Need for a Working Classification System for Sudden and Unexpected Infant Deaths

Since the 1980s, the rate of sudden infant death syndrome (SIDS) has declined worldwide; this is largely attributed to “Back to Sleep” campaigns. However, concurrently, there have been increases in the rates of other sudden and unexpected infant deaths (SUIDs), and the overall SUID rate has not improved in the past decade. This “diagnostic shift” is partly due to standardization of, and improvement in, death scene investigations; many cases that would have been classified 20 years ago as SIDS (International Classification of Disease, Tenth Revision [ICD-10] R95) are now being classified as accidental suffocation (ICD-10 W75) and, when there is uncertainty about the cause of death, ill defined (ICD-10 R99). While this diagnostic shift has been helpful in some respects, there is now a great deal of variability in, and confusion about, how these deaths are categorized. When an infant dies after rolling prone onto a pillow, when is the case an accidental suffocation death, and when is it SIDS? Depending on the jurisdiction in which the infant dies and the inclination of the medical examiner or coroner, the cause of death may be determined to be accidental suffocation, positional asphyxia, SIDS, or ill defined. The difficulty is compounded by the lack of diagnostic features in asphyxial deaths and the fact that the majority of these deaths are unwitnessed because they usually occur when the infant, and most, if not all, of the household members, are asleep. If there are witnesses, their reliability may also be difficult to ascertain because people are rarely willing to cast or assume blame for an infant’s death. Blame is often implied when there is an accidental death but not when it is a SIDS death.

The inconsistency in how deaths are categorized has made it virtually impossible to track trends, clarify potentially lethal sleep conditions, and develop consistent safe sleep messages, both domestically and internationally. For instance, Japan has one of the lowest SIDS rates in the world. As parent-infant bed-sharing is the norm in Japan, the SIDS statistic is often cited as rationale that bed-sharing must not be dangerous. However, when one looks closely at the vital statistics data, Japan is also one of the few countries that uses R96 (other sudden death, cause unknown) to classify these deaths. When one compares rates of all sudden and unexpected deaths nationally, Japan’s rate is on par with that in other developed countries.

Even in peer-reviewed literature, there is a disturbing lack of uniformity and consistency in the use of definitions and terminology relating to unexpected infant death. One example is the term SUID, which is used in North America to describe sudden and unexpected infant death. This term is not consistently agreed on; SUDI (sudden and unexpected death in infancy) is the equivalent European/English term.
In this issue of Pediatrics, Shapiro-Mendoza et al describe a unique classification system that they have applied to 436 US SUIDs that were reported in 2011. Others have developed SUID classification systems, but all have limitations and none have been consistently adopted. Shapiro-Mendoza and colleagues’ classification system recognizes and acknowledges the uncertainty underlying many cause and manner-of-death determinations but may also provide some clarity regarding risk factors and dangerous sleep conditions, which is critically important when providing policy guidelines and developing educational interventions. We get a glimpse of the rich data that might be available if the Centers for Disease Control and Prevention SUID Case Registry were to be expanded nationally. In the 9 states currently in the registry, <1% of SUIDs were associated with no unsafe sleep factors. Soft bedding, overlay, and wedging or entrapment accounted for the mechanism of death in the vast majority of cases. This has tremendous implications for counseling our families about how and where their infant sleeps.

As with any large endeavor, there are potential issues. With this classification system, it will be important to ensure consistency in data entry among the hundreds of people responsible for this task in the individual jurisdictions. The accuracy of the data analysis and the conclusions drawn will only be as accurate as the data that are entered into the system. Shapiro-Mendoza and colleagues have, however, provided an impressive classification system that addresses many of the problems that arise from inconsistencies in coding and classification and that have frustrated the work of infant mortality committees worldwide over the past decade in their attempts to try to identify specific factors that may be crucial in causing infant deaths. This classification system and the Centers for Disease Control and Prevention SUID Case Registry present great potential to increase our understanding of how to best identify risk factors to keep our sleeping infants safe.

REFERENCES

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