

## VIEWPOINT

# Protecting Infants From Sleep-Related Deaths

## A Wake-up Call

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### Overview

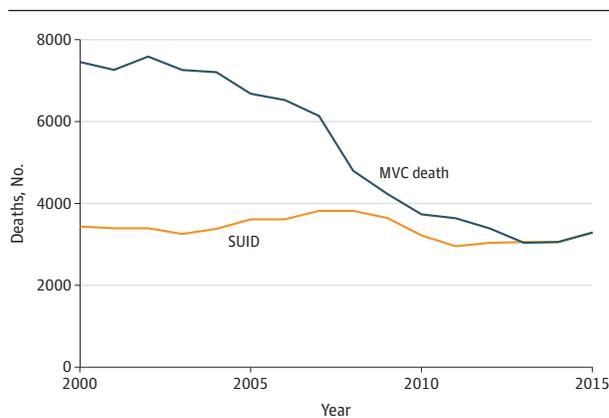
Why has no substantial progress been made in preventing sleep-related infant deaths? Approximately 3700 infants (aged  $\leq 1$  year) have died each year in the past 15 years, most of whom died before age 6 months. No recent breakthrough has occurred for this public health issue, which kills a surprisingly large number of society's most vulnerable—typically healthy infants. After the 1992 American Academy of Pediatrics recommendation regarding sleep position and the National Institutes of Health-led Back to Sleep campaign, infant deaths significantly declined; however, since the late 1990s, the decline in sleep-related infant deaths has plateaued. In 2015, there were 3684 sudden unexpected infant deaths (SUIDs), a total that is essentially unchanged from the 3716 SUIDs in 1999. By comparison, childhood deaths from motor vehicle crashes decreased dramatically in this same period. With the recent decline in deaths from crashes, SUIDs now claim as many lives as all deaths from crashes in infants, children, and teenagers combined (aged  $< 20$  years) (Figure). How can we begin to make real gains and prevent these tragic deaths?

### Public Misperception

Most SUIDs go unreported in the news. Without such reports, the public perception is not informed by reality, and the true risk of SUID is underestimated, limiting the interest of parents in following prevention guidance. Perhaps the news media choose not to report these deaths out of sensitivity to grieving families, but this lack of reporting suggests to parents that SUIDs happen rarely. By comparison, deaths of teenagers from crashes are commonly reported in the news. Parents fear their teenager's early years of driving, during which the risk for fatal crashes is high. This fear that keeps parents of driving teenagers up at night contrasts with the relative comfort of parents who bring a baby into their bed in hopes of getting some sleep. This practice occurs despite statistics that show, in a given year, SUID is 9 times more likely than a motor vehicle crash death of an 18-year-old driver. (According to the National Center for Statistics and Analysis, 3684 infants died suddenly and unexpectedly in 2015, whereas 404 drivers aged 18 years died in crashes that same year [<https://crashstats.nhtsa.dot.gov/Api/Public/ViewPublication/812363>].)

According to the theory of planned behavior, individuals must perceive the risk of a behavior to be motivated to change.<sup>1</sup> Bed sharing raises SUID risk, yet it is commonly practiced by parents from all race/ethnicity groups, even when those parents know they are being videotaped at night as part of a study.<sup>2</sup> Despite the excellent, long-standing efforts of the American Academy of Pediatrics,<sup>3</sup> the National Institutes of Health (Safe to Sleep campaign), and others, we are only beginning to learn what might work to effectively promote safe sleep.<sup>4</sup>

**Figure. Annual Number of Unintentional Motor Vehicle Crash (MVC) Deaths Among Persons Younger Than 20 Years and Sudden Unexpected Infant Death (SUID) Among Persons Younger Than 1 Year in the United States from 2000 to 2015**



Unintentional MVC deaths are defined by these *International Classification of Diseases, Tenth Revision (ICD-10)* underlying cause-of-death codes: V30-V39 (4-.9), V40-V49 (4-.9), V50-V59 (4-.9), V60-V69 (4-.9), V70-V79 (4-.9), V81.1-V82.1, V83-V86 (0-.3), V20-V28 (3-.9), V29 (4-.9), V12-V14 (3-.9), V19 (4-.6), V02-V04 (1-.9), V09.2, V80 (3-.5), V87 (0-.8), and V89.2. The underlying cause of SUID is a combination of these *ICD-10* cause-of-death codes: sudden infant death syndrome (R95), unknown cause (R99), and accidental suffocation and strangulation in bed (W75). These numbers are from the Multiple Cause of Death files for 2000 to 2015, which were compiled from data provided by the 57 vital statistics jurisdictions of the Vital Statistics Cooperative Program (<https://wonder.cdc.gov/ucd-icd10.html>).

### Lack of Surveillance System

To ensure that public perception of a public health problem is in line with reality, we must start with all the facts. In public health, the facts come from a surveillance system, which is the cornerstone of prevention. Currently, we lack such a system for SUID that provides details beyond the limited and, at times, questionable information on the death certificate. In contrast, the decline in childhood deaths from crashes has been informed by a time-tested, high-quality, and accessible surveillance system called the Fatality Analysis Reporting System. Built by the National Highway Traffic Safety Administration, this system contains rich information on the casualties, vehicles, and crash de-

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tails of every fatal traffic collision in the United States. The availability of this system has allowed researchers, policy makers, and the traffic safety community to carefully study and track deaths from crashes. The lack of such a national SUID surveillance system hampers efforts to address this enormous public health problem.

The current death certificate–based SUID data are also limited by wide variations in the way death certificates are completed across the United States<sup>5</sup> and by an unfortunate computer idiosyncrasy at the National Center for Health Statistics.<sup>6</sup> The term *SUID* is a combination of 3 *International Classification of Diseases, Tenth Revision*, diagnoses of infant death: sudden infant death syndrome (SIDS), accidental strangulation and suffocation in bed, and unknown cause. As more infant deaths have received death scene investigations, more SUIDs have been found to be associated with an unsafe sleeping situation, and the use of SIDS as a cause of death has appropriately fallen. However, the computer algorithm used at the National Center for Health Statistics assigns the cause of death as SIDS even for a number of causes that death certifiers might choose specifically to avoid the term SIDS, including “sudden unexplained infant death or SUID” and “sudden unexplained (or unexpected) death in infancy or SUDI.”<sup>6</sup> Researchers have found that 5 deaths for which the death certifier chose to write “not SIDS” were assigned the code for SIDS by the algorithm.<sup>6</sup>

The SUID Case Registry is a promising effort being built with funding from the Centers for Disease Control and Prevention and

the National Institutes of Health to create a true SUID surveillance system.<sup>7</sup> The registry is organized around Child Death Review systems; so far, 16 states and 2 jurisdictions provide rich and detailed information on approximately 30% of SUIDs that occur in the United States.<sup>7</sup> If expanded to include all states, this registry will have the level of detail necessary to begin to tease out SUIDs associated with unsafe sleep from those with likely organic causes that are not detected by routine autopsy, such as central nervous system abnormalities and cardiac arrhythmias. Federal funding to expand the registry to a national surveillance system should be a priority for legislative advocacy.

## Conclusions

Ultimately, no vision other than zero SUIDs is acceptable. Considering the approximately 3700 SUIDs each year, we have a long way to go. From a public health standpoint, our lack of progress is unacceptable. In the years since the decrease in SUIDs began to plateau, more than 50 000 of our youngest and most precious citizens have died. The suffering that their families have endured is immeasurable. Investments in surveillance and prevention of SUIDs have lagged those of traffic safety by several decades, but the road ahead is clear. We must correct the current misperception of SUID risk, invest to create a national SUID surveillance system, and support innovation to find what works to promote safe sleep effectively.

## ARTICLE INFORMATION

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