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## Challenges and Opportunities in Identifying, Reviewing, and Preventing Maternal Deaths

**Amy St. Pierre, MBA, Julie Zaharatos, MPH, David Goodman, PhD, and William M. Callaghan, MD, MPH**

CDC Foundation and the Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, Georgia.

### Abstract

Despite many efforts at the state, city, and national levels over the past 70 years, a nationwide consensus on how best to identify, review, and prevent maternal deaths remains challenging. We present a brief history of maternal death surveillance in the United States and compare the three systems of national surveillance that exist today: the National Vital Statistics System, the Pregnancy Mortality Surveillance System, and maternal mortality review committees. We discuss strategies to address the perennial challenges of shared terminology and accurate, comparable data among maternal mortality review committees. Finally, we propose that with the opportunity presented by a systematized shared data system that can accurately account for all maternal deaths, state and local-level maternal mortality review committees could become the gold standard for understanding the true burden of maternal mortality at the national level.

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Recent studies and letters published in this journal and others highlight efforts across the country to identify, review, and prevent maternal deaths at the state and local levels. States such as Colorado, Illinois, and Maryland and cities such as Philadelphia have published successes, and as of July 2017, no fewer than 30 other states and cities are undertaking similar initiatives (Johnson CT. Maternal deaths from suicide and overdose in Colorado, 2004–2012 [letter]. *Obstet Gynecol* 2017;129:946).<sup>1–3</sup> Despite these efforts at the state and city levels and national efforts over the past 70 years, a nationwide consensus on how best to identify, review, and prevent maternal deaths remains a challenge. At first glance, identifying a maternal death might be seen as easy. However, unlike identifying specific causes of death, identifying women who die during pregnancy or at some defined interval after the end of a pregnancy from causes directly or indirectly related to the event of pregnancy presents challenges. At the most recent annual Maternal Mortality and Severe Maternal Morbidity Meeting, hosted by the American College of Obstetricians and Gynecologists (ACOG) and the Centers for Disease Control and Prevention (CDC) on May 7, 2017, in San Diego, California, attendees and facilitators discussed the pressing need for consensus on the

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Corresponding author: Amy St. Pierre, MBA, 600 Peachtree Street NE, Suite 1000, Atlanta, GA 30308; astpierre@cdc.gov.

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terminology used to discuss maternal deaths in the United States. In response, we present a brief history of maternal death surveillance and strategies to address the perennial challenges of shared terminology and accurate, comparable data.

## BRIEF HISTORY OF MATERNAL DEATH SURVEILLANCE

During the 20th century, three major systems of maternal death surveillance evolved in the United States, each with different purposes, methods, and corresponding terminology (Table 1). The National Vital Statistics System provides maternal death counts using death certificates submitted by states and since 1915 has published maternal mortality rates (deaths/100,000 live births). The National Vital Statistics System produces maternal mortality rates by applying the World Health Organization's International Classification of Diseases codes to death certificates submitted by states. In this system, maternal deaths are defined temporally as deaths that occur during pregnancy or within 42 days of the end of pregnancy. The causality is defined as from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes. The latter causes include such things as motor vehicle accidents, most cancers, homicides, and other events and conditions judged not to be causally related to the care of or physiology of pregnancy. These counts and rates serve as the official statistics on maternal mortality in the United States and are used for international comparisons by the World Health Organization and others.

The National Vital Statistics System relies solely on death certificates, which are readily available but limited in detail. Death certificate data provide a very high-level national view of maternal deaths and trends over time, but do not enable understanding of what really happened to cause a woman's death. Finally, notions about "accidental or incidental" causes may change over time.

The need to examine maternal deaths in greater detail to develop strategies for prevention has been recognized for a century. Beginning in the 1930s, maternal mortality review committees formed at the state and local levels to address this need. In 1930, both the Committee on Public Health Relations of the New York Academy of Medicine and the Philadelphia County Medical Society set out to study maternal deaths. Philadelphia began the first organized case review of deaths in 1931, accessing medical records and details of a woman's life and death not accessible through vital records. Between 1931 and 1940, Philadelphia's maternal mortality review committee expanded to conduct case review and analyze cases at multiple hospitals each month, revealing a high percentage of preventable deaths. Corrective measures to improve practice were taken, namely the prevention of "unnecessary obstetric operations, injudicious use of drugs, and other operative measures by unqualified physicians." By 1940 maternal mortality in the city had dropped from 680 to 230 deaths per 100,000 births.<sup>4</sup> It is likely that the review process contributed to the decline in maternal mortality, because although clinical care for women advanced during this time period, antibiotics and blood banking were not yet available.<sup>5</sup>

In the next two decades, maternal mortality review committees convened around the country. By 1968, 44 states and the District of Columbia were conducting maternal mortality review.

However, 1988 a survey by ACOG found that the number of states with active review committees had dropped to 27 (Entman SS, Atrash HK, Koonin LM, Smith JC. Maternal mortality surveillance [letter]. *AmJ Public Health* 1988;78:1499–500.). This drop was attributed to a decrease in maternal deaths, difficulty interpreting the small number of deaths, and fear of litigation by physician committee members (Entman et al, *AmJ Public Health*).

In 1986, as a response to the declining number of review committees and to the need for understanding maternal deaths beyond coded death certificate data, the Pregnancy Mortality Surveillance System was developed. Formed on the recommendation of the CDC–ACOG Maternal Mortality Study Group and housed within the CDC’s Division of Reproductive Health, the Pregnancy Mortality Surveillance System introduced the following terms:

### **Pregnancy-associated death**

umbrella term for all deaths during pregnancy or within 1 year of pregnancy, regardless of cause

### **Pregnancy-related death**

the death of a woman while pregnant or within 1 year of pregnancy termination—regardless of the duration or site of the pregnancy—from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes<sup>6</sup>

### **Pregnancy-associated but not related death**

the death of a woman during pregnancy or within 1 year of the end of pregnancy from a cause that is not related to pregnancy The Pregnancy Mortality Surveillance System asks state Divisions of Vital Statistics to cast a broad net to identify potential maternal deaths by using pregnancy checkbox information, cause of death information, and linkages of deaths of women of reproductive age back to birth certificates and fetal death certificates. Medical epidemiologists review death certificates and linked birth or fetal death certificates, determine underlying causes of death, and decide whether a death was pregnancy-related or pregnancy-associated but not related. The System imposes a clinical point of view to the information contained in vital records that is not under the constraints of the statistical accounting imposed by the limited codes in the International Classification of Diseases.

The Pregnancy Mortality Surveillance System produces the U.S. pregnancy-related mortality ratio (pregnancy-related deaths/100,000 live births). Pregnancy Mortality Surveillance System data have shown increases from 13.2 pregnancy-related deaths per 100,000 births in 1999 to 17.3 deaths in 2013.<sup>7</sup> Although the Pregnancy Mortality Surveillance System allows a clinical interpretation not possible through the National Vital Statistics System, it remains limited to information primarily derived from death and birth certificates.

## **A NOTE ON THE PREGNANCY CHECKBOX**

Throughout the past century, there have been efforts to improve the quality of death certificate data. Underascertainment of maternal deaths from vital records led to efforts to

introduce a specific question regarding recent pregnancy history to the U.S. Standard Certificate of Death. In 2003 a specific question that prompts the death certifier to indicate timing of death in relation to pregnancy was added to the U.S. Standard Certificate of Death.<sup>7</sup> However, states varied in timing of adoption subsequent to its introduction, and they may use a nonstandard checkbox that does not capture timing in a way that enables recoding equivalent to the standard checkbox. As of July 2017, 46 states and the District of Columbia have adopted the standard pregnancy checkbox question (personal communication, Dr. Donna Hoyert, 2017). Adoption of the pregnancy checkbox facilitates identification but also leads to misclassification (false-positive), wherein a woman is indicated as being pregnant within 1 year of her death but in fact was not pregnant. Davis et al write that the adoption of the pregnancy checkbox “appears to be the main driver of the increases in [maternal mortality ratios] over the last decade, both by increasing maternal death case identification and potentially maternal death misclassification.”<sup>8</sup>

Despite findings that the pregnancy checkbox contributes both true and false maternal deaths to maternal mortality rates, the real risk of maternal death remains unacceptably high, with persistent geographic and racial disparities. Because maternal mortality review committees use data sources beyond vital records, they are best poised to accurately identify, comprehensively review, and specifically recommend actions that prevent mortality and morbidity.

## REVIEW COMMITTEE TERMINOLOGY

The 1956 *Guide for Maternal Death Studies*, published by the Committee on Maternal and Child Care of the American Medical Association to support state maternal mortality review committees, noted that, despite the number of states reviewing deaths at that time, great differences in terminology and processes made comparison of results across states impossible.<sup>9</sup> These challenges persist, but today states and cities have a renewed interest in shared terminology and processes and new tools for collecting comparable data.

In the context of review committees, the terms pregnancy-associated, pregnancy-related, and pregnancy-associated but not related aid understanding of contributors to deaths and enable committees to identify and act on opportunities for prevention. By accessing information beyond vital records, committees review all pregnancy-associated deaths and establish temporal (during pregnancy, within 42 days, or between 43 days and 1 year of the end of pregnancy) and causal relationships to pregnancy. This breakdown of timing may inform quality improvement efforts and interventions by stakeholders who encounter women at different times before, during, after, and between pregnancies.

Although review committees are tasked with categorizing all pregnancy-associated deaths, they may be unable to determine whether certain deaths are pregnancy-related or not. For example, determining pregnancy relatedness is particularly difficult in the case of suicides and drug overdoses. In such cases, the committee may simply note that it was unable to determine pregnancy-relatedness and proceed to evaluate preventability and recommendations for action. Moreover, determinations about the effect of pregnancy on known or unknown chronic health conditions are likely increasingly difficult the farther one

gets from the end of a pregnancy; in such cases, relatedness may rely on mutually agreed on, albeit somewhat arbitrary, time cutoffs.

Beyond assessing pregnancy-relatedness, committees are tasked with evaluating preventability. A death is considered preventable if the committee determines that there was at least some chance of the death being averted by one or more reasonable changes to patient, family, health care provider, facility, systems, or community factors.<sup>10</sup> This definition of preventability prompts committees to look beyond the narrow view that is afforded by reviewing death certificates alone and helps them to then prioritize within leading causes of death and formulate recommendations for action. Consensus on this terminology is a critical starting point for collaboration across committees.

## **BUILDING U.S. CAPACITY TO REVIEW AND PREVENT MATERNAL DEATHS**

As part of its commitment to supporting states, the CDC's Division of Reproductive Health, in partnership with the Association of Maternal & Child Health Programs and the CDC Foundation, is leading the Building U.S. Capacity to Review and Prevent Maternal Deaths initiative to promote maternal mortality review as the best way to understand why maternal deaths occur and what can be done to prevent them. The initiative also provides a national forum for review committees to share findings and best practices. Funding for this initiative was provided with support from Merck on behalf of its Merck for Mothers program.

The initiative provides tools and trainings that support fully functional, sustainable review committees. A key tool, the Maternal Mortality Review Information Application, is a data system to help committees produce relevant and comparable data to inform policy, process, clinical care, and public health.<sup>11</sup> The data system promotes standardized terminology and data collection to allow sharing between states and to increase opportunities for translating data to action. Using data from four state-based committees, the initiative recently released the first Report From Maternal Mortality Review Committees: A View Into Their Critical Role.<sup>12</sup> The report serves as a proof of concept for combining data from multiple committees.

Although great strides have been made, challenges remain. Review committees must operate with available resources, which are often limited and in-kind. Because resources dictate breadth of scope, committees have differing scopes of case review.<sup>13</sup> Committees cast a wide net to review as many pregnancy-associated deaths as possible to determine relatedness, but also need a defined scope to be systematic when they do not have the resources to fully abstract and review all cases. At the peak of maternal mortality review committees in the 1960s, several large states used an intrastate regional model of review when deaths were too numerous to review efficiently and in a timely manner at the state level.<sup>5</sup> This regional approach remains relevant as some states grapple with large numbers of pregnancy-associated deaths. Today the use of a common data collection system enables such an approach, just as small states could adopt such an approach to implement an interstate regional model. Ultimately, funding for committees remains an important issue, as do authority and protections to operate.<sup>13</sup>

Committees today also face increasing numbers of deaths resulting from emerging causes that were rarely recognized in the past such as mental health conditions and opioid overdoses. The Report From Maternal Mortality Review Committees shows that mental health conditions were a leading underlying cause of death among non-Hispanic white women in Georgia, Colorado, Delaware, and Ohio.<sup>12</sup> The report also shows that a maternal death is often the result of a number of contributing factors. On average, three to four contributing factors were identified for each pregnancy-related death.<sup>12</sup> Some committees have found that they are able to better identify and address emerging causes of death by expanding the membership of their committees to include medical examiners, psychiatrists, injury prevention and mental health experts, social workers, and representatives from community-based organizations. At times committees themselves are best poised to implement identified actions; in other cases, implementation by other stakeholders may be necessary.

Review committees are uniquely poised to identify opportunities for action despite difficulties in classifying deaths as pregnancy-related or not; in one example, Colorado's committee has effectively identified possible points of intervention for women at risk for self-harm.<sup>1</sup> Although such deaths were traditionally seen as outside the scope of review committees, increasing prevalence and awareness of these tragic occurrences and their potential preventability compel committees to address them. The challenge of classification need not prevent committees from developing recommendations to improve systems of care for women of reproductive age; there is not a body better positioned to increase understanding of the burden of deaths by suicide and drug overdose among this population to inform policy and programmatic actions.

State and local-level committees review each death with relevant contextual knowledge about the place in which it occurred. Although a heavy lift, with the opportunity presented by a systematized shared data system that can accurately account for all maternal deaths, state and local-level review committees could become the gold standard for understanding the true burden of maternal mortality at the national level. With shared terminology and processes, we can move closer to a clear understanding of why maternal deaths continue to occur. With a clear understanding, we can move beyond and respond to calls to action and focus our efforts to improve care for women, reduce mortality and morbidities, and eliminate disparities. The effort has been hard and will continue to be difficult. We must persevere for the benefit of women and families.

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Table 1.

## Systems of Maternal Mortality Surveillance in the United States

Data Source	National Vital Statistics System	Pregnancy Mortality Surveillance System	Maternal Mortality Review Committees
Timeframe	During pregnancy—42 d	During pregnancy—1 y	During pregnancy—1 y
Source of classification	ICD, 10th Revision codes	Medical epidemiologists, utilizing Pregnancy Mortality Surveillance System codes	Multidisciplinary committees
Terms	Maternal death	<ul style="list-style-type: none"> <li>• Pregnancy-associated death</li> <li>• Pregnancy-related death</li> <li>• Associated but not pregnancy-related death</li> </ul>	<ul style="list-style-type: none"> <li>• Pregnancy-associated death</li> <li>• Pregnancy-related death</li> <li>• Associated but not pregnancy-related death</li> </ul>
Measure	Maternal mortality rate (no. of maternal deaths/100,000 live births)	National pregnancy-related mortality ratio (no. of pregnancy-related deaths/100,000 live births)	State or local-level pregnancy-related mortality ratio (no. of pregnancy-related deaths/100,000 live births)
Purpose	Show national trends and provide a basis for international comparison	Analyze clinical factors associated with deaths, publish information that may lead to prevention strategies	Understand medical and nonmedical contributors to deaths; prioritize interventions that may reduce maternal deaths
Strengths	<ul style="list-style-type: none"> <li>• Strongest source of historical data, dating back to 1900</li> <li>• Reliable basis for international comparison</li> <li>• Relies on readily available data from death certificates</li> </ul>	Most clinically relevant national measure of burden of maternal deaths	<ul style="list-style-type: none"> <li>• Allows for the most accurate identification and comprehensive review of deaths</li> <li>• Allows specific recommendations for actions to inform local, state, and national prevention strategies informed by local context</li> </ul>
Challenges	<ul style="list-style-type: none"> <li>• Constrained by statistical accounting imposed by the limited codes in the ICD</li> <li>• Does not capture sufficient detail to inform prevention strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Limited to information primarily derived from death and birth certificates</li> <li>• Does not capture detailed information on contributors to deaths</li> </ul>	<ul style="list-style-type: none"> <li>• Resource-intensive <ul style="list-style-type: none"> <li>○ Reliant on data from multiple sources, including medical records, social records, autopsy reports, and informant interviews</li> <li>○ Requires review by multiple stakeholders</li> </ul> </li> <li>• Currently, variations in processes across jurisdictions inhibit use of data for national surveillance</li> </ul>

ICD, International Classification of Diseases.