The Sudden Unexpected Infant Death Case Registry: A Method to Improve Surveillance

abstract

This article describes a multistate population-based surveillance system for monitoring sudden unexpected infant deaths (SUIDs) known as the SUID Case Registry pilot program. The pilot program represents collaboration between the Centers for Disease Control and Prevention and the National Center for Child Death Review (NCCDR), which is funded by the Health Resources and Services Administration. The SUID Case Registry builds on existing child death review system activities and protocols. The objectives of the SUID Case Registry are to collect accurate and consistent population-based data about the circumstances and events associated with SUID cases, to improve the completeness and quality of SUID case investigations, and to use a decision-making algorithm with standardized definitions to categorize SUID cases. States who participate in the pilot program commit to review all SUID cases in their state by using their multidisciplinary state and local child death review teams. These teams request and review data from death scene investigators, medical examiners and coroners, law enforcement, social services, pediatric and obstetric providers, and public health per usual, but as part of the pilot program, supplement their SUID case reviews by discussing additional medical, environmental, and behavioral factors, and entering this data using the NCCDR Web-based Case Reporting System. This new surveillance system aims to improve knowledge of factors surrounding SUID events and improve investigation practices. The surveillance system will allow researchers and program planners to create prevention strategies and interventions, ultimately reducing SUIDs and injury-related infant deaths. *Pediatrics* 2012;129:e486–e493

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KEY WORDS

SIDS, SUID, child death review, surveillance, infant mortality, infant injury

ABBREVIATIONS

CDC—Centers for Disease Control and Prevention
CDR—Child Death Review
NCCDR—National Center for Child Death Review
NVDRS—National Violent Death Reporting System
SIDS—sudden infant death syndrome
SUID—sudden unexpected infant death
SUID-CR—Sudden Unexpected Infant Death Case Registry

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INTRODUCTION

Recently, attention has focused on three particular causes of sudden unexpected infant death (SUID): sudden infant death syndrome (SIDS), unknown cause, and accidental suffocation and strangulation in bed. We define SUID as the death of a previously healthy infant <365 days old without an obvious cause before a medicolegal investigation. These SUIDs accounted for about 4000 US infant deaths in 2007, with 2323 classified on US death certificates as SIDS, 1058 as unknown causes, and 588 as accidental suffocation or strangulation in a sleep environment.[1] Determination of the cause of SUID can vary on the basis of available scene investigation evidence and the diagnostic practices of certifiers.[2,3] Many SUIDs are associated with unsafe sleep environments. To accurately determine the cause of death for SUID, the medical examiner or coroner needs a thorough scene investigation, detailed clinical history, and autopsy findings.[4] Several pathologic markers have been proposed, but currently no reliable marker exists at autopsy to distinguish a suffocation death from SIDS.[2]

Although SIDS declined by ~50% during the 1990s, a less dramatic decline has been observed in recent years.[5–7] This less dramatic decline is likely explained by increasing rates of infant deaths classified as "accidental suffocation" and "unknown cause."[5] Certifiers appear to be moving away from attributing the cause of death to SIDS and favoring other determinations, such as "unknown cause" and "accidental suffocation."[6] Reasons for this diagnostic shift are unknown, but may be a result of stricter adherence to SIDS definitions, improved availability of death scene investigation data, and influence from local and child death review teams.[4,6] With increased attention on sleep-related suffocation deaths that are potentially preventable, accurate and reliable surveillance estimates that are based on standardized reporting and classification practices are essential for accurate and consistent monitoring of SUID trends and are critical for developing effective prevention messages and other interventions.

Currently, vital statistics data are the primary source for monitoring US trends and characterizing circumstances surrounding SIDS and other SUIDs. However, death certificates are limited in their ability to fully describe the circumstances surrounding SUID events, and thus cannot provide sufficient data to inform policy and program decisions.[6,8] The new SUID Case Registry (SUID-CR) complements surveillance of SUID using death certificates by providing more detailed data about case investigation findings so that the medical, environmental, and behavioral factors associated with SUID can be described in greater detail. These additional descriptive data will allow the application of standardized definitions developed especially for the new SUID-CR to categorize SUID cases. This categorization system groups SUID cases that have similar characteristics. Grouping injury-related SUID cases can guide prevention activities. For example, if a number of suffocation deaths that have resulted from hazards in the sleep environment are identified by using the SUID-CR categories, Child Death Review (CDR) teams and other program planners can use this new information to improve their injury prevention messages, especially those aimed at promoting safe sleep. The SUID-CR will also categorize deaths by availability of investigation data, which is needed to quantify the number of unexplained infant deaths in which a case investigation is missing or incomplete. This new knowledge can be used to focus efforts aimed at improving the thoroughness of SUID case investigations.

METHODS

SUID-CR Objectives

The objectives of the SUID-CR are to collect accurate and consistent population-based data about the circumstances and events surrounding SUID cases, to improve the completeness and quality of SUID case investigations, and to categorize SUID cases by the use of a decision-making algorithm with standardized definitions. This categorization system will not only allow improved monitoring of SUID trends, but will also assist program planners and policy makers with identifying targeted strategies to reduce potentially preventable infant deaths.

CDR and the SUID-CR

To assess the practicality of collecting more detailed medical history, scene investigation and autopsy data for SUID cases, the Centers for Disease Control and Prevention (CDC) conducted a feasibility study during 2007 and 2008. Seven states that were already contributing to the National Violent Death Reporting System (NVDRS) participated. The NVDRS collects data on violent deaths from a variety of sources, including death certificates, police reports, medical examiner and coroner reports, and crime laboratories.[9] Many of these sources would be essential to a SUID surveillance system. For the feasibility study, state NVDRS coordinators identified SUID cases and used CDC's Sudden Unexplained Infant Death Investigation Reporting Form to abstract extant data from medical examiner and coroner reports from 2005 to 2006 that were available to NVDRS and considered critical for SUID case investigations.[10] Although the study found that the collection of detailed SUID investigation data were valued by state program and policy makers, efforts to identify and abstract data on nonviolent infant deaths were too labor intensive for the NVDRS system. Stakeholders

suggested that CDR teams might be a more suitable system for gathering this information. With the use of multidisciplinary teams, the CDR system already identifies and reviews SUID cases through collaborations with medical examiners and coroners, law enforcement, as well as social services and public health representatives. This collaboration allows CDR teams to access medical examiner and coroner reports that a comprehensive SUID surveillance system would require. The use of the CDR system for SUID surveillance would prevent the duplication of efforts and provide data for population-based SUID surveillance. In addition, enhancing the CDR system could improve the quality and comprehensiveness of collected SUID data and improve team activities aimed at SUID prevention.

In response to the feasibility study, CDC convened 2 national meetings with experts to collect ideas and suggestions for developing a national SUID surveillance system. In March and July 2008, experts in medicolegal death investigation, injury surveillance, SUID and injury prevention, epidemiology, and pediatrics met in Atlanta, Georgia. The first meeting focused on developing a program model that addressed information flow and organizational structure. The second meeting identified specific questions that SUID surveillance could answer, such as determining the extent to which unsafe sleep environments play a role in infant deaths. After these meetings, CDC identified the National Center for Child Death Review (NCCDR), which is funded by the Health Resources and Services Administration, and the NCCDR's Web-based data collection tool, the Case Reporting System, as the most efficient system to integrate SUID-specific variables for SUID surveillance. This new surveillance system is now referred to as the SUID-CR. The name is based on preferences voiced by parents who experienced the loss of an infant from SIDS.

Building on and Enhancing CDR

The purpose of the CDR process is to conduct a comprehensive, multidisciplinary review of infant and child deaths; to better understand how and why children die; and to use the findings to take action to prevent future deaths, thereby improving the health and safety of all children.[11,12] State-mandated or -enabled CDR teams currently function in 49 states, all of which already review sudden infant deaths, such as SIDS, as part of their review process. Thirty-seven of the states have local review teams, whereas 12 states review deaths only at the state level.[13] State and local teams in 39 states were using the NCCDR Web-based Case Reporting System on a voluntary basis as of December 2011.[14]

Through a competitive CDC proposal process, 13 states expressed interest in a SUID-CR system by submitting a proposal to participate in the pilot program. An objective review committee at CDC scored state proposals based on an ability to demonstrate timely identification, notification and review of SUID cases, and evidence of access to medical examiner and coroner records including reports from autopsies, death scene investigations, first responders, law enforcement, social services, and public health and medical providers. The committee also considered the annual number of SUID cases expected in the state and representation of racially, ethnically, and geographically diverse populations. To maintain uniformity in data-reviewing and -entry procedures, the states in the pilot program have agreed to follow NCCDR and CDC SUID-CR protocols. CDC awarded funding to 5 states—Colorado, Georgia, Michigan, New Jersey, and New Mexico—in August 2009. State public health personnel implement child death review based on state mandates and may include teams that are state-only, regional or county, or a combination of these types. CDC expects that the funded states will collect information on >530 SUID cases per year, ranging from 30 cases in New Mexico to 200 cases in Georgia.

Funded states received specialized training at CDC to learn about the program model and SUID-specific variable definitions and data sources. The grantees conducted their own state and local trainings for their respective child death review teams. During the first year of the pilot program, each state received a 2 to 3 days on-site, one-on-one technical assistance from a 2-person team consisting of a CDC and a NCCDR representative that included an observation of a SUID review followed by feedback. Monthly conference calls provide an opportunity for the states to discuss barriers to data collection, provide progress updates, and share strategies. Grantees keep communication logs to document any difficulties encountered by local, regional, or state teams. Also, grantees identified their first year strengths and challenges during a technical assistance meeting at CDC. At the CDC meeting, grantees worked with CDC and other SIDS and SUID experts to develop plans for improvement.

The SUID-CR Pilot Program

Before the SUID-CR was implemented, state CDR teams reviewed cases per state mandates and voluntarily entered data into the Web-based NCCDR Case Reporting System. With the SUID-CR, grantees identify, review, and enter every SUID case in their state. In partnership with the NCCDR, the SUID-CR enhances previous monitoring activities by collecting and analyzing data from death scene information, medical examiner/coroner records, birth certificates, death certificates, law enforcement records, social service records, and pediatric and obstetric medical records. Unlike conventional SUID surveillance activities that solely

rely on vital statistics, the SUID-CR includes data on the circumstances and factors associated with an unexpected infant death, as well as information about the comprehensiveness of death scene investigations and autopsies conducted. These data are captured in the updated Case Report System, the data collection tool for the SUID-CR.

SUID-CR Variables

In implementing the SUID-CR, CDC and NCCDR reviewed existing variables in the NCCDR Case Reporting System and created or modified existing SUID-specific variables to address significant questions identified by researchers, program directors, and policy makers. As part of its collaboration with CDC, the NCCDR has added or modified these SUID-specific variables in its updated NCCDR Case Report and Web-based Case Reporting System.

These variables can be divided into two types: individual-based (Table 1) and system-based variables (Table 2). Variables with information about the circumstances and events leading to or associated with a SUID case are the individual-based variables. Alternatively, variables that contain information about the components and completeness of a case investigation, including scene investigation, autopsy, and medical records review, are the system-based variables.

Individual-Based Variables

Individual-based variables provide a detailed description of the environmental, behavioral, and medical characteristics surrounding each SUID case. Examples of individual-based variables include infant and maternal health status factors (eg, infant immunizations, maternal smoking before and during pregnancy) and factors observed at the death scene (eg, type of

TABLE 1 List of Individual-Based Variables, SUID-CR Pilot Program

Infant Information	**Primary Caregiver(s)**
Age at death	Was infant adopted?
Race	Age of caregiver(s) at time of death
Ethnicity	Caregiver(s) income
Gender	Caregiver(s) education
State of residence	Caregiver(s) substance abuse
Insurance status of infant	Caregiver(s) maltreatment as victim
Birth defects, disability or chronic illness	Caregiver(s) maltreatment as perpetrator
History of maltreatment	Caregiver(s) diagnosed with any mental health issues
Gestational age	Number of previous infant or child deaths in family
Birth weight	Previous infant deaths attributed to SIDS
Single or multiple gestation	
Mother's number of pregnancies[a]	**Supervisor Information**
Mother's number of live births[a]	Caregiver(s) police record
Mother's number of children living[a]	Caregiver(s) use of alcohol
Mother's prenatal care/number of visits[a]	
Mother's prenatal medical complications	**Incident Information**
Maternal alcohol use during pregnancy	Place of death (eg, home versus center)
Fetal alcohol effects on infant	
Maternal substance abuse during pregnancy	**Official Manner and Primary Cause of Death**
Maternal smoking before pregnancy[a]	Death certificate official manner and cause of death
Maternal smoking during pregnancy by trimester[a]	
Breastfeeding[a]	**Detailed Information by Cause of Death**
Injury to mother during pregnancy[a]	Infant exposed to second hand smoke
Abnormal newborn screening[a]	Thermal environment at death scene
Medical history[a]	History of seizures
Recent medical complications in past 72 h[a]	
Injury in last 72 h[a]	**Death in a Sleep Environment**
Immunizations in last 72 h[a]	Incident sleep place (eg, crib versus adult bed versus couch)
Medication(s) in last 72 h[a]	Sleep position last placed
Last meal[a]	Sleep position found
	Usual sleep location
	Usual sleep position
	Shared sleep surface?
	New sleep environment
	Placed to sleep with a pacifier[a]
	Fan used in room at time of death[a]
	Objects or persons obstructing airway
	Objects or persons sharing sleep surface
	Room sharing[a]
	Were safe sleep products used?

[a] Denotes a new variable added for states in the SUID-CR Pilot Program Case Registry pilot program only.

TABLE 2 List of System-Based Variables, SUID-CR Pilot Program

Investigation Information
Death referred to medical examiner or coroner?
Autopsy performed? By whom? If no, because parents or caregivers object?
Autopsy tests and procedures conducted, including:[a]
Autopsy in situ examination[a]
Autopsy microscopic examination[a]
Autopsy sampled tissues[a]
Autopsy weights of tissues[a]
Vitreous test[a]
Radiograph series[a]
CAT scan[a]
Metabolic screening[a]
Genetic testing[a]
Toxicology performed? Abnormal?
Histology performed? Abnormal?[a]
Microbiology performed? Abnormal?[a]
Other abnormal pathology report[a]
Blood chemistry performed? Abnormal?[a]
Radiograph performed? Abnormal?
Did the medical examiner or coroner have access to death scene and medical history information before determining cause of death?[a]
Agencies that conducted a death scene investigation[a]
Was there agreement between the cause of death on the pathology report and on the death certificate?

CAT, computed axial tomography.

[a] Denotes a new variable added for states in the SUID-CR Pilot Program Case Registry pilot program only.

sleep surface, sleep position, bed sharing, pacifier use).

System-Based Variables

The system-based variables are used to assess the comprehensiveness of the case investigation, including details about the death scene investigation and autopsy (Table 2). CDR teams ascertain whether death certifiers had important scene investigation (eg, scene re-creation by using a doll) and medical history data available before determining cause of death. In addition, teams list the components of each SUID autopsy.

Program Model

The program model for the SUID-CR demonstrates how information will flow from local to state to national levels, beginning with case notification and identification and ending with action being taken on the basis of recommendations (Fig 1). The model may be modified as the pilot program adapts solutions to identified issues in implementations.

Case Identification and Notification

SUID cases are identified from any infant deaths referred to a medical examiner or coroner office for investigation. CDR teams are notified of infant deaths through a variety of mechanisms. Ideally, teams are notified by phone or electronically from the medical examiner's or coroner's office when an infant death occurs. State vital statistics offices often provide quarterly reports to CDR teams identifying infant and child deaths. In addition, some teams scan obituaries as a supplemental method for case identification.

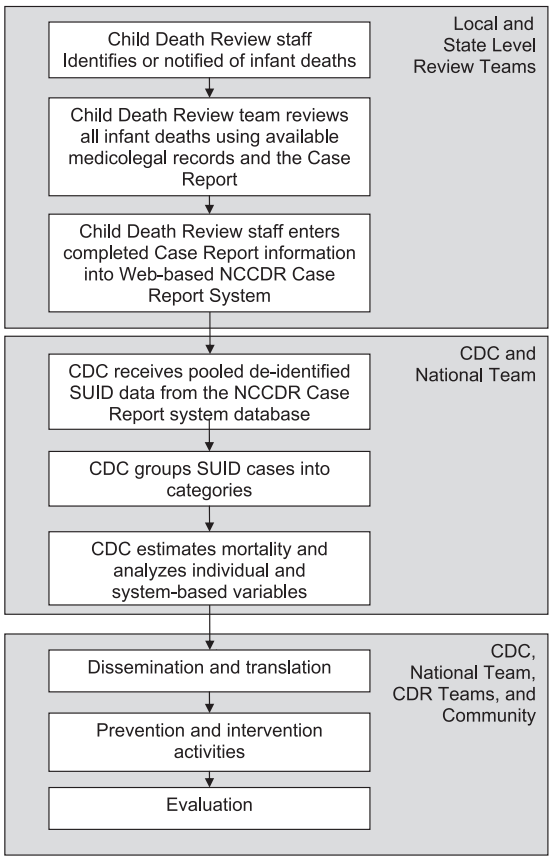

FIGURE 1
SUID-CR program model.

Case Review

According to state mandates and local protocols, CDR teams participating in the SUID-CR continue to collect case information from medicolegal and social service and public health records for their review of infant deaths. During a SUID case review, teams discuss the case and address the SUID-specific questions in the Case Report. Ideally, reviews occur monthly at the local level.[15] The goal for the SUID-CR is to review each SUID case within 90 days of identification. Some states in the pilot program have set up special committees to review only infant deaths.

More detailed review and discussion of the components of the death scene investigation and autopsy for each case is the major difference between a SUID case review and a nonpilot program SUID case review. The SUID-CR funded states have received specialized training in identifying factors that may have or probably contributed to an infant's death. The child death review teams in the seven funded states almost always make recommendations to not only improve death investigations and autopsies but to develop strategies that will prevent similar infant deaths.

Data Entry

Before the SUID-CR was implemented, state CDR teams voluntarily entered data into the Web-based NCCDR Case Reporting System after the review meeting as resources allowed. As part of the cooperative agreement, states in the SUID-CR pilot program now use the NCCDR Case Reporting System to enter data for every SUID case reviewed.

Pooled Data Set

States participating in the SUID-CR have agreed to share their SUID data with NCCDR and CDC to create a pooled data set. Twice a year, CDC receives de-identified information and data for all SUID cases entered into the NCCDR Case

Reporting System by states in the pilot program.

Categorization

In collaboration with partners who have expertise as researchers and clinicians in SIDS and SUID, CDC will group SUID cases into categories by using a decision-making algorithm developed specifically for the pilot surveillance system. This algorithm considers the thoroughness of the case investigation as well as the presence of individual and systems variables to categorize cases into explained and unexplained categories. Importantly, these categories were created to distinguish accidental suffocation deaths by mechanism of death (eg, suffocation prone and face down in soft bedding versus strangulation by entrapment between a mattress and wall).

Data Analysis

By using the pooled data set, CDC will estimate mortality rates of specific SUID categories and analyze individual-based variables to describe characteristics associated with these categories. System-based variables will be used to evaluate SUID case investigation practices.

Dissemination and Translation

Although many state and local CDR teams already make recommendations and action plans on the basis of their findings, the SUID-CR model calls for teams to identify and discuss factors that likely contributed to each infant's death and identify areas to target for prevention activities at their review meetings. CDR teams also discuss and make recommendations to improve the scene investigation and the autopsy, which in turn assists key stakeholders in identifying opportunities to improve SUID case investigations and possibly identify resources to facilitate more extensive investigations. CDC will synthesize the aggregated state recommendations. These recommendations, as well as other SUID-CR updates, will be communicated to participating states and partners in e-mail updates at least semiannually. In addition, CDC will write surveillance summaries and evaluation reports and disseminate this information through presentations at professional conferences and trainings, and through peer-reviewed literature, as well.

Prevention and Intervention Activities

Because an important objective of SUID surveillance is to use public health action to reduce infant mortality, CDC and states will educate program planners and policy makers about SUID surveillance findings and recommendations. Because surveillance findings will identify unsafe sleep practices that are related to injury, these findings and recommendations can be used to inform prevention activities and public health messages aimed at reducing potentially preventable infant deaths. Other findings can point to interventions to enhance death scene investigations and autopsies.

Evaluation

SUID-CR pilot states implement ongoing process and monitoring activities that focus on improving the timeliness of case review; quality of data; and participation of law enforcement, medical examiners, and coroners in case reviews. States report on their progress quarterly. These quarterly reports include an evaluation of the timeliness of case identification, review and identification of SUID-specific variables with >20% missing or unknown data, and documentation of plans for improvement. States also report their strategies to improve participation of medicolegal representatives at team reviews. After the 3-year pilot program, CDC and NCCDR plan to evaluate the SUID-CR's ability to monitor SUID trends and characteristics accurately, reliably, and efficiently.[16]

Progress to Date

The SUID-CR pilot program was designed to be an iterative process for both the grantees and the CDC, with inherent procedures for identifying ways to improve the data quality and the efficiency and timeliness of the system. The 3-year pilot program includes an ongoing process for evaluation and correction. The process evaluation not only helps document successes, but also identifies areas in need of change, and as such areas are identified, changes are made and documented.

Currently, the program is in its third year and several successes and challenges have been identified. From January 1, 2010 through June 30, 2011, state grantees successfully identified >835 SUID cases. For 2010, 610 cases were identified, 548 reviewed, and 374 were considered complete. By tracking the number of cases identified and reviewed for each state, we have evidence that grantees are meeting or exceeding the number of cases expected yearly in their states, thus demonstrating the ability of states to conduct population-based SUID surveillance. By monitoring cases as they go through review, data entry and quality assurance process, we have identified delays at the time of data entry. Grantees had initially focused efforts on identifying and reviewing cases within 90 days, but now are also addressing time lags in data entry.

Grantees have enhanced their capacity to bring infant death investigation and autopsy information to case reviews. This is evident by improvements in completeness of variables related to the infant's medical history, autopsy and death scene investigation before and after the implementation of the SUID-CR (Table 3). A variable was considered "complete" if it had no unknown or missing responses.

Progress reports from grantees suggest that the SUID-CR pilot program has improved not only the data quality of SUID cases reviews, but also the data quality for all child death reviews. This was accomplished through improved communication with the medicolegal professionals involved in infant and child death investigation.

Ongoing feedback and monitoring of progress has led to several other program improvements. One improvement was creating a modified version of the Case Report (launched in March 2011) which improved question clarity and incorporated additional questions about the components of the death scene investigation and cause-of-death determination. Review teams are concentrating efforts to examine not only what was discovered during cases investigations, but also how these investigations were accomplished. This represents a shift in how these teams functioned previously and offers local opportunities to improve the quality and/or comprehensiveness of infant death investigation.

CONCLUSIONS

Built on state-based CDR programs, the SUID-CR pilot program aims to generate valid, reliable, and timely population-based public health surveillance and programmatic data for SUID. Access to comprehensive data that describe the medical, environmental, and behavioral factors associated with SUID cases will allow researchers and prevention program planners to have an improved understanding of the circumstances leading to infant sleep-related deaths and create prevention strategies, ultimately preventing many infant deaths. Grantees have also developed and implemented a robust continuous quality improvement system and invigorated the CDR system by improving data collection and review for all childhood deaths. Moreover, states can use SUID-CR surveillance data for program planning and evaluation as well as modifying public health practice and policy for state injury prevention and maternal and child health programs.

TABLE 3 Comparison of Selected Variables Collected By Child Death Review Teams Before (2007–2009) and After (2010) the Implementation of the SUID-CR Pilot Program

	Records With Valid Responses, %	
	Before	After
Infant medical history		
Birth weight	57.8	94.4
History of chronic disease or disability	72.1	94.7
Death scene information		
Child's position most relevant to the death	60.8	89.1
Place where child found	76.2	87.2
Autopsy		
Toxicology performed	75.6	97.0
Radiograph performed	55.3	89.5

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