Classifying Infant Deaths with a Focus on Prevention Strategies

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Despite some progress in recent decades, the infant mortality rate in the United States remains stubbornly higher than in many other industrialized nations. From time to time, researchers interested in estimating what proportion of fetal and infant mortality might be preventable have devised classifications of perinatal and infant deaths by underlying cause of death, gestational age and/or birthweight, and related factors. These factors include the widely used perinatal periods of risk (PPOR) framework,¹ a method for identifying infant deaths associated with preterm birth,² and numerous strategies for classifying causes of perinatal death, one of the more recent of which is the Causes of Death and Associated Conditions, or CODAC.³ The approach proposed by Dollfus et al. in 1990 involved classification of infant deaths in the state of North Carolina into nine groups based on underlying cause of death, with further differentiation based on preventability.⁴

The Dollfus classification was not without limitations, some of which were addressed in a subsequent analysis by Sowards.⁵ Among the more significant, the original classification grouped only those International Classification of Diseases, Ninth Revision (ICD-9) underlying cause-of-death codes that appeared in the North Carolina death certificate file. The modifications proposed by Sowards corrected some of the more notable omissions, especially for congenital anomalies, respiratory conditions, and external causes of death. However, neither classification mapped the entire ICD rubric to identify erroneous codes that occur when cause-of-death certification is incomplete. Examples include reporting a condition only as the immediate cause with no other contributing causes; if the condition listed can be coded to the ICD, it becomes the underlying cause of death regardless of plausibility. For example, if polydactyly (extra fingers or toes) is listed as the immediate cause of death with no contributing causes, it will become the underlying cause of death because it is a condition that can be coded to the ICD 10th Revision (ICD-10), irrespective of the absence of any biological or physiological pathway from this condition to death. There are also conditions for which the absence of the words “infant” or “congenital” causes the condition to be coded outside the congenital anomalies or perinatal

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rubrics both in ICD-9 and ICD-10; an example of this condition is diaphragmatic hernia, coded in ICD-9 as 756.6 if congenital but as 553.3 if not, and in ICD-10 as Q79.0 if congenital and as K44 if not.

In this issue of *Public Health Reports*, Nakamura et al. present an updated version of the Dollfus classification.⁶ Utilizing the 1996 National Center for Health Statistics (NCHS) multiple cause-of-death file, the authors were able to classify infant deaths based on underlying cause-of-death codes in both ICD-9 and ICD-10. Although the primary innovation lies in recasting the Sowards version of the Dollfus classification from ICD-9 to ICD-10, in several areas the range of conditions covered is expanded or refined. In Table 3 of the article by Nakamura et al., it is apparent that the updated classification yields a similar distribution of leading causes of infant death, with considerable movement across categories compared with the modified classification proposed by Sowards.⁵ For prematurity and related causes, due to incorporation of the approach devised by Callaghan et al.,² while the updated classification identifies 8,976 infant deaths, compared with 8,381 according to the modified classification, 452 cases (5.4%) were classified elsewhere in the updated classification. On the other hand, 12.7% of cases in the prematurity and related causes category in the modified classification were classified to other categories in the Nakamura et al. classification scheme.

A similar redistribution occurred for infant deaths due to congenital anomalies, with more than 10% of those so classified in the modified classification falling into other categories in the updated scheme.⁶ This difference is not unexpected, as shown by Hoyert in a study of changes in coding of birth defects in death certificates across ICD revisions.⁷ Sudden infant death syndrome (SIDS) remains the third leading cause of infant death, and most cases fall into the same category in both classifications. SIDS included ICD-9 code 798.0 in the original Dollfus classification and 798.0–799.0 in Sowards' modification, while Nakamura et al. assign ICD-10 code R95 to SIDS. Emerging thinking today focuses on the broader concept of sudden unexplained infant death (SUID), which includes several conditions classed as external causes in the new classification.⁸ Sleep-related SUID includes SIDS, unknown cause, and accidental suffocation or strangulation in bed; the latter conditions may be listed as the underlying cause of death depending on the medical examiner or coroner involved.

It should be noted that although the updated Dollfus classification uses ICD-10 codes, NCHS has been coding underlying and multiple cause of death for all U.S. death certificates since 1999. Thus, the new

classification does not require recoding of cause-of-death data for implementation purposes unless trend analyses using data from 1998 or earlier are the focus of study. However, the transition from ICD-9 Clinical Modification (ICD-9-CM) to ICD-10-CM across the U.S. health-care system on October 1, 2015, will undoubtedly affect other administrative health databases and aspects of documentation of perinatal health care and outcomes.

Taking another look at Table 3 in Nakamura et al.,⁶ another concern with the updated Dollfus classification involves the 15.6% of infant deaths in the "not classified" category. Those deaths not classified are very heterogeneous and include all infant deaths not classified to one of the other eight categories. The updated classification improves on the 18.4% of cases that fall into this category in the modified classification, but almost one in six infant deaths do not fall into one of the leading cause-of-death categories.⁶

As public health practitioners and perinatal epidemiologists ponder the utility of the proposed updated Dollfus classification, it seems worthwhile to consider how it might be used in concert with other initiatives. For example, the PPOR approach separates perinatal and infant deaths by age at death (i.e., fetal, neonatal, and postneonatal death) and birthweight (i.e., <1,500 grams and ≥1,500 grams). Combining the updated Dollfus classification and stratifying infant deaths by age at death, birthweight, and leading cause may yield clearer insights into which cases might be preventable through community-based initiatives, thereby extending the utility of PPOR-based perinatal/infant mortality programs. Likewise, the classification of infant deaths by cause might enhance the approach to state-level initiatives concerning infant mortality identified by the State Infant Mortality Collaborative.⁹

Meanwhile, the goal of implementing a comprehensive approach to perinatal mortality prevention remains elusive. Today, we are no closer to being able to determine and classify underlying cause of fetal death in the United States than we were two decades ago.¹⁰ Additionally, although now more commonly included in databases of perinatal outcomes, fetal deaths or stillbirths continue to receive limited attention despite now being more numerous than neonatal deaths in most jurisdictions. In 2012, the national fetal death rate was 6.1 deaths per 1,000 live births, compared with a national infant death rate of 6.0 deaths per 1,000 population.¹¹ Challenges in the accurate completion of the cause-of-death certification section of infant death certificates persist and include lack of training of physicians in proper completion of death certificates, limited numbers of qualified obstetric and pediatric

pathologists, state regulations concerning medical examiners and coroners, and lack of a standardized approach to perinatal autopsy documentation for incorporation into cause-of-death certification.

Although it requires more clinical information than commonly collected on vital statistics documents, the CODAC classification³ could be modified fairly easily to yield a tool capable of classifying the cause of death for all stillbirths, neonatal deaths, and postneonatal deaths. CODAC has recently been applied to cause-of-death reporting for all perinatal deaths in the United Kingdom, demonstrating continuing challenges with classifying fetal deaths but achieving reasonable results for neonatal deaths.¹² Even as researchers seek to improve the utility of data collected on death certificates, it would be worthwhile to think outside of the box to improve our approach to classifying the leading causes of perinatal and infant death and developing prevention strategies based on those findings.

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