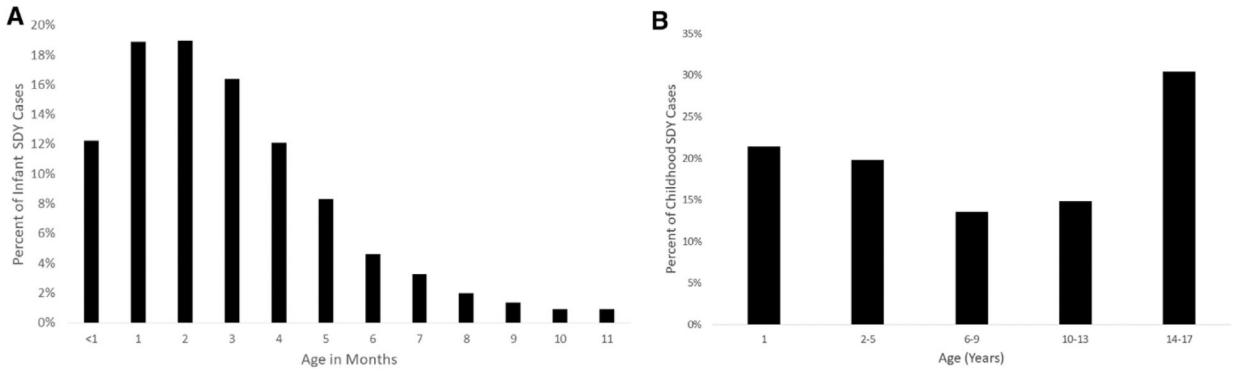

Figure 2.

A, Percentage of SDY cases by age at death, infants (n = 889), SDY Case Registry, 2015–2016. Infant SDY cases peaked at 1 and 2 months of age and tapered thereafter. **B**, Percentage of SDY cases by age at death, children (n = 243), SDY Case Registry, 2015–2016. Childhood SDY was lowest among children 6–9 years of age and greatest in 14- to 17-year-old children.

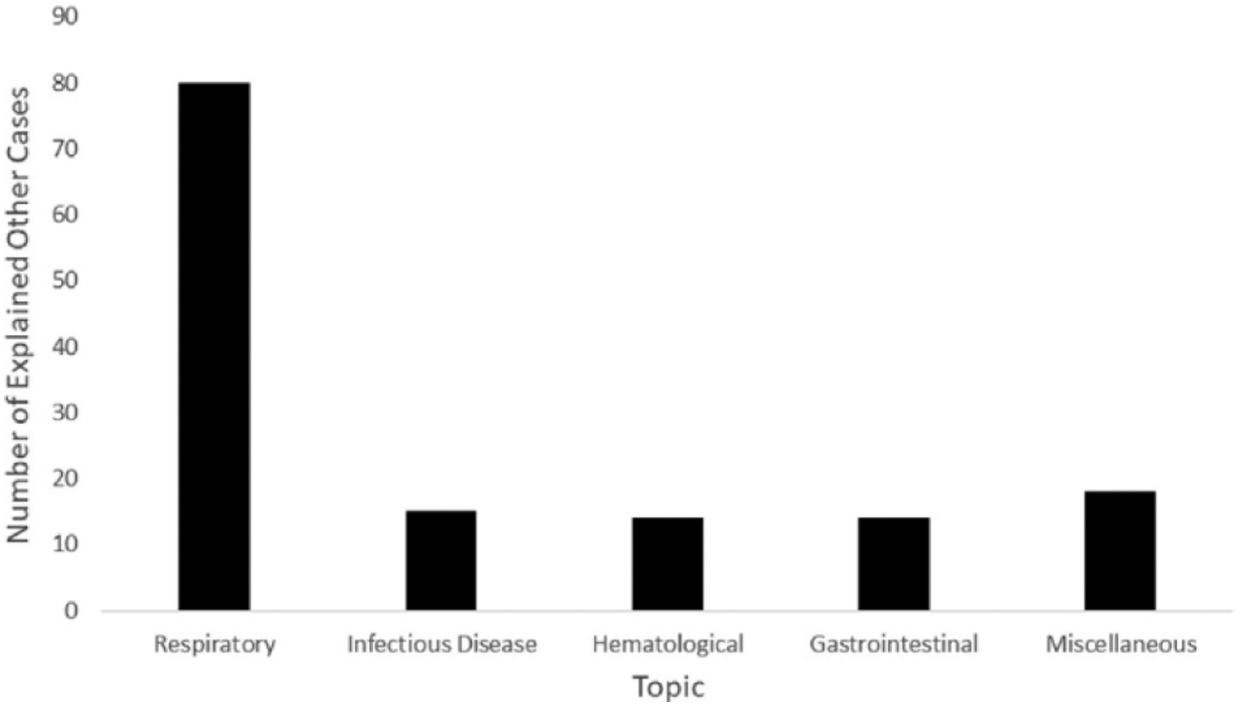

Figure 3.

Number of infant and child *Explained Other* deaths by topic (n = 141), SDY Case Registry, 2015–2016. Respiratory illnesses caused most *Explained Other* cases of SDY among infants and children.

Table I.

Characteristics of infants and children in the SDY case registry, 2015–2016

Characteristics	Infants (<365 d old) n (%)	Children (1–17 y old) n (%)	Overall (0–17 y old) n (%)	Autopsy (0–17 y old) n (%)
SDY cases identified	975 (74)	344 (26)	1319	1209 (92)
Incomplete case information	85 (9)	37 (11)	122 (9)	76 (62)
Drowning *	†	†	46 (13)	38 (83)
Motor vehicle accident driver *	‡	19 (12)	19 (6)	13 (68)
SDY cases analyzed	889 (79)	243 (21)	1132	1082 (96)
Characteristics				
Sex				
Male	494 (56)	142 (58)	636 (56)	609 (96)
Female	394 (44)	98 (40)	492 (43)	470 (96)
Unknown/missing	†	†	†	†
Race				
White	445 (50)	119 (49)	564 (50)	537 (95)
Black	377 (42)	104 (43)	481 (42)	464 (96)
Other/multiracial	55 (6)	16 (7)	71 (6)	66 (93)
Unknown/missing	†	†	16 (1)	15 (94)
Ethnicity				
Hispanic/Latino	65 (7)	23 (9)	88 (8)	82 (93)
Not Hispanic/Latino	810 (91)	215 (88)	1025 (91)	981 (96)
Unknown/missing	†	†	19 (2)	19 (100)
Age				
<30d	109 (12)	‡	109 (10)	109 (100)
1 mo	168 (19)	‡	168 (15)	168 (100)
2 mo	169 (19)	‡	169 (15)	169 (100)
3 mo	146 (16)	‡	146 (13)	145 (99)
4 mo	108 (12)	‡	108 (10)	108 (100)
5 mo	74 (8)	‡	74 (7)	73 (99)
6 mo	41 (5)	‡	41 (4)	41 (100)

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Characteristics	Infants (<365 d old) n (%)	Children (1–17 y old) n (%)	Overall (0–17 y old) n (%)	Autopsy (0–17 y old) n (%)
7 mo	29 (3)	‡	29 (3)	28 (97)
8–11 mo	45 (5)	‡	45 (4)	44 (98)
1 y	‡	52 (21)	52 (5)	48 (92)
2–5 y	‡	48 (20)	48 (4)	33 (69)
6–9 y	‡	33 (14)	33 (3)	25 (76)
10–13 y	‡	36 (15)	36 (3)	28 (78)
14–17 y	‡	74 (30)	74 (7)	63 (85)
Categories				
Explained	268 (30)	139 (57)	407 (36)	376 (92)
Unexplained	621 (70)	104 (43)	725 (64)	706 (97)
Explained categories				
Infant suffocation	192(22)	‡	192 (17)	192 (100)
Neurologic	†	†	16 (1)	12(75)
Cardiac	20 (2)	38 (16)	58 (5)	57 (98)
Myocarditis/endocarditis	7 (35)	19 (50)	26 (45)	26 (100)
Congenital heart disease	†	†	10 (17)	9 (90)
Other cardiomyopathy[§]	†	†	8 (14)	8 (100)
Hypertrophic cardiomyopathy	†	†	7 (12)	7 (100)
Coronary artery anomalies	†	†	7 (12)	7 (100)
Other	51 (6)	90 (37)	141 (12)	115 (82)
Respiratory	35 (69)	45 (50)	80 (57)	69 (86)
Asthma	†	†	23 (29%)	17 (74)
Infectious disease	†	†	15 (11)	12 (80)
Hematologic	†	†	14 (10)	8 (57)
Gastrointestinal	†	†	14 (10)	11 (79)
Miscellaneous	6 (12)	12 (13)	18 (13)	15 (88)
Unexplained categories				
Possible cardiac	23 (3)	31 (13)	54 (5)	46 (85)
SUDEP	†	†	32 (3)	22 (69)
Possible cardiac/SUDEP	†	†	9 (1)	8 (89)

Characteristics	Infants (<365 d old) n (%)	Children (1–17 y old) n (%)	Overall (0–17 y old) n (%)	Autopsy (0–17 y old) n (%)
Unexplained infant/child	595 (67)	35 (14)	630 (56)	630 (100)
Possible cardiac criteria (n = 63)				
Personal history of cardiac disease or arrhythmia	†	†	20 (32)	12 (60)
Family history of heritable cardiac condition or sudden death <50 years	†	†	13 (21)	13 (100)
Nonspecific autopsy findings	†	†	12 (19)	12 (100)
Suspicious clinical history	†	†	10 (16)	9 (90)
Multiple criteria	†	†	8 (13)	8 (100)
Activity				
Sleeping/resting	848 (95)	106 (44)	954 (84)	942 (99)
Playing/exercise	‡	31 (13)		26 (84)
Explained cardiac,	‡	9 (24)		19 (95)
possible cardiac and possible cardiac/SUDEP	‡	11 (28)		
Other nonexertional activities[¶]	27 (3)	50 (21)	77 (7)	56 (73)
Unknown	12 (1)	56 (23)	68 (6)	50 (74)

[*] Drownings and deaths of drivers in motor vehicle accidents that were deemed after investigation and review to be accidental, without suspicion of an underlying cardiac or neurological trigger, were excluded from all analyses.

[†] To protect confidentiality, cells with fewer than 6 data points were suppressed, and some cells were suppressed to protect confidentiality of neighboring cells.

[‡] Not applicable.

[§] Other cardiomyopathy: arrhythmogenic cardiomyopathy, dilated cardiomyopathy, left ventricular noncompaction, or restrictive cardiomyopathy.

[¶] Other nonexertional activities: bathing, riding in a vehicle, eating, receiving medical treatment, voiding, etc.

Table II.

Rates of SDY among infants and children the SDY Case Registry, 2015–2016

Characteristics	Infant Deaths (<365 d old) Per 100 000 live births	Childhood Deaths (1–17 y old) Per 100 000 children
SDY cases analyzed	120	1.9
Characteristics		
Sex		
Male	130	2.1
Female	108	1.5
Race		
White	88	1.3
Black	206	3.2
Other/multiracial	105	1.9
Ethnicity		
Hispanic/Latino	70	1.3
Not Hispanic/Latino	125	1.9
Age		
<1 y	120	*
1 y	*	7
2–5 y	*	1.6
6–9 y	*	1.1
10–13 y	*	1.2
14–17 y	*	2.4
Categories		
Explained	36	1.1
Unexplained	83	0.8
SUID†	106	*
Explained categories		
Infant suffocation	26	*
Cardiac	2.7	0.3
Other	6.9	0.7
Respiratory	4.7	0.3
Unexplained categories		
Possible cardiac	3.1	0.2
Unexplained infant/child	80	0.3
SUDEP‡	0.2/100 000 live births and children	
Activity		
Sleeping/resting	114	0.8
Playing/exercise	*	0.2
Other nonexertional activities§	3.6	0.4

*Not applicable.

[†]The SUID mortality rate included *Unexplained Infant* and *Explained Infant Suffocation* cases. SIDS cases were captured within the *Unexplained Infant* category.

[‡]Due to the low frequency of infant SUDEP, infant and child SUDEP cases were considered together, and live birth and child populations were combined as the denominator to calculate a pediatric SUDEP mortality rate.

[§]Other nonexertional activities: battling, riding in a vehicle, eating, receiving medical treatment, voiding, etc.