State of Illinois
Illinois Department of Public Health

Illinois Maternal Morbidity and Mortality Report

October 2018

Acknowledgements

Illinois Department of Public Health Staff

Amanda Bennett, PhD, MPH
Tanya Dworkin, JD
Trishna Harris, DNP, APN, WHNP-BC, CNM
Abigail Holicky, MPH
Ashley Horne, MSPH
Shannon Lightner, MSW, MPA
Nancy Martin, EMT-P
Andrea Palmer, MPA, MBA, CHSM
Miranda Scott, MBA, MALS, BSN, RN, LNC
Alexander Smith, BA
Kelly Vrablic, MPH

Maternal Mortality Review Committee

Robert Abrams, MD, Maternal-Fetal Medicine Specialist, Southern Illinois University
Jennifer Banayan, MD, Cardiac and Obstetric Anesthesiologist, University of Chicago
Deborah Boyle, FACOG/MD, BSN, Maternal-Fetal Medicine Specialist, University of Chicago
Joan Briller, MD, FACC, FASE, FAHA, Cardiologist, University of Illinois at Chicago
Stacie Geller, MPH, PhD, Researcher, University of Illinois at Chicago
Robert Gessner, Forensic Medicine, Illinois Coroners and Medical Examiners Association
Robin L. Jones, MD, Obstetrician, Rush University
Abby Koch, MA, Researcher, University of Illinois at Chicago
Olga Lazala, PhD, APN, CNS/CNM, RNC-OB, Certified Nurse Midwife, Advocate Health and University of Illinois at Chicago
Kathryn Lindley, MD, FACC, Cardiologist, Washington University
Jerome Leow, MD, Pathologist, Rush University
Gary Loy, MD, Maternal-Fetal Medicine Specialist, Rush University
Kevin Madsen, MD, Maternal-Fetal Medicine Specialist, Advocate Good Shepherd Hospital
Lisa Masinter, MD, MPH, MS, Director of Research, Alliance Chicago
Paula Melone, DO, Maternal-Fetal Medicine Specialist, Loyola University Medical Center
Frank Nagorka, JD, EMT-P, Emergency Medicine and Law Specialist, Attorney at Law
Heather Nixon, MD, Obstetric Anesthesiologist, University of Illinois at Chicago
Brielle Osting, AM, MPP, Infant Mortality Reduction Coordinator, EverThrive Illinois
Beth Plunkett, MD, MPH, Obstetrician and Gynecologist, Northshore University Health System
Barbara Scavone, MD, Obstetric Anesthesiologist, University of Chicago
Shirley Scott, MS, RN-BC, C-EFM, APN, Perinatal Advance Practice Nurse, University of Illinois
Lee Smith, Family Case Manager, Mt. Sinai Community Institute
Michael Socol, MD, Maternal-Fetal Medicine Specialist, Northwestern University
Patrick Thornton, CNM, PhD, Certified Nurse Midwife, University of Illinois at Chicago
Paloma Toledo, MD, MPH, Anesthesiologist, Northwestern University

Maternal Mortality Review Committee- Violent Deaths

Thomas Barker, Law Enforcement Officer, Chicago Police Department

Deborah Boyle, FACOG/MD, BSN, Maternal-Fetal Medicine Specialist, University of Chicago

Erica Davis, MS, MA, Chicago Department of Public Health

Kara Driscoll, MD, ABPN, Psychiatrist, the Allegro Center

Stacie Geller, MPH, PhD, Researcher, University of Illinois at Chicago

Robert Gessner, Forensic Medicine, Illinois Coroners and Medical Examiners Association

Cindy Guerra, Law Enforcement Officer, Chicago Police Department

Nora Harms-Pavelski, Illinois Department of Children and Family Services

Katherine Kane-Willis, MA, Policy Analyst, Chicago Urban League

Jo Kim, PhD, Clinical Psychologist, University of Chicago

Carrie Klima, CNM, PhD, FACNM, Nurse Midwife, University of Illinois at Chicago

Abby Koch, MA, Researcher, University of Illinois at Chicago

Jerome Loew, MD, Pathologist, Rush University

Bahakia Madison, Addiction Drug Counselor, Chicago State University

Denise McCaffrey, BSW, Child Abuse Prevention Specialist, Prevent Child Abuse Illinois

Cindy Mitchell, RN, BSN, MSHL, Perinatal Center Administrator, St. John's-Springfield

Jaclyn Rodriguez, BSN, BS, RN, SANE-A, Sexual Assault Nurse Examiner Coordinator, Office of the Illinois Attorney General

Shirley Scott, MS, RN-BC, C-EFM, APN, Perinatal Advance Practice Nurse, University of Illinois

Lita Simanis, LCSW, Social Worker, AMITA Health/Alexian Brothers Health System

Vickie Smith, BA, Executive Director, Illinois Coalition against Domestic Violence

Amber Truehart, MD, Obstetrician/Gynecologist, University of Chicago

Teresa Tudor, Program Manager, Illinois Department of Human Services, Bureau of Domestic Violence, Sexual Assault and Human Trafficking

Carol Warshaw, MD, Psychiatrist, National Center on Domestic Violence, Trauma, and Mental Health, Hektoen Institute for Medical Research

Maripat Zeschke, RNC-EFM, MSN, Perinatal Center Administrator, Rush University Medical Center

Other Contributors

Chelsea Dade, MS

Isisah Duckworth, MPH, MBA

Pat Mitchell, MBA, RN

Virginia Reising, DNP, RN, PEL-CSN, PHNA-BC

For more information, please contact the Office of Women's Health and Family Services at DPH.MCH@illinois.gov.

Suggested Citation: Illinois Maternal Morbidity and Mortality Report. Illinois Department of Public Health. (October 2018)

The Illinois Department of Public Health would like to acknowledge the 93 Illinois women who died within one year of their pregnancy during 2015, and their loved ones.

We hope that our efforts to better understand the underlying causes of maternal mortality in Illinois will help prevent others from suffering from a similar fate.

525-535 West Jefferson Street • Springfield, Illinois 62761-0001 • www.dph.illinois.gov

Dear Colleagues,

The Illinois Department of Public Health (IDPH) is pleased to share this *Maternal Morbidity and Mortality in Illinois Report*. This Report is the culmination of more than a year of work done by two IDPH committees tasked with reviewing maternal deaths that occurred in 2015. The two committees, the Maternal Mortality Review Committee (MMRC) and the Maternal Mortality Review of Violent Deaths Committee (MMRC-V), are both subcommittees of the Perinatal Advisory Committee (PAC), an advisory board to IDPH.

The goal of this Report is to identify statewide trends in maternal mortality and, ultimately, provide recommendations to prevent maternal mortality and improve the health of Illinois residents. The recommendations included in this Report focus on five primary categories: hospitals, health care providers, health insurance plans and managed care organizations, the State of Illinois, and women and their families. Each set of recommendations addresses specific areas of concern based on the committees' findings and proposes actions which, once implemented, are expected to reduce maternal mortalities.

The subcommittees are continuing their work. They have started reviewing 2016 maternal deaths in an effort to identify changing trends and areas for statewide improvement with the ultimate goal of preventing maternal mortality. A report on the 2016 findings will be issued after the 2016 reviews are completed.

IDPH extends its sincere appreciation to those who serve on the MMRC and the MMRC-V. Those members have contributed their time and expertise to reviewing maternal deaths and developing this Report. Together, we can prevent maternal mortality and improve the health of Illinois residents.

Sincerely,

Nirav D. Shah

Nirav D. Shah, M.D., J.D.
Director, Illinois Department of Public Health

Executive Summary

Maternal morbidity (severe pregnancy complications) and mortality (death) are viewed internationally as indicators used to judge the overall health status of a country, state, or community. There has been a great deal of attention given to the rising rate of maternal mortality in the United States, and efforts to understand the reasons for the increase. The Illinois Department of Public Health (IDPH) identifies all pregnancy-associated deaths, or deaths occurring while a woman is pregnant or within a year of pregnancy, to collect data on maternal mortality. IDPH has worked with two committees, the Maternal Mortality Review Committee and the Maternal Mortality Review Committee for Violent Deaths, to review cases of maternal death that occurred during 2015. The aim of these committees is to better understand the causes of maternal mortality and develop statewide recommendations to prevent future maternal deaths, as well as determine whether the deaths were pregnancy-related (occurring due to a pregnancy complication) and whether they were preventable.

Key Findings:

- ✓ In Illinois during 2008-2016, an average of **73 women died** within one year of pregnancy.
- ✓ In Illinois, non-Hispanic Black women are **six times as likely to die** of a pregnancy-related condition as non-Hispanic White women.
- ✓ In Illinois, 72% of the pregnancy-related deaths and 93% of violent pregnant-associated deaths were deemed **preventable** by the review committees.
- ✓ **Obesity contributed to 44% of pregnancy-related deaths** in Illinois during 2015.
- ✓ In Illinois, the average cost for a delivery with severe maternal morbidity is four times more than a delivery without complications. During 2016-2017, there was a total of $107.5 million in hospital charges related to deliveries with severe maternal morbidity.

Key Recommendations:

- ✓ Illinois should **expand Medicaid eligibility for the postpartum period** from 60 days to one year after delivery and health insurance plans should **cover case management and outreach for postpartum high-risk women** for up to one year after delivery.
- ✓ The General Assembly should pass legislation to **adopt the American College of Obstetricians and Gynecologists' recommended maternal levels of care** within the state's regional perinatal system.
- ✓ The State should **create or expand home visiting programs to target high-risk mothers**, such as doula programs, in Illinois during pregnancy and the postpartum period. The State should also expand efforts to provide universal home visiting to all mothers within three weeks of giving birth.
- ✓ Illinois should **increase access to substance use and mental health services** statewide for pregnant and postpartum women.
- ✓ Hospitals should have **clear policies for emergency departments to identify pregnant and postpartum women**, and to consult with an obstetrical provider for all women with specific triggers indicative of pregnancy or postpartum complications.
- ✓ Health insurance plans should **separate payment for visits in the postpartum period from labor and delivery** (unbundle postpartum visit services from labor and delivery).

The Importance of Maternal Health

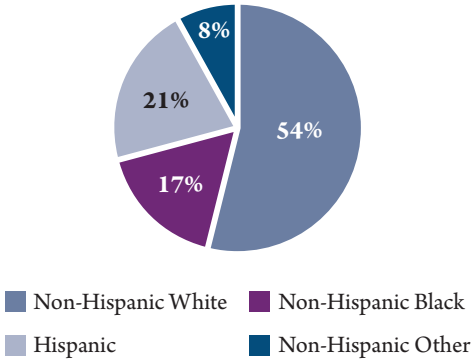
A woman's health and well-being are important across her lifespan as they can impact the health of her children, family, community, and future generations. Maternal health is defined as the health of women during pregnancy, childbirth, and in the postpartum period, and is a critical time for a woman's health. Typically women have more interaction with and access to health care services during pregnancy. Pregnancy can highlight larger concerns such as underlying chronic disease. It provides an opportunity to identify, treat, and manage conditions to improve a woman's overall health.

Maternal Health in Illinois

According to the most recent United States Census, Illinois is the fifth most populous state in the United States with 12.8 million residents, including 2.5 million women of reproductive age (15-44 years).[2] Illinois is also fifth in the nation for total number of births each year with approximately 150,000 occurring during 2016. Compared to all other states, Illinois ranked seventh for the number of White births, sixth for the number of Hispanic births and sixth for the number of Black births.[3]

Among Illinois live births in 2016, 54 percent were to White women, 17 percent were to Black women, 21 percent were to Hispanic women, and 8 percent were to non-Hispanic women of other races women (includes women identifying as Asian, Pacific Islander, American-Indian and those who indicated multiple races on the birth certificate) (Figure 1).[4]

Figure 1: Percent of Live Births by Race/Ethnicity, Illinois 2016



Illinois is a racially and ethnically diverse state. It also has geographic considerations that influence the availability of health care resources and impact health outcomes. Approximately two-thirds of the Illinois population resides in Cook County (includes the city of Chicago) and the five counties surrounding it. The remainder of the Illinois population lives in smaller urban areas or rural areas. Illinois is composed of a diverse range of communities, each with unique health care needs and barriers to care.

[1] Maternal Health. (2018). http://www.who.int/maternal-health/en/

[2] Annual Estimates of the Resident Population for Selected Age Groups by Sex-2017 Estimates for Illinois. (2018) United States Census Bureau American Fact Finder: https://www.census.gov/data/datasets/2017/demo/popest/state-detail.html#par_textimage_2063038847

[3] Martin, J. A., Hamilton, B. E., Osterman, M. J., Driscoll, A. K., & Drake, P. (2018). Births: Final data for 2016.

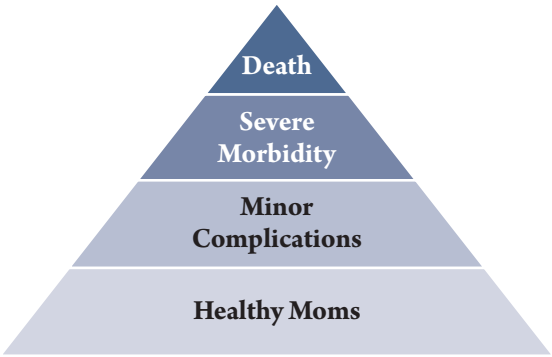
[4] Illinois Vital Statistics: Birth certificate data 2016

Maternal Health as a Continuum

Maternal health outcomes experienced by women in the perinatal and postpartum period occur across a continuum. The continuum begins with healthy moms (normal outcome with no complications), who make up the largest group of women. Then there is a spectrum of complications that women may experience, with complications becoming rarer as they become more severe (Figure 2). The most severe outcome at the end of the continuum is women who die during or after pregnancy. This report focuses on the two most severe outcomes in this continuum: severe maternal morbidity and maternal mortality. These events can highlight opportunities to improve women's health and health care.

Broadly defined, maternal mortality is the death of a woman during pregnancy or close in time to pregnancy. Severe maternal morbidity includes unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman's health. Both of these levels on the continuum are considered sentinel events that highlight critical issues in women's health and the health care system. Thus, studying cases of severe maternal morbidity and mortality and analyzing these data are essential to learning and identifying opportunities for improvement.

Figure 2: Maternal Health Continuum



Maternal morbidity and mortality are viewed internationally as indicators used to judge the overall health status of a country, state, or community. In the United States, maternal mortality is a relatively rare event, with approximately 700 women dying as a result of pregnancy or pregnancy-related complications each year.[5] However, while maternal mortality is declining elsewhere in the world, the rate of maternal mortality in the United States has been increasing and vast disparities exist between racial and ethnic groups.[6] The rate of maternal mortality in the United States is three to four times higher than other developed nations.[7] During 2011-2014 in the United States, pregnancy-related mortality ratios were four times higher for Black women than White women.[7]

The worrisome trend and racial disparity in the United States has led to an increase in media attention related to maternal mortality. The state of Illinois has been devoting resources to the collection and review of maternal deaths for more than a decade to monitor maternal deaths and describe societal impact. IDPH and partners work in collaboration to monitor, review, and quantify these important public health issues. While the majority of data in this report describe adverse outcomes for women who were recently pregnant, these data also reveal opportunities to positively improve women's health throughout life and reiterate the importance of women's health before and between pregnancies.

[5] Building U.S. Capacity to Review and Prevent Maternal Deaths. (2018). Report from nine maternal mortality review committees. http://reviewtoaction.org/Report_from_Nine_MMRCs

[6] Alkema, L., Chou, D., Hogan, D., Zhang, S., Moller, A. B., Gemmill, A., & Say, L. (2016). Global, regional, and national levels and trends in maternal mortality between 1990 and 2015, with scenario-based projections to 2030: a systematic analysis by the UN Maternal Mortality Estimation Inter-Agency Group. *The Lancet*, *387*(10017), 462-474.

[7] Pregnancy Mortality Surveillance System. (2018). https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-mortality-surveillance-system.htm

Given the persistent racial disparities in maternal health outcomes in Illinois and across the nation, it is apparent that disparities are the result of more than simply access to health care services. While health insurance and availability of services can remain major barriers for women, there are many other social and systemic issues that profoundly affect women's health. Factors such as poverty, quality of education, health literacy, employment, housing, availability of childcare, and neighborhood safety all deeply affect a woman's ability to thrive and be healthy. These factors are sometimes referred to as the "social determinants" of health and they affect a woman's ability to seek and receive health care, in addition to affecting her underlying health status.

It is important to also acknowledge racism as a driving force of the social determinants of health and as a barrier to achieving health equity and optimal health for all people.[8] Racism, including systematic racism and provider bias, negatively affects the quality of health care.[9] The impact of racism on health outcomes is particularly important for Illinois as it is a racially and ethnically diverse state, but remains very segregated. Chicago is consistently ranked as one of the most racially segregated cities in the United States. [10]

The purpose of this report is to describe the state of severe maternal morbidity and maternal mortality in Illinois. Derived from the actual deaths that occurred among Illinois women during 2015, this report also includes concrete recommendations about what can be done to prevent future negative outcomes for Illinois women. This includes an in-depth look at some of the social factors that are associated with poor maternal outcomes, and a discussion of how the data can inform effective actions to improve maternal health.

[8] Racism and Health. (2018). Retrieved from the American Public Health Association https://www.apha.org/topics-and-issues/health-equity/racism-and-health

[9] Hoffman, K. M., Trawalter, S., Axt, J. R., & Oliver, M. N. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proceedings of the National Academy of Sciences*, *113*(16), 4296-4301.

[10] Glaeser, E., Vigdor, J. (2012). The End of the Segregated Century: Racial Separation in America's Neighborhoods, 1890-2010. https://www.manhattan-institute.org/pdf/cr_66.pdf on September 7, 2018.

Severe Maternal Morbidity

Identifying and Calculating Severe Maternal Morbidity (SMM)

The term "severe maternal morbidity" represents a group of potentially life-threatening unexpected maternal conditions or complications that occur during labor and delivery. A standard method to identify severe maternal morbidity uses *International Classification of Diseases, version 10* (ICD-10) diagnosis and procedure codes to identify 21 indicators that are associated with high risk of maternal death.[11]

For this report, 2016 and 2017 Illinois hospital discharge data were used to identify deliveries with any of these complications. Severe maternal morbidity rates were calculated in alignment with guidelines from the Centers for Disease Control and Prevention (CDC) with one exception: blood transfusions were not included as an indicator of severe maternal morbidity in this report. Blood transfusions were excluded from this analysis due to reduced ability to accurately identify cases in the hospital discharge data and inconsistency across Illinois birthing hospitals in documenting this procedure.

Hospitalization records for more than 280,000 deliveries to Illinois residents were included in this analysis. Severe maternal morbidity rates in this report are calculated by dividing the number of severe maternal morbidity cases by the number of total deliveries, and multiplying by 10,000. This gives a rate that represents the number of women experiencing severe maternal morbidity out of every 10,000 deliveries. The national transition from ICD-9 to ICD-10 codes during late 2015 has prevented reliable trend analysis of severe maternal morbidity, thus only rates from 2016-2017 are included in this report.

2016-2017 Illinois Severe Maternal Morbidity Data

Illinois's severe maternal morbidity rate for 2016-2017 was **51.4 per 10,000 deliveries**. This means that about 1 in 200 women who delivered a baby experienced severe maternal morbidity.

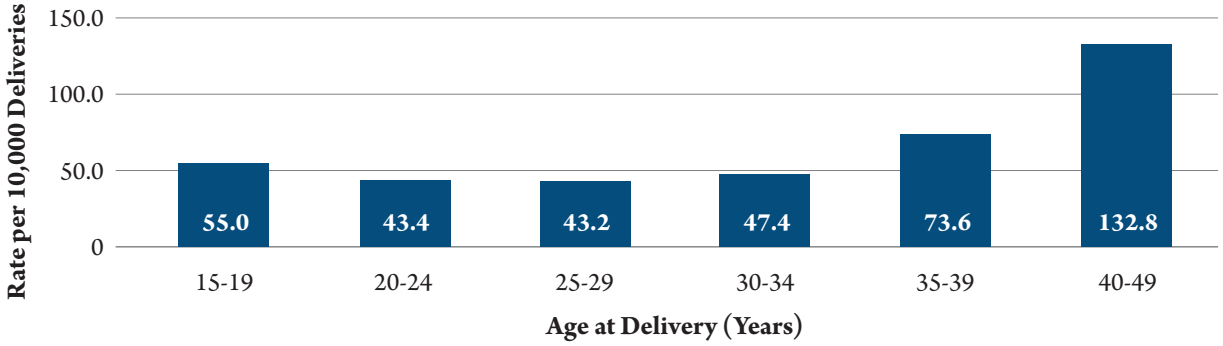
The top five most common severe maternal morbidity indicators in Illinois during 2016-2017 were hysterectomy, disseminated intravascular coagulation (DIC), acute renal failure, sepsis, and adult respiratory distress syndrome (Table 1). **Table 1. Top Five Severe Maternal Morbidity Indicators and Description- Illinois, 2016-2017**

Condition or Procedure	Rate per 10,000 Deliveries	Description
Hysterectomy	11.6	Removal of a woman's uterus
Disseminated intravascular coagulation	11.6	Blood clots form inside blood vessels
Acute renal failure	9.0	The kidneys cannot filter waste from the body (kidney failure)
Sepsis	7.6	Whole-body immune response to an infection, including inflammation
Adult respiratory distress syndrome	6.8	Fluid builds up in the lungs and blocks oxygen from going to the organs (respiratory failure)

To better understand how severe maternal morbidity impacts certain subgroups of Illinois' population, the severe maternal morbidity rate was calculated separately by characteristics of interest, including maternal age, race and ethnicity, insurance type, and IDPH health region.

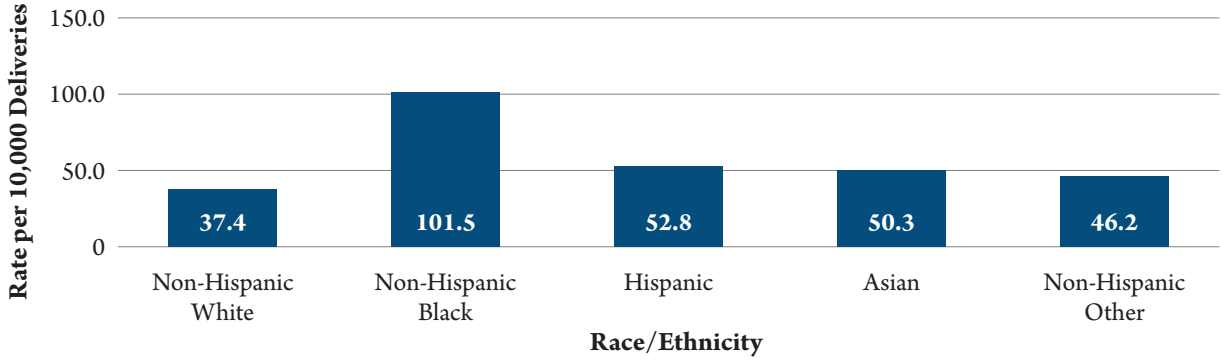
[11] Severe Maternal Morbidity in the United States. (2017). Centers for Disease Control and Prevention https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html

Figure 3: Severe Maternal Morbidity by Age
Illinois, 2016-2017



Women over the age of 40 years had the highest rate of severe maternal morbidity (132.8 per 10,000 deliveries) during 2016-2017 (Figure 3). Women between the ages of 35 and 39 years had the next highest rate of severe maternal morbidity (73.6 per 10,000 deliveries). Women between the ages of 15 to 19 years had the third highest rate of severe maternal morbidity (55.0 per 10,000 deliveries).

Figure 4: Severe Maternal Morbidity by Race/Ethnicity
Illinois, 2016-2017

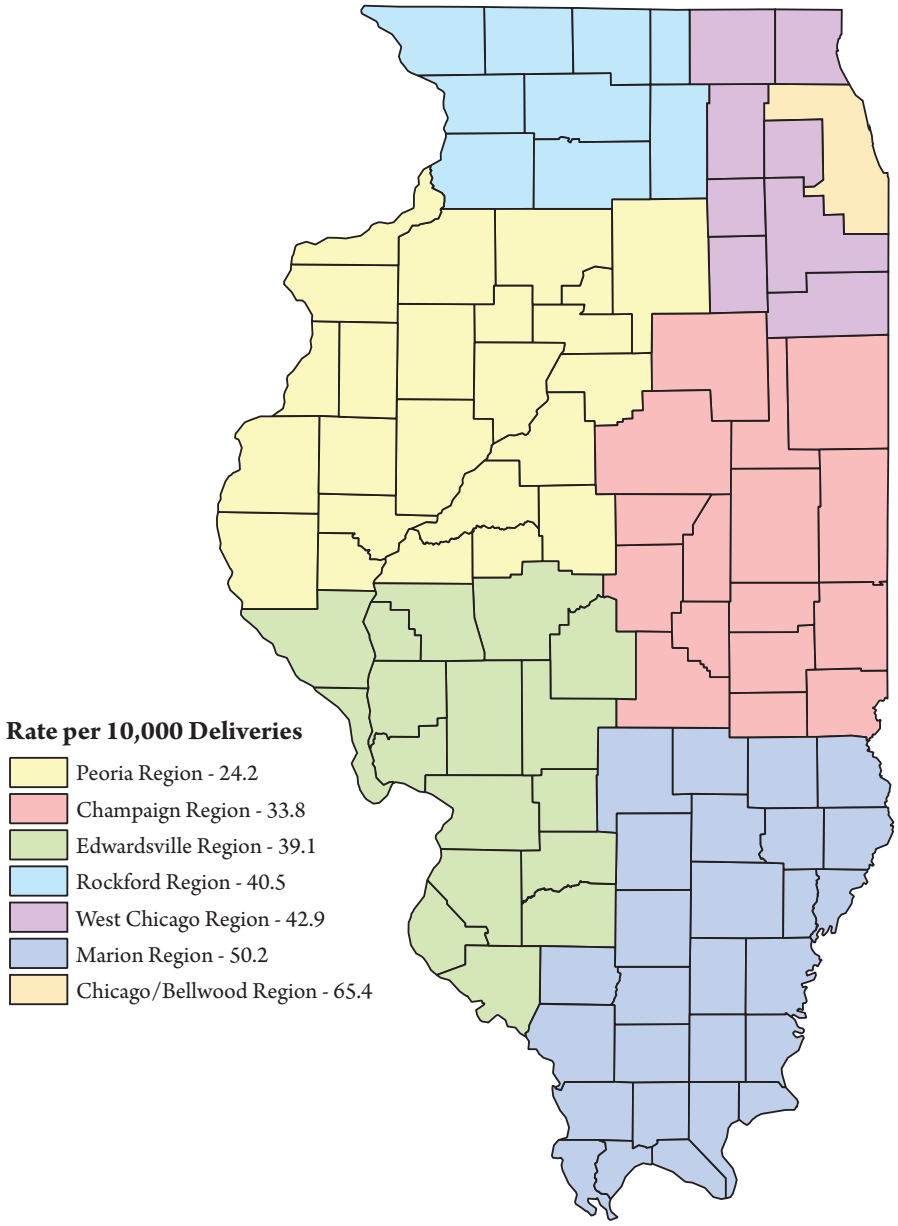


Black women had the highest rate of severe maternal morbidity in Illinois during 2016-2017 with a rate of 101.5 per 10,000 deliveries (Figure 4). This is almost three times as high as the rate for White women.

Women with public insurance (i.e. Medicaid-) had a higher rate of severe maternal morbidity during 2016-2017 (57.1 per 10, 000 deliveries) than women with private insurance (48.6 per 10,000 deliveries).

The rate of severe maternal morbidity also varied by geographic region in Illinois. Women in the Chicago/Bellwood IDPH Region had the highest rate of severe maternal morbidity during 2016-2017 (65.4 per 10,000 deliveries) (Figure 5). Women living in the Marion IDPH Region had the second highest rate of severe maternal morbidity (50.2 per 10,000 deliveries). Women living in the Peoria IDPH Region had the lowest rate of severe maternal morbidity (24.2 per 10,000 deliveries).

Figure 5: Severe Maternal Morbidity Rates by IDPH Region, 2016-2017



Impact of Severe Maternal Morbidity

Severe maternal morbidity can pose a large burden on Illinois' health care delivery system, including increased medical costs and longer lengths of stay for women after labor and delivery. There can also be re-hospitalizations in the postpartum period for complications due to severe maternal morbidity. During 2016-2017, there was a total of $107.5 million in hospital charges related to deliveries with severe maternal morbidity. During 2016-2017, the average charges for a delivery with severe maternal morbidity were four times higher than a delivery without severe maternal morbidity complications ($72,678 vs $18,119).

It is also important to consider severe maternal morbidity in conjunction with common chronic health conditions affecting pregnant women, including diabetes and hypertension (high blood pressure). Among Illinois women with severe maternal morbidity during 2016-2017, 45.1 percent had hypertension, 13.1 percent had diabetes, and 8.3 percent had both diabetes and hypertension. This is much higher than women without severe maternal morbidity (12.1 percent had hypertension, 8.2 percent had diabetes, and 1.8 percent had both conditions).

Uses of Severe Maternal Morbidity Data

Severe maternal morbidity data has several uses for the state, including setting priorities and as part of prevention and quality improvement efforts. For example, the topic of severe maternal morbidity was included in the Maternal and Child Health Section of the Illinois State Health Assessment, released in January 2016. The State Health Assessment is a systematic approach to collecting, analyzing, and using data to mobilize communities, develop priorities, garner resources, and plan actions to improve the public's health.[12] The data and topics included in the State Health Assessment informed decision making for the strategies identified the Illinois State Health Improvement Plan, a guide to reaching the goals of the *Healthy Illinois 2021* initiative.

Severe maternal morbidity events are considered "near miss" events and provide a rich opportunity to highlight both challenges and successes in the midst of providing care to a woman with complications. Illinois is the first state in the nation to implement a statewide severe maternal morbidity review. A research and implementation team from the University of Illinois at Chicago has been working closely with the 10 regionalized perinatal centers and the State's Maternal and Child Health (Title V) program to implement consistent facility-level reviews of severe maternal morbidity cases. For this review, a case of severe maternal morbidity is defined as a woman who has been admitted to an intensive care or critical care unit and/or has been transfused four or more units of packed red blood cells. Perinatal administrators abstract significant information from medical records and review the cases with staff at the hospital where the event took place. The goal of this review is for the clinical team to learn from what went well and from what could be improved in the process of caring for women. The review team also identifies potentially preventable factors that contributed in the progression to severe morbidity.

[12] Healthy Illinois 2021: State Health Assessment. (January 2016).
http://www.healthycommunities.illinois.gov/documents/State-Health-Assessment-Final-091316.pdf

Maternal Mortality

Maternal mortality is the death of a woman while pregnant or close in time to pregnancy. Maternal mortality serves as an indicator of the quality of health and health care of a community. Different categories of maternal mortality are used to track and analyze these deaths. Traditionally, many organizations have used a cut-off of deaths within 42 days of pregnancy to study maternal death. But there are many reasons why this short time period may not be appropriate. Instead, Illinois uses the following standard definitions defined by the CDC:[13]

> *Pregnancy-Associated Death* = The death of a woman during pregnancy or within one year of the end of a pregnancy from any cause.
>
> *Pregnancy-Related Death* = The death of a woman during pregnancy or within one year of the end of a pregnancy from a pregnancy complication. The death is due to a chain of events initiated by the pregnancy or the aggravation of an unrelated condition by the physiologic effects of pregnancy.

Pregnancy-associated deaths, therefore, represent the overall umbrella of all women who die within one year of pregnancy. Pregnancy-associated deaths can then be broken down into two sub-categories: those related to pregnancy, and those unrelated to pregnancy. Tracking pregnancy-associated deaths overall, as well as pregnancy-related deaths, are important for understanding maternal mortality.

There are two important phases for tracking and understanding maternal mortality in Illinois. The first phase is to identify all pregnancy-associated deaths. The second phase involves reviewing certain types of pregnancy-associated deaths to closely examine the cause of death, identify factors that influenced the death, and develop potential recommendations for preventing future deaths.

Identifying and Counting Maternal Deaths

Since 2002, Illinois has followed the CDC recommendation to identify all pregnancy-associated deaths. Illinois uses multiple methods simultaneously to ensure pregnancy-associated deaths are accurately identified and counted each year. First, the state database of death certificates is used to identify deaths that may be pregnancy-associated. There is a checkbox on the death certificate that indicates whether a woman was pregnant at the time of death or pregnant within the last year. Some specific cause of death codes indicate that a death may have been related to pregnancy. Death certificates for any woman age 15 to 50 years are also checked against the databases of birth certificates and fetal death certificates to look for matching information. If there is a birth or fetal death record in the twelve months prior to a woman's death, her death is flagged as a pregnancy-associated death.

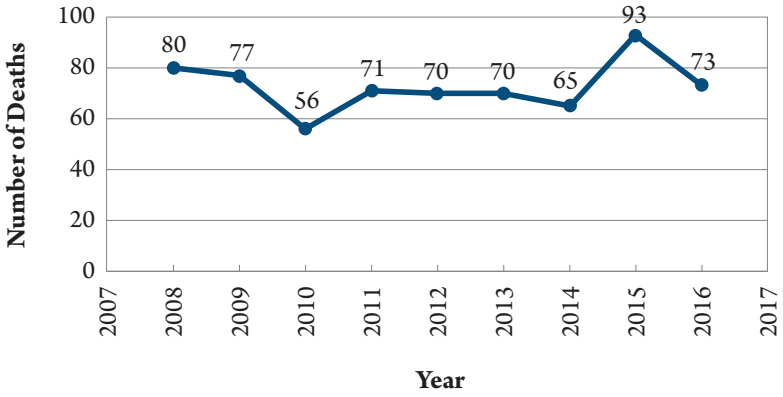
In addition to the state public health data systems, there are other ways that maternal deaths are identified in Illinois. All Illinois hospitals are required by the State to report any known pregnancy-associated deaths to IDPH within 24 hours. In addition, IDPH completes regular searches of major newspapers throughout Illinois to identify articles or obituaries that indicate the death of a woman while pregnant or within one year of pregnancy. For example, if an obituary mentions that a deceased woman has a surviving child who is less than one year old, the woman's case is flagged as a potential pregnancy-associated death.

[13] Committee Facilitation Guide. (2017). http://reviewtoaction.org/rsc-ra/term/80

Once the list of potential cases is complete, IDPH contacts the hospitals and health centers where the women received care to request medical records from the time of her most recent pregnancy to her death. These medical records provide details about the woman's death and her medical history. For instance, records are routinely requested from the hospital where the woman died, the hospital where she gave birth, and the physician office or health center where she received prenatal care. When relevant, records are also requested from police departments, sheriff's offices, and medical examiner or coroner's offices. IDPH is constantly reviewing records to identify additional hospitals or health care providers that may be able to send more records that provide information on the case. Hospitals and medical providers are required to provide copies of all medical records related to maternal deaths within 30 days of IDPH's request. IDPH compiles this information to confirm and accurately track the number of pregnancy-associated deaths in Illinois each year.

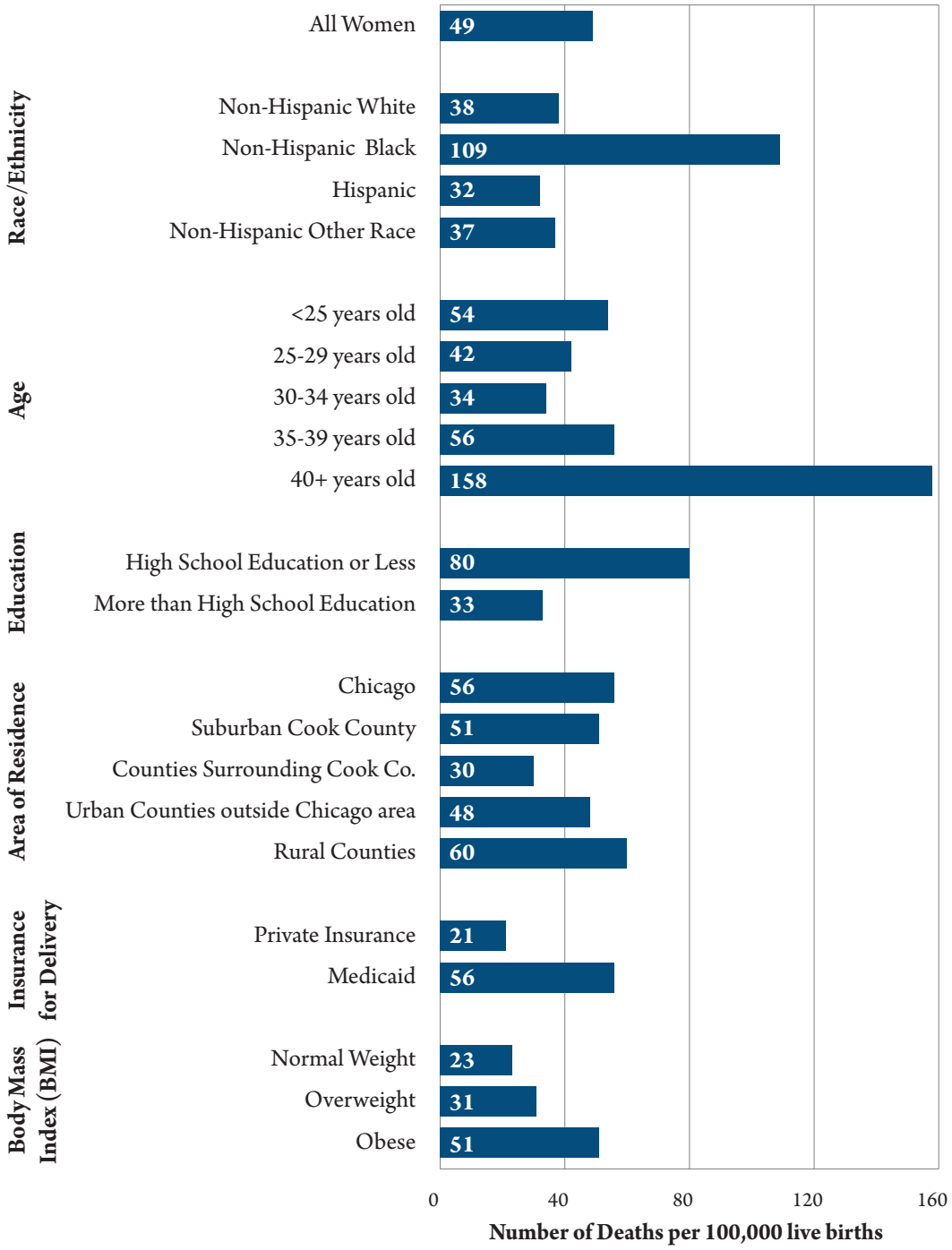
During 2008-2016, a total of 655 Illinois women died within one year of pregnancy. The average annual number of women who died within one year of pregnancy was approximately 73 women. The lowest number of deaths occurred during 2010 (56 deaths) and the highest number of deaths occurred during 2015 (93 deaths). Despite some annual fluctuation, there is no obvious upward or downward trend in pregnancy-associated deaths during the last nine years in Illinois (Figure 6).

Figure 6: Number of Pregnancy-Associated Deaths, Illinois 2008-2016



In Figure 7, the pregnancy-associated mortality ratio (PAMR) is shown for different sub-groups of women. The PAMR is a more meaningful than case counts when comparing the likelihood of pregnancy-associated death across different groups. The PAMR is calculated by dividing the number of pregnancy-associated deaths by the number of live births for each sub-group, and then multiplying by 100,000. The PAMR is interpreted as the number of deaths that occurred for every 100,000 live births in a specific group of women.

Figure 7: Pregnancy-Associated Mortality Ratio (PAMR), By Demographics, Illinois 2014-2016



Data interpretation example: *The bar on the chart referring to non-Hispanic Black women means that for every 100,000 births among non-Hispanic Black women, 109 non-Hispanic Black women experienced a pregnancy-associated death.*

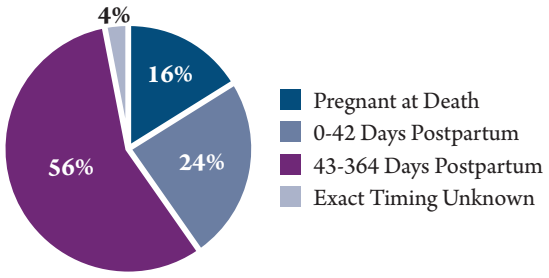
During 2014-2016, there were 231 pregnancy-associated deaths, which translated to a PAMR of 49 deaths for every 100,000 live births in Illinois (Figure 7).

However, pregnancy-associated mortality is not equally experienced by all groups of women. There are significant differences in the PAMR for women based on their race/ethnicity, age, education level, location of residence, insurance type, and body mass index (BMI).

- Black women were about three times as likely to die within a year of pregnancy as women of any other race/ethnicity.
- Women ages 30-34 had the lowest PAMR. Younger women had a slightly higher risk of death within one year of pregnancy, but the largest increase in risk was present for women in their 40s. Women over age 40 years were almost five times as likely to die within one year of pregnancy as women who were 30-34 years old.
- Women with a high school education or less were about two and a half times as likely to die within one year of pregnancy as women who had more than a high school education.
- Across the state of Illinois, the PAMR was highest for women living in rural counties and in the city of Chicago. Women who lived in the counties surrounding Cook County had the lowest PAMR.
- Women on Medicaid during pregnancy were two and a half times as likely to die within one year of pregnancy as women with private insurance.
- A higher BMI was also related to a higher likelihood of death within one year after pregnancy. Obese women were more than twice as likely as normal weight women to die within one year of pregnancy.

Understanding the differences in the likelihood of pregnancy-associated death is an important first step in understanding who is most affected by this public health problem, and how to target interventions and resources.

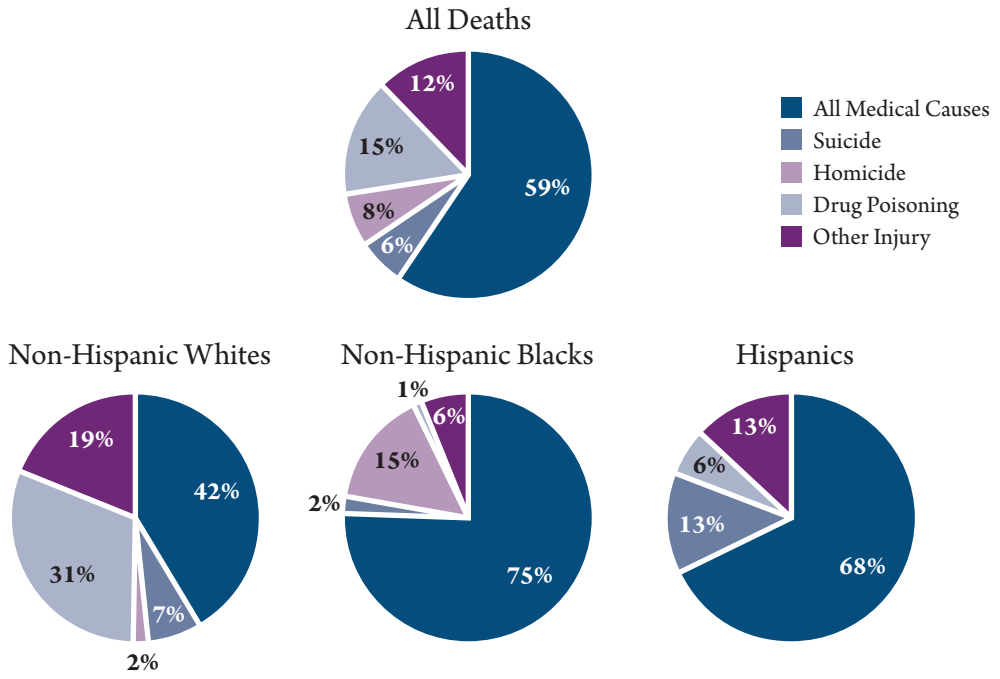
Figure 8: Timing of Pregnancy -Associated Deaths, Illinois 2014-2016



Of the pregnancy-associated deaths that occurred during 2014-2016, 16 percent of deaths occurred to women while they were pregnant, 24 percent occurred within 42 days of the most recent pregnancy, and 56 percent occurred between 43 and 364 days after the most recent pregnancy (Figure 8). An additional four percent of women who died were known to have had a pregnancy within the last year, but the exact timing was unknown.

These data demonstrate the importance of tracking deaths to one year postpartum (rather than the traditional measure of the first 42 days) as the majority of all pregnancy-associated deaths occur after 42 days postpartum.

Figure 9: Underlying Cause of Death for Pregnancy-Associated Deaths, Overall and by Race/Ethnicity, Illinois 2014-2016



The "underlying cause" field on the death certificate is used to categorize the type of pregnancy-associated death. For pregnancy-associated deaths that occurred during 2014-2016, 59 percent were related to medical causes of death, such as hemorrhage, infection, cardiac conditions, or cancer (Figure 9). A total of 29 percent of all pregnancy-associated deaths during this time period were deemed "violent deaths," which were caused by suicide (6 percent), homicide (8 percent), or drug overdose (15 percent). The final 12 percent of pregnancy-associated deaths were related to other types of injury, which were mostly caused by motor vehicle crashes.

During 2014-2016, the most common causes of pregnancy-associated deaths differed by race/ethnicity:

- While medical causes were the most common cause of death for all three racial/ethnic groups, medical deaths comprised a smaller e proportion of pregnancy-associated deaths for White women than they did for Hispanic and Black women.
- Suicide was a very rare cause of pregnancy-associated death for Black women (3 percent), but accounted for slightly more pregnancy-associated deaths for White women (7 percent) and Hispanic women (13 percent).
- Homicides accounted for 15 percent of all pregnancy-associated deaths for Black women. In contrast, homicide was a very rare cause of pregnancy-associated death for White women (2 percent) and did not cause any pregnancy-associated deaths for Hispanic women.
- Drug overdose comprised 31 percent of all pregnancy-associated deaths for White women. In contrast, overdoses accounted for only 1 percent of pregnancy-associated deaths for Black women and only 6 percent of pregnancy-associated deaths for Hispanic women.
- Violent deaths (homicides, suicides, and drug overdoses combined) accounted for 40 percent of deaths to White women, but only 19 percent of deaths to Black women and Hispanic women.

The variation in the leading causes of death raises questions about why these differences occur and how to prevent deaths effectively in different communities. These questions cannot be answered by the death certificate data alone, and they draw attention to the need for more comprehensive review of pregnancy-associated deaths.

Reviewing and Assessing Maternal Deaths

Though information from death certificates and other public health records may help identify counts of maternal deaths, these records cannot determine the preventability of cases or the factors involved in the case. The CDC recommends review of maternal deaths by a multidisciplinary committee as a means of gathering additional information about how the woman died, whether the death was preventable, and opportunities for preventing future maternal deaths.

Illinois was one of the first states to implement maternal mortality review, and created the state Maternal Mortality Review Committee (MMRC) in 2000. Additionally, a second state committee, the Maternal Mortality Review Committee on Violent Deaths (MMRC-V) was formed in 2015 to review deaths of women who died due to homicide, suicide, or drug overdose. These committees are structured as sub-committees of the state's Perinatal Advisory Committee, with the purpose of providing expert recommendations to IDPH on how to improve maternal and infant health.

In 2016, IDPH sought technical assistance from the CDC to evaluate opportunities to strengthen Illinois' process for reviewing maternal deaths. CDC had been consulting with many states across the country to strengthen the capacity for reviewing maternal deaths and to learn about experiences and practices of other states. CDC staff visited Illinois for a technical assistance meeting, helped evaluate the state's procedures and processes, and provided resources on best practices for state-based maternal mortality review.

Several key opportunities for improving Illinois' maternal mortality review process were identified. While the committee had existed for many years, its focus had primarily been on the clinical factors influencing maternal death. CDC advised Illinois to shift the MMRC approach to be more population health focused and to consider social and non-medical factors that may have contributed to a death. Overall, IDPH saw a need for more structured administrative and technical support to the committees, especially in terms of chart abstraction and data analysis. As a result, IDPH committed to taking a more active role in supporting the committee meetings, participating in reviews, and collecting and analyzing data.

There was also a need to systematize the procedures for the committee, most notably for the process of creating case abstracts (summaries) and standardizing the data collected on each case. To align with national work, Illinois adopted the use of standard CDC data collection forms and resources. This ensured that the data collected by the Illinois MMRC and MMRC-V would be consistent with other review committees across the country.

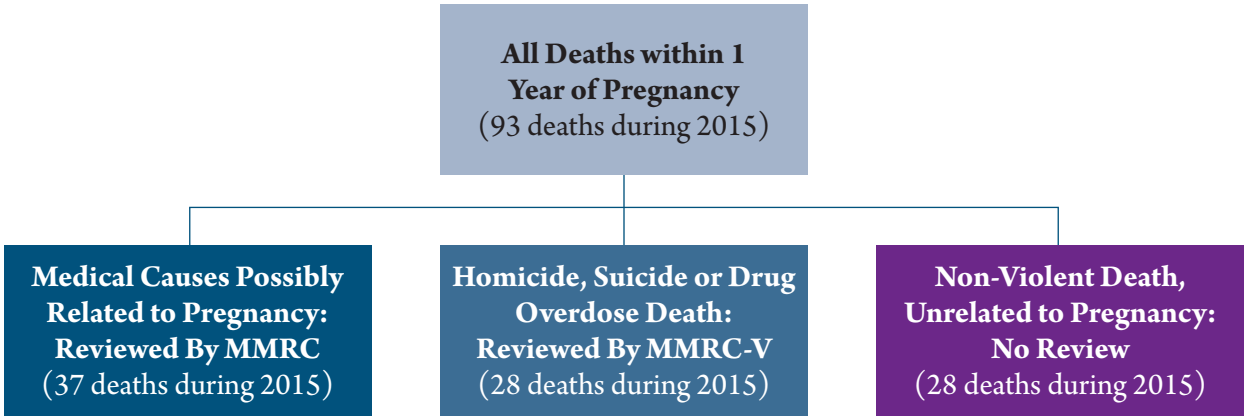
In the end, IDPH led a thorough re-design of the state MMRC and MMRC-V, with seven specific goals framing the change:

1. Ensure population-based state-level reviews
2. Improve timeliness of reviews
3. Develop sustainable systems for data collection and abstraction
4. Improve review efficiency and focus
5. Widen MMRC membership to diversify the expertise and racial/ethnic makeup of the committee
6. Generate public health focused recommendations
7. Use data to identify trends, emerging issues, and action steps

Starting in early 2017, Illinois MMRC and MMRC-V implemented the new abstraction and review process. The first stage of this process is to select cases for review by the two committees. IDPH staff review pregnancy-associated deaths records. The causes of death are reviewed and cases are sorted into one of three categories: cases assigned to MMRC, cases assigned to MMRC-V, or cases not requiring a detailed review.

- The MMRC is charged with reviewing all pregnancy-associated deaths from medical causes that were potentially related to pregnancy.
- The MMRC-V is charged with reviewing all pregnancy-associated deaths due to homicide, suicide, or drug overdose.
- Deaths that do not fall under either of these definitions are still counted in the state total of pregnancy-associated deaths, but they are not reviewed by the state committees. An example of a death that would not be reviewed would be most deaths related to cancer or to motor vehicle crashes.

Figure 10: Pregnancy-Associated Deaths by Review Type, Illinois 2015



From April 2017 to August 2018, the Illinois MMRC and MMRC-V completed reviews of the pregnancy-associated deaths that occurred during 2015. A total of 65 cases were reviewed – 37 by the MMRC and 28 by the MMRC-V (Figure 10). The remaining 28 cases were not reviewed because they did not fit the specific types of deaths under the purview of each committee.

After the cases were sorted and assigned to each committee, the case abstracts were prepared. Regardless of the committee that completed the review, the abstraction process was the same. The abstractor reviewed all the medical and other relevant records (such as police records) that were collected during the case identification process. A summary of the case was then written using templates developed by the CDC. The abstract included key information about the woman's medical history, social factors, and the timeline of events leading up to the woman's death. Ultimately the abstracts were what the committee used to make decisions about preventability and key factors in the case.

To guide the discussion during the meetings and collect standard information on each death, both the MMRC and MMRC-V used a standardized data collection form developed by the CDC called the "Committee Decision Form."[13]

This form walks the committee through key questions about each death, including the following:

1. **What was the cause of death?**

   Both committees focus on the underlying cause of death, which is the medical condition or event that led to the woman's death. The committees also evaluate whether they agreed with the cause of death listed on the death certificate.

2. **Was the death related to pregnancy?**

   A pregnancy-related death is defined as a "death from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy."[14] Using this definition, the committee considered whether the woman would have died if she had not been pregnant.

3. **Was the death potentially preventable?**

   Preventable deaths are defined as those having "at least some chance of the death being averted by one or more reasonable changes to patient, family, community, provider, and/or systems factors."[14] The committees may also differentiate between cases with some chance or a good chance of being prevented.

4. **What factors contributed to the death?**

   These factors are the steps along the way that, if altered, may have prevented the woman's death. The committees are encouraged to consider factors related to the patient, health care providers, facilities/hospitals where the woman sought care, the community where the woman lived, or to the systems that influence the lifestyle, care, and health services for the woman.

5. **What recommendations could be implemented to prevent future deaths?**

   Committees considered the "lessons learned" from each case and how various interventions could have prevented the woman's death. The recommendations were shaped for each case individually, but also repeated across cases when common themes or factors were present.

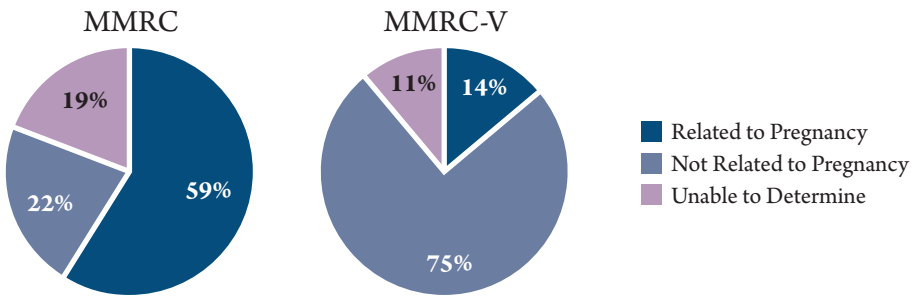
After case review, the data from the committees' decision forms are recorded by IDPH and aggregated with the other cases from the same case year. The information can be combined with data from death certificates and other sources to carry out detailed analyses of the data on the reviewed cases.

The next section of this report represents an analysis of the case review data for the deaths occurring during 2015. This is the culmination of the first year of maternal mortality reviews under the state's re-designed process, and the first time that maternal mortality review data have been publicly reported by IDPH.

[14] Building U.S. Capacity to Review and Prevent Maternal Deaths. (2018). Report from nine maternal mortality review committees. http://reviewtoaction.org/Report_from_Nine_MMRCs

Pregnancy-Related Deaths During 2015

Figure 11: Deaths Determined to Be Related to Pregnancy, Illinois Maternal Mortality Reviews 2015



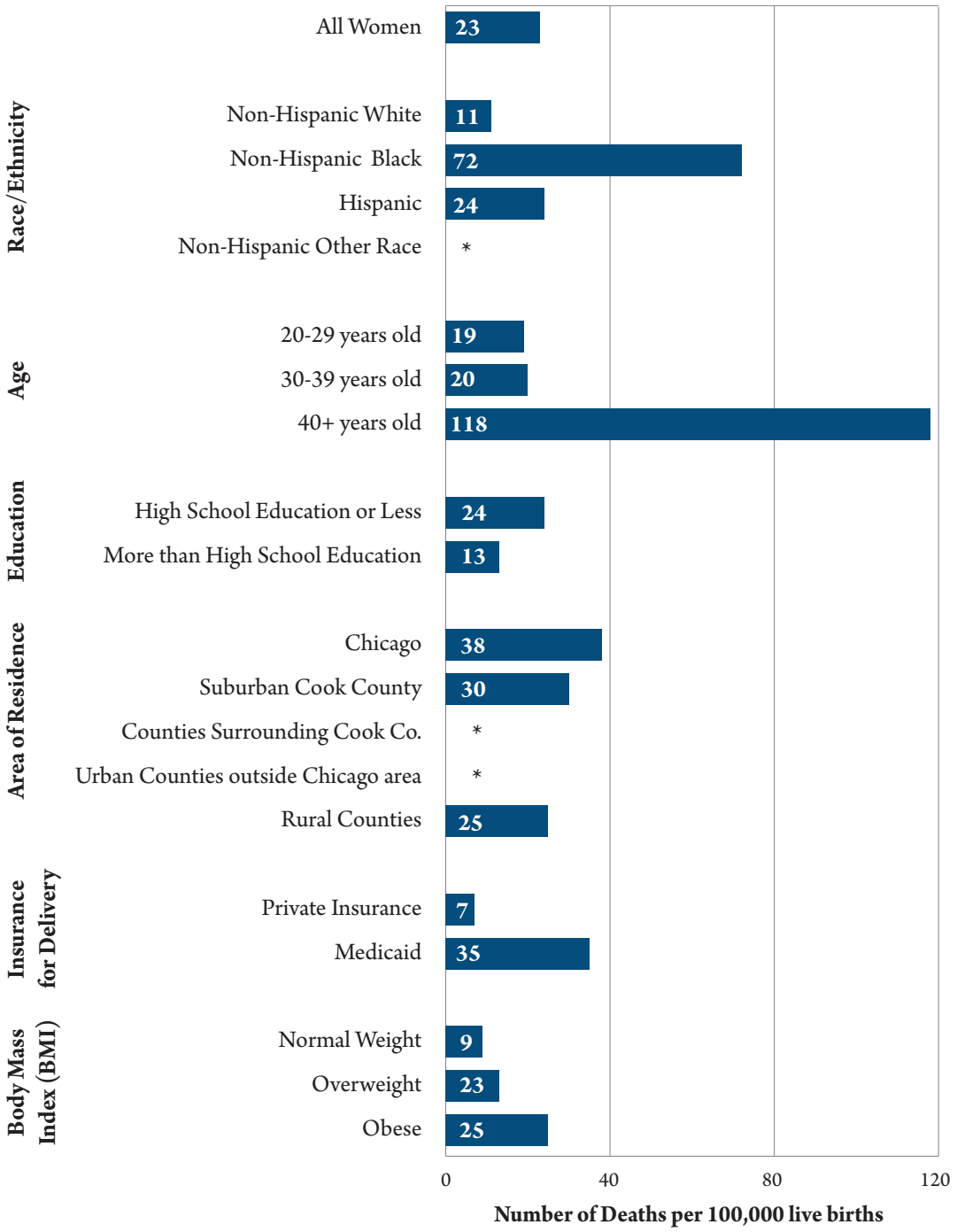
Of the 37 cases reviewed by the MMRC, 59 percent (22 cases) were determined to be related to pregnancy and 22 percent (8 deaths) were determined to be not related to pregnancy (Figure 11). For 19 percent of cases (7 deaths), the committee was unable to determine definitively whether the death was related to pregnancy, usually due to incomplete information or uncertainty about the woman's cause of death.

Of the 28 cases reviewed by the MMRC-V, 14 percent (4 deaths) were determined to be related to pregnancy and 75 percent (21 cases) were determined to be not-related to pregnancy. For 11 percent of cases (3 deaths), the committee was unable to determine whether the death was pregnancy-related.

For the purposes of the rest of this section, the deaths determined to be related to pregnancy and those unable to be determined are combined for analysis of all "pregnancy-related" deaths. We made the decision to include the cases where relation to pregnancy was unable to be determined because the committee could not positively rule out a relation to pregnancy. Including these deaths captures the group that may have been related to pregnancy (even if not definitely determined). Between the two committees, 36 case reviews are combined in an analysis of pregnancy-related deaths; this represents 38.7 percent of all pregnancy-associated deaths that occurred during 2015.

Figure 12 shows the "pregnancy-related mortality ratio" (PRMR) for different sub-groups of women. The PRMR is calculated by dividing the number of deaths that were determined by the committees to be pregnancy-related, or undetermined, by the number of live births for each sub-group, and then multiplying by 100,000. The PRMR is interpreted as the number of pregnancy-related deaths that occurred for every 100,000 live births in a specific group of women.

Figure 12: Pregnancy-Related Mortality Ratio (PRMR), By Demographics, Illinois 2015



** Fewer than 5 deaths is not reported due to small sample size*

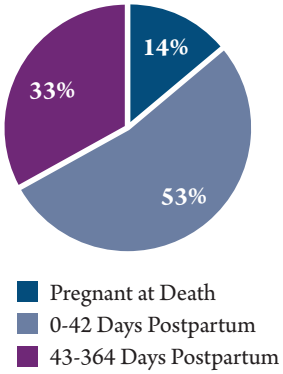
Data interpretation example: *The bar on the chart referring to non-Hispanic Black women means that for every 100,000 births among non-Hispanic Black women, 68 non-Hispanic Black women experienced a pregnancy-related death.*

During 2015 there were 36 pregnancy-related deaths, which translated to a PRMR of 23 deaths for every 100,000 live births in Illinois (Figure 12).

However, pregnancy-related mortality is not equally experienced by all groups of women. There are differences in the PRMR for women based on their race/ethnicity, age, education level, location of residence, insurance type, and BMI.

- Black women were about six times as likely to die from a pregnancy-related cause as White women. Hispanic women were about twice as likely as White women to die from a pregnancy-related cause.
- Women in their 40s were about six times as likely to die from a pregnancy-related cause as women in their 20s or 30s.
- Women with a high school education or less were about twice as likely to die from a pregnancy-related cause as women who had more than a high school education.
- Across the state of Illinois, women who lived in Chicago were the most likely to die from a pregnancy-related cause.
- Women on Medicaid during pregnancy were nearly five times as likely as women with private insurance to die from a pregnancy-related cause.
- A higher BMI was related to a higher likelihood of pregnancy-related death. Obese women were more than twice as likely as normal weight women to die from a pregnancy-related cause.

Figure 13: Timing of Pregnancy-Related Deaths, Illinois 2015

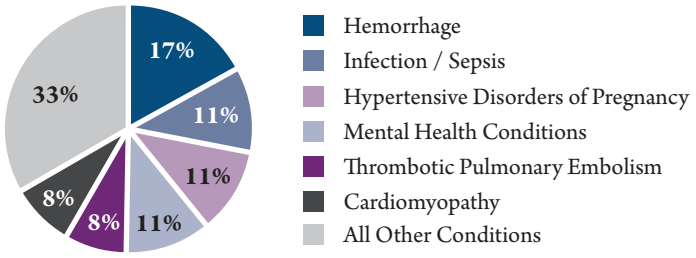


Identifying these differences in the burden of pregnancy-related death across the population is an important first step in understanding who is most affected by this public health problem, and how to appropriately target prevention activities.

Of the pregnancy-related deaths during 2015, 14 percent of deaths occurred during pregnancy, 53 percent occurred within 42 days of the most recent pregnancy, and 33 percent occurred between 43 and 364 days after the most recent pregnancy (Figure 13).

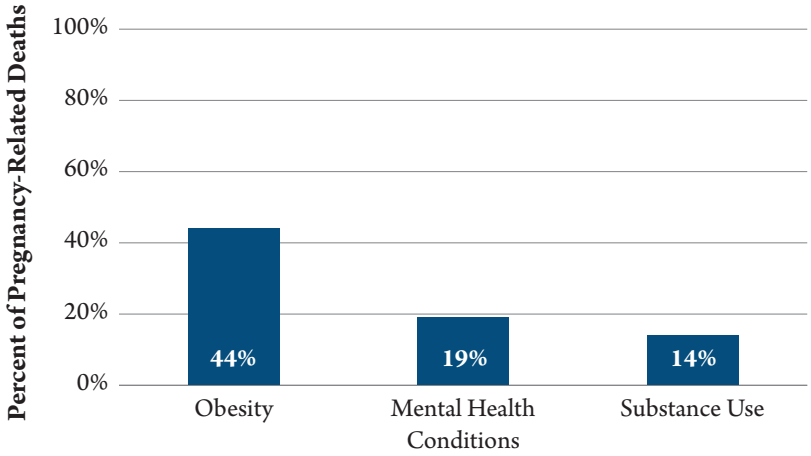
While most pregnancy-related cases occur while pregnant or within the first six weeks postpartum, about one in three cases occurs more than 42 days postpartum. This demonstrates the importance of the committees continuing to review cases through the first full year postpartum to ensure a review of all pregnancy-related deaths.

Figure 14: Underlying Cause of Death for Pregnancy-Related Deaths, Illinois 2015



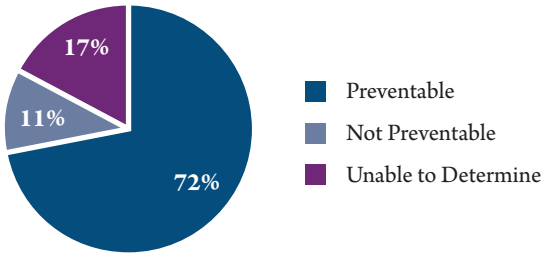
For the 36 pregnancy-related deaths in Illinois, there were many different causes of death (Figure 14). The top six most common causes were hemorrhage (6 deaths), infection/sepsis (4 deaths), hypertensive disorders of pregnancy (4 deaths), mental health conditions (4 deaths), thrombotic pulmonary embolism (3 deaths), and cardiomyopathy (3 deaths). All other conditions combined accounted for the remaining 12 cases (33 percent).

Figure 15: Factors that Contributed to Pregnancy-Related Deaths, Illinois 2015



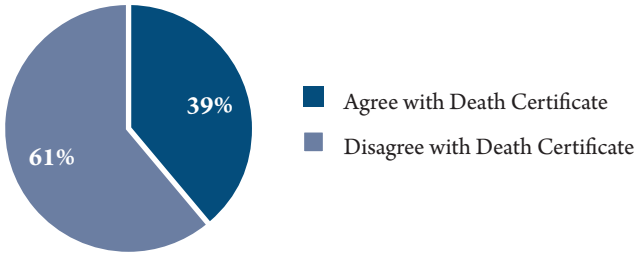
The committees also discussed and determined whether other specific factors contributed to the pregnancy-related deaths. Of the 36 pregnancy-related deaths, obesity contributed to 44 percent (16 deaths), mental health conditions contributed to 19 percent (7 deaths), and substance use contributed to 14 percent (5 deaths) (Figure 15).

Figure 16: Potential Preventability of Pregnancy-Related Deaths, Illinois 2015



After discussion of the cause of death and contributing factors, the committees determined whether the death was potentially preventable. For 72 percent of the pregnancy-related deaths, the committee determined there was at least some chance of the death being prevented (Figure 16). For 11 percent of cases, the death was determined to be not preventable. For the remaining 17 percent, the committee was unable to determine whether the death was preventable – either because key information was missing from the records, or because the committee could not reach consensus on the case.

Figure 17. Committee Agreement with Cause of Death Listed on Death Certificate, Pregnancy-Related Deaths, Illinois 2015



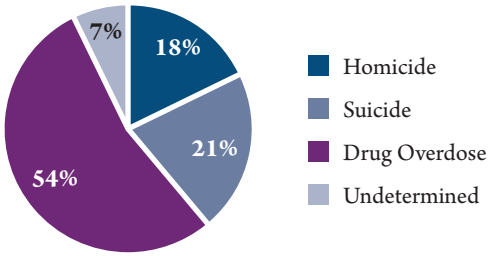
The committees agreed with the cause of death listed on the death certificate in only 39 percent of the pregnancy-related deaths (Figure 17). Often, the committees were able to identify a more specific underlying cause of death than was listed on the death certificate. This finding highlights the importance and relevance of maternal mortality review as a way to better understand the reasons women are dying, trends in major causes of deaths, and how to prevent such deaths. If only the death certificate information had been used to identify cause of death, important information about the true causes of death may have been missed.

Violent Pregnancy-Associated Deaths During 2015

The Illinois MMRC-V reviews all pregnancy-associated deaths that are suspected to be the result of homicide, suicide, or drug overdose. From April 2017 to May 2018, the MMRC-V reviewed 28 deaths that occurred during 2015.

While few of these deaths are related to pregnancy (see Figure 11), it is important to review these deaths to better understand the experience of violence, mental disorders, and substance use disorders among Illinois women. Pregnancy and the postpartum period represent a unique opportunity for medical providers to identify concerns related to mental health, substance use, or violence, to link women to needed services, and to provide needed treatment and support services. There is evidence that the rate of drug overdose-related deaths is rising among all Illinois women of reproductive age, and among pregnancy-associated deaths.[15] Ongoing review of these cases will inform prevention efforts.

Figure 18. Cause of Death, Violent Pregnancy-Associated Deaths, Illinois 2015



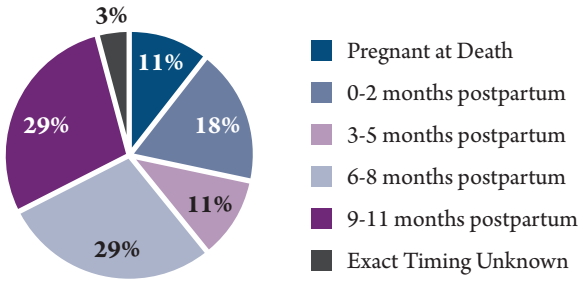
Of the 28 cases reviewed by the MMRC-V, 18 percent (5 deaths) were homicides, 21 percent (6 deaths) were suicides, 54 percent (15 deaths) were drug overdoses, and 7 percent (2 deaths) were undetermined (Figure 18).

For the purposes of this report, these four categories are mutually exclusive – meaning that each case is classified into only one of the four groups. In the case that a suicide was completed by intentionally overusing a drug or medication, these cases are included in the "suicide" category and not the "drug overdose" category.

As already shown in Figure 9, women of different races/ethnicities are more likely to experience different types of violent pregnancy-associated deaths. The most common categories of violent death were drug overdose for White women, homicide for Black women, and suicide for Hispanic women. This speaks to the need for studying each of these three categories in more detail and understanding the experience of different women across the state of Illinois.

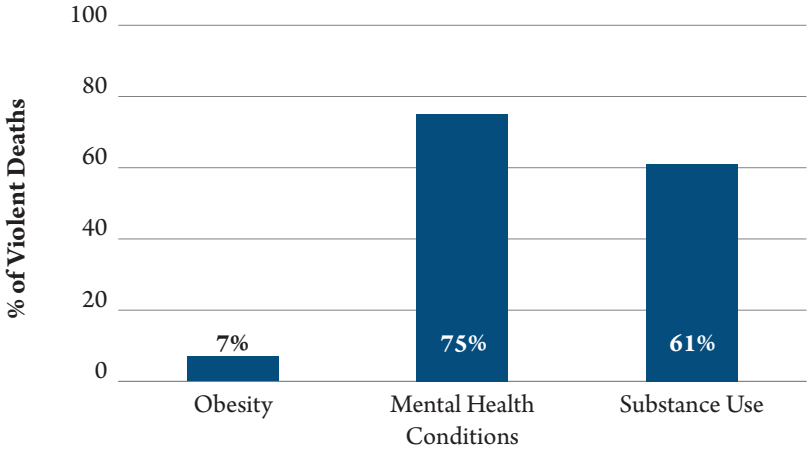
[15] Data Snapshot: Drug Poisoning and Opioid-Related Deaths among Illinois Women of Reproductive Age. (May 2018). http://www.dph.illinois.gov/sites/default/files/publications/publicationsowhdrug-poisoning-and-opioid-deaths-among-women_0.pdf

Figure 19. Timing of Violent Pregnancy-Associated Deaths, Illinois 2015



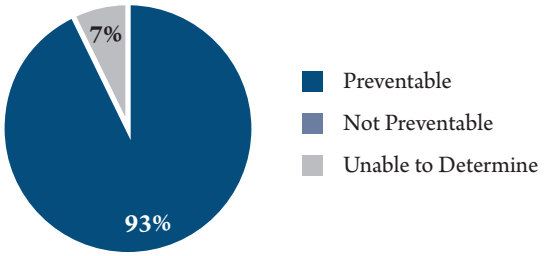
Of the 28 violent death cases that were reviewed, the vast majority of the deaths occurred more than 42 days postpartum. Figure 19 shows a more specific breakdown of the timing of violent pregnancy-associated deaths in Illinois. Only 11percent of the cases (3 deaths) occurred while the woman was pregnant, while more than half of the violent deaths occurred at least six months after pregnancy. Thus, to continue identifying opportunities for prevention of violent pregnancy-associated deaths, it is important for the MMRC-V to continue reviewing deaths during the first full year postpartum.

Figure 20. Factors that Contributed to Violent Pregnancy-Associated Deaths, Illinois 2015



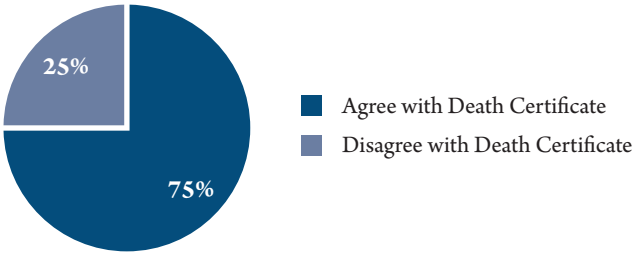
The MMRC-V also discussed and determined whether other specific factors contributed to the pregnancy-related deaths. Of the 28 violent pregnancy-associated deaths, obesity contributed to only 7 percent (2 cases), but mental health conditions contributed to 75 percent (21 cases), and substance use contributed to 61 percent (17 cases) (Figure 20).

Figure 21. Potential Preventability of Violent Pregnancy-Associated Deaths, Illinois 2015



After discussing the cause of death and contributing factors, the MMRC-V determined whether the death was potentially preventable. For 93 percent of the violent pregnancy-associated deaths (26 deaths), the committee determined there was at least some chance of the death being prevented (Figure 21). For the remaining 7 percent of cases (2 deaths), the committee was unable to determine whether the death was preventable – mostly because of an unclear cause of death or a lack of records about the services the woman had received.

Figure 22. Committee Agreement with Cause of Death Listed on Death Certificate, Violent Pregnancy-Associated Deaths, Illinois 2015



The MMRC-V agreed with the cause of death listed on the death certificate in 75 percent of the violent pregnancy-associated deaths (Figure 22). This finding highlights the importance and relevance of maternal mortality review as a way to more accurately understand why women are dying and how to prevent such deaths. If only the death certificate information had been used to identify cause of death, important information about the true causes of death may have been missed.

Maternal Mortality Case Examples

The following section includes five real examples of Illinois women who died within a year of pregnancy during 2015. While every race and ethnicity experiences maternal mortality, not every case presents a good opportunity for sharing. In several cases, details would need to be de-identified in order to protect the identity of the woman who died, and we simply did not have a case in Illinois for each race and ethnicity that could be shared.

Each case example generated rich discussion during the MMRC and MMRC-V meetings, and many important lessons can be learned from each woman's death. These are only brief excerpts of a full case, but represent some of the key themes identified by the committees. The excerpts include key discussion points made by the committees, but do not encompass the full complexity of these women's stories.

Maternal Mortality Case Example - Mary

"Mary" was a Black woman in her 40s who did not have routine medical care prior to becoming pregnant. At her first prenatal care visit during her first trimester, she was diagnosed with severe high blood pressure, type II diabetes, and obesity. She attended all prenatal care visits and was on blood pressure medication. Yet during her pregnancy, she still had several visits to the emergency room due to her uncontrolled high blood pressure. Mary delivered a full-term baby with no delivery complications. At seven months postpartum, Mary presented to the emergency department with leg swelling and was found to be in acute kidney failure. During this visit, Mary told the providers that she had been experiencing leg swelling and pain since her recent delivery, but thought these were normal side effects of pregnancy. She was admitted to the hospital and over the next six weeks, Mary's health continued to worsen. She eventually died due to heart and organ failure, which were related to her severe high blood pressure.

What can we learn from Mary's death?
Mary's death highlights the importance of helping women become as healthy as possible prior to pregnancy. Chronic conditions like diabetes and high blood pressure can drastically affect a pregnancy and need to be diagnosed and managed before a woman becomes pregnant. Throughout her pregnancy, Mary saw a specialist who was focused on the baby's development, but her own chronic conditions were not prioritized in her care. Additionally, there was a lack of education provided to Mary about the severity of her health conditions and the potential signs and symptoms of complications she should look for in the postpartum period.

Maternal Mortality Case Example - Jasmine

"Jasmine" was a Black woman in her 20s. Throughout the end of her pregnancy, she had frequent pain in her side, and pain and numbness in her foot and calf. During her pregnancy, Jasmine visited hospital emergency departments eight times for various reasons, including pain. She delivered a healthy full-term baby, but experienced severe leg pain during her hospital stay. She was discharged from the hospital with instructions to return for a MRI if pain continued. Jasmine went to the emergency department twice in the week following the birth of her child. First she was admitted to the hospital for pain management, and discharged the next day with instructions to use ice packs and pain medications. Three days later, she went back to the emergency department due to continued leg swelling and back pain. Her examination was limited due to her pain level and not all leg veins were thoroughly examined for blood clots. She was discharged and told to follow up with her primary care physician. During each of these visits, she was screened for drug use and repeatedly had negative tests. One week later, Jasmine collapsed at home and was transported to the hospital in cardiac arrest. Jasmine died of a pulmonary embolism 18 days after giving birth, which was the result of an undetected blood clot travelling to her lungs. Her death was associated with inactivity, obesity, and deep venous thrombosis, which was not identified at previous hospital visits.

What can we learn from Jasmine's Death?
Despite complaints of leg pain and swelling during multiple hospital visits, Jasmine was not thoroughly screened for blood clotting issues, and her condition was misdiagnosed as back pain. There was a lack of care coordination between facilities, and Jasmine's pain was not taken seriously. Providers appear to have misinterpreted her pain as "drug-seeking" behavior, showing how implicit bias or prejudice can affect the care a woman receives. If providers had recognized her leg pain as a blood clot issue, Jasmine's life might have been saved.

Maternal Mortality Case Example - Nia

"Nia" was a Black woman in her early 20s with a history of obesity, high blood pressure, and drug use. Nia delivered a full-term baby with no delivery complications. In the two months following her delivery, she went to multiple emergency departments due to shortness of breath, chest pain, and cough; she received diagnoses of pneumonia and influenza. Following her flu diagnosis, doctors noticed possible heart failure evidence on her chest x-ray that was missed before she was discharged home. She returned to a different emergency department and was instructed to see a specialist for her heart. One week later, she went to the emergency department with abdominal pain, cramping, and fever. Doctors determined her gallbladder was the source of the issue and she was scheduled for gallbladder removal surgery. While being given anesthesia for surgery, Nia went into cardiac arrest and died before the surgery could be completed. She died 79 days after her baby was born. During her autopsy, she was found to have postpartum cardiomyopathy and stimulant drugs in her system.

What can we learn from Nia's death?
During prenatal care, Nia was identified as having multiple risk factors for postpartum complications (chronic disease and drug use). Due to lack of care coordination between her prenatal care provider and multiple emergency departments, at no time during her recurring emergency department visits was Nia identified as a postpartum patient. As a result, Nia was ultimately misdiagnosed as having a gallbladder condition when she was really suffering from postpartum cardiomyopathy. Her heart was not strong enough to withstand the anesthesia given for the (unnecessary) surgery. If the hospital had done a cardiac test before the surgery, it would have shown Nia was a poor candidate for surgery and treatment for her cardiomyopathy could have been started.

Maternal Mortality Case Example - Jessica

"Jessica" was a White woman in her late 30s. She had a normal pregnancy, which resulted in a full-term delivery. Shortly after the birth of her child, she began experiencing symptoms of postpartum depression, including anxiety and stress. She talked to her doctor and was prescribed an anti-depressant by her obstetrician. Over the next month, she visited the emergency department twice with symptoms of excessive worrying and mood swings. She had a positive suicide risk assessment during her second visit and was released with education materials and instructions to contact her doctor. Three weeks later, she voluntarily checked herself into a behavioral health center and reported a plan for suicide. She was discharged home after a two week stay. No step down treatment was provided. Four months after the birth of her child, Jessica died by suicide. After her death, a loved one reported no noticeable changes in the way she had recently acted, but she had not yet returned to work due to her condition. She had no evidence of drug or alcohol use at the time of death and no foul play was suspected.

What can we learn from Jessica's death?
Jessica's story highlights the importance for the community and postpartum support systems to be aware of the signs of postpartum depression. There are also multiple examples where care coordination to ensure proper follow-up care was lacking, including after she screened positive for suicide risk and after discharge from the behavioral health center.

Maternal Mortality Case Review - Emily

"Emily" was a White woman in her 30s. She had a history of domestic violence, suicidal thoughts, schizophrenia, depression, anxiety, substance use, and drug seeking behavior. Throughout her pregnancy and until her death, Emily had routine behavioral health check-ups where she received counseling and medication. Emily stopped taking the medication for schizo-affective disorder while pregnant and expressed hesitancy to start again because of her desire to breastfeed. In the six months after the birth of her child, Emily went to the emergency department more than 20 times for various reasons, including pain. While some providers noted concerns of opioid dependence, Emily was continuously prescribed opioids during emergency department visits. Shortly before her death, she was discharged from the hospital because there were no female psychiatric inpatient beds available. Eight and a half months after delivery, Emily went into cardiac arrest and died. The cause of death was cardiomyopathy (weakening of heart muscle) due to intoxication by a prescription pain reliever.

What can we learn from Emily's Death?
While the Prescription Monitoring Program (PMP) was consulted and showed frequency of pain medications dispensed, Emily was never properly identified as having an opioid use disorder, nor was she offered substance use treatment. Her husband was not aware of the full extent of her illness and was not equipped to support her treatment. Emily did not have a routine source of medical care. The attempts made by behavioral health or emergency department providers to connect her to care were unsuccessful due to lack of communication, care coordination, and inadequate access to necessary mental health resources in her community.

Discussion

Opportunities for Prevention

An integral part of the maternal mortality review process is identifying factors that contributed to the maternal death, and action steps that could have prevented the death. When the major factors affecting deaths are analyzed across the entire group of case reviews, it can provide even more powerful data on opportunities for prevention at a population level.

Several overarching themes emerged from the factors contributing to Illinois maternal deaths in 2015, including:

- **Poor communication** between providers prohibits comprehensive care.
- **Lack of care coordination** is a universal issue for all women.
- Hospitals lack **clear policies and procedures around the identification and treatment of pregnant and postpartum women;** policies are not consistent across hospital departments.
- Providers and hospitals routinely **miss opportunities for screening and assessment** for both physical and mental health conditions, as well as social issues.
- **Providers do not know where to refer pregnant and postpartum women** with mental health and substance use disorders, or lack resources for ensuring patient follow-up.
- **Inadequate provider skill and knowledge** reduces the quality of care and there is a need to educate all provider types who treat pregnant and postpartum women.
- **Access to care**, especially specialty care and behavioral health services, is still an issue, even for women with insurance.
- There is **limited public awareness about postpartum health** problems and concerns.

Recommendations

Throughout MMRC and MMRC-V meetings, IDPH recorded every recommendation developed in response to every case that was reviewed. The full list of these recommendations for the year was then prioritized by the two Committees based on feasibility and impact. To have the largest effect on prevention, IDPH worked with the MMRC and MMRC-V to identify groups integral to implementing the recommendations. These entities or groups all have a shared role in the promotion of women's health and opportunities for prevention of maternal mortality.

Based on the themes that emerged from the 2015 maternal mortality cases, the Illinois MMRC and MMRC-V made recommendations that are specifically tailored towards hospitals, health care providers, health insurance plans, managed care organizations, the State of Illinois, and women and their families.

Recommendations for Hospitals

There are many opportunities for preventing maternal mortality through the improvement of hospital practices. The Committees felt that poor communication and care coordination within and between hospitals led to poor outcomes for pregnant and postpartum women. In addition, there were unclear policies and practices for identifying and treating pregnant and postpartum women, especially for substance use, depression, and domestic violence, in addition to identifying and treating well-established complications that may occur in pregnancy or in the postpartum period. While many hospitals are conducting routine screenings and assessments on pregnant and postpartum women, many still are not. The Committees stressed the importance of coordinating consultations and supporting patients who need further specialized care by connecting them directly to the specialty or additional care they need, therefore, reducing a barrier to seeking treatment.

Specifically, the Committees recommended:

1. Hospitals should implement best practices and review updated guidelines and techniques for risk assessment/screening and subsequent consultation and referral practices to improve outcomes for pregnant and postpartum women. This should include peer review, interdisciplinary morbidity and mortality reviews, patient safety bundles, and screening tools for mental health, substance use, and violence. Hospital quality improvement efforts should include use of the patient safety bundle for the "Reduction of Peripartum Racial/Ethnic Disparities".

2. Hospitals should have clear policies for emergency departments to identify pregnant and postpartum women (up to one year post-pregnancy), and seek consultation from an obstetrical provider for all pregnant or postpartum women with specific triggers indicative of pregnancy or postpartum complications.

3. Birthing hospitals should ensure that women are connected with a primary care or obstetrical provider and scheduled for a postpartum visit prior to hospital discharge.

4. Hospitals should require that medical providers and emergency department staff utilize both the Prescription Monitoring Program database and internal medical records to check for past opiate prescriptions and/or patterns of drug seeking behavior in pregnant and postpartum patients. When there is evidence of frequent opioid use, hospitals should develop standardized protocols to facilitate a successful referral for pain management and/or substance use treatment, including education for patients and family regarding overdose prevention and information on how to obtain and use naloxone.

Recommendations for Health Care Providers

Health care providers, especially those who see pregnant and postpartum women in an outpatient setting, have significant opportunity to prevent maternal mortality. Based on the deaths reviewed in 2015, the Committees found opportunities for providers to better understand the role that a woman's pregnancy and postpartum status may have on her underlying health and chronic conditions. There are also opportunities to refer women to specialists who may be able to assist primary care providers in managing pregnant and postpartum women with high-risk or underlying health conditions. To help address the opioid epidemic, which this report identifies as especially impacting pregnant and postpartum women in Illinois, obstetrical providers need to adopt safe prescribing practices to prevent unnecessary levels of opioids prescribed post-delivery.

Specifically, the Committees recommended:

1. Providers who treat pregnant and postpartum women, including obstetric, primary care, and subspecialty providers, should ensure they are aware of best practices for treating these women. This includes recommended screenings, assessments, family planning services, and the recognition of signs and symptoms of potential pregnancy or postpartum complications, as well as appropriate consultation and referral practices.
2. When taking a patient history, providers should always ask a woman of reproductive age if she has been pregnant within the past year in order to appropriately determine the importance of the recent pregnancy on the patient's current symptoms. Providers should actively encourage pregnant or postpartum patients to discuss any symptoms or change in health status.
3. Obstetrical providers should refer pregnant women with underlying chronic conditions to the appropriate specialist and ensure coordinated care with these specialists.
4. Providers should adopt the recent recommendation from the American College of Obstetricians and Gynecologists (ACOG), which states that it may not be appropriate for all women to wait six weeks for the first postpartum visit.
5. In an effort to reduce opioid use, providers should adopt ACOG's safe prescribing practices for opioids after delivery.

Recommendations for Health Insurance Plans and Managed Care Organizations

Because health insurance plans, including managed care organizations, provide opportunities for pregnant and postpartum women to access prenatal, postpartum, and specialty care, they also have significant opportunities to adopt practices that may prevent maternal mortality. The majority of the deaths that occurred in 2015, occurred in the late postpartum period. As a result, the Committees felt strongly that the Illinois Medicaid program should adopt the recent recommendations from ACOG to allow postpartum women to access health care for up to one year. Insurance plans and Medicaid managed care organizations (MCOs) also have opportunities to improve access to care and case management in the postpartum period, which can also reduce postpartum deaths.

Specifically, the Committees recommended:

1. Illinois should expand Medicaid eligibility for the postpartum period from 60 days to one year.
2. Health insurance plans regulated by the State of Illinois should be required to cover case management and outreach for postpartum high-risk women for up to one year after delivery.

3. Medicaid MCOs should prioritize and facilitate specialty care for pregnant women. This could be accomplished through the following efforts:
    a. Provide access to all necessary subspecialty care for pregnant women, including referrals for mental health services and treatment. If there are no contracted specialists within an MCO, then the MCO should be required to facilitate care outside of network.
    b. Provide transportation and supportive housing to, and facilitate childcare services for, pregnant women to reduce barriers for women seeking subspecialty care.
4. Health insurance plans should separate payment for visits in the postpartum period from labor and delivery (unbundle postpartum visit services from labor and delivery).

Additionally, the Committees discussed the possibility of recommending that pregnant and postpartum women be exempt from Medicaid managed care, but decided there was not enough evidence to warrant this recommendation at this time. Instead, the Committee will continue to study the potential benefits and risks of this policy recommendation throughout the next year of case reviews.

Recommendations for the State of Illinois

The State of Illinois administers home visiting and substance use treatment programs, regulates hospitals and the Emergency Medical Services (EMS), and introduces and passes legislation. These various roles present numerous opportunities for prevention of maternal mortality within the systems that support pregnant and postpartum women.

Specifically, the Committees recommended:

1. The General Assembly should pass legislation to adopt ACOG's recommended maternal levels of care within the regionalized perinatal system in Illinois, including working with the State's Emergency Medical System (EMS) to ensure pregnant women are being brought to the appropriate level of care facility.
2. IDPH should disseminate data and materials to raise public awareness about the importance of prenatal care and maternal health.
3. The State should create or expand home visiting programs to target high-risk mothers in Illinois during pregnancy and the postpartum period, such as doula programs, and expand efforts to provide universal home visiting to all mothers within three weeks of giving birth.
4. The State should expand financial support for regional and state perinatal quality improvement entities, including the Administrative Perinatal Centers and the Illinois Perinatal Quality Collaborative, to support ongoing education, technical assistance, and training, and to address racial/ethnic disparities in maternal mortality.
5. The Illinois Department of Human Services should increase access to substance use and mental health services statewide for pregnant and postpartum women, and ensure that programs are gender responsive, trauma informed, serve women with young children, and prioritize justice-involved pregnant and postpartum women.
6. IDPH should engage the Illinois Chapter of the American Academy of Pediatrics in creating a quality improvement initiative to expand the efforts of pediatricians conducting a postpartum depression screening at well baby visits during the first year of life.

Recommendations for Women and Their Friends and Families

While reviewing the 2015 deaths, the Committees did not come up with many recommendations directed towards women and those who care for them, as they did not feel that there were many things a woman or her friends and family could have done differently to change her outcome. However, the Committees did feel that there are opportunities for prevention that can and should be communicated to women and their families, in order to address maternal mortality.

Specifically, the Committees recommended:

1. Women should have annual check-up visits with a primary care provider to identify and manage chronic conditions, and to discuss how to be as healthy as possible before or between pregnancies.
2. Pregnant and postpartum women should always identify that they are pregnant or were pregnant within the last year whenever they get medical care.
3. Pregnant and postpartum women should identify new or emerging symptoms to providers, regardless if they feel that they are unrelated to pregnancy or not a significant symptom.
4. Friends and family of pregnant or postpartum women can support those they love by encouraging them to attend their medical appointments, discuss symptoms with a health care provider, and educate themselves on identifying symptoms and signs of postpartum complications.
5. Friends and family of someone with an opioid use disorder should obtain naloxone and learn how and when to administer it – this could potentially save a life.
6. Friends and family of pregnant women should learn the signs and symptoms of depression, anxiety, and mood changes, and seek help for those they love. They can call the Illinois postpartum depression support hotline for mothers and families: 866-364-MOMS (866-364-6667)

CONCLUSION

IDPH recognizes the tremendous impact that social factors have on maternal morbidity and mortality in the state of Illinois. Recent discussions nationally and locally about the social determinants of health challenge us to look at the economic, educational, social, and environmental factors within communities as the drivers of health inequities and the vast racial disparities seen in this report.

IDPH remains committed to identifying and reviewing maternal deaths and morbidities and will build upon these findings and recommendations over the coming years. IDPH welcomes efforts to disseminate and implement these recommendations.

Printed by Authority of the State of Illinois
P.O.#6019586 25 10/18

IOCI 19-192