“IT’S IN THE NEWS, IT’S IN THE HOSPITAL, BUT WHAT ARE WE REALLY DOING ABOUT IT? ADDRESSING MATERNAL AND NEONATAL MORTALITY”

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Directions

Please read the following module and complete the Post-Test and Evaluation.

This module was designed to be completed on your computer, rather than printed if possible.

If you have any questions, please contact Perinatal Systems at 803-434-2912 or PerinatalSystems@PalmettoHealth.org
By the end of the program, participants will be able to:

- verbalize definitions of maternal mortality and morbidity (Maternal morbidity, Maternal mortality, Pregnancy related death versus Pregnancy associated death)
- identify leading causes of maternal deaths
  - a. Importance of Maternal time of death (during pregnancy, within 42 days postpartum, 43 days to 1 year postpartum)
  - b. Review other characteristics associated with maternal mortality rates (age, ethnicity, etc)
- identify challenges of preventability, themes for improvement current federal/state law associated with Maternal mortality
  - a. Preventability (contributing factors)
  - b. Improvement (safety bundles)
  - c. Current laws/regulations
- verbalize definitions and rates of neonatal mortality (Neonatal Mortality Definition/Rates, Neonatal Death, Infant Death)
- identify leading causes and increased efforts to prevent neonatal deaths
  - a. Birth Defects
  - b. Preterm Birth/Low birth weight
  - c. SIDS
  - d. Maternal Pregnancy complications
  - e. Injuries (suffocation)
  - f. Prevention
    1. Improvements/advancements in neonatal care
    2. Education/Safe sleep environment
    3. Improved newborn screening test
Maternal Mortality
IN THE NEWS...

Are we paying attention?

Local Headlines – Maternal and Neonatal Mortality


Mother’s Matter Series
- WLTX

South Carolina ranks 8th in highest death rates among new mothers
In the series Mothers Matter, we explore why women are dying during childbirth and why black women, in particular, are affected more often.
Figure 1. Maternal mortality ratio (MMR, maternal deaths per 100 000 live births), 2015

Issues with maternal Mortality are not just a problem for the United States. We have to recognize the impact at the World level as well as National, State and Local levels.
We know from the news recently that maternal mortality in the United States is high. With that knowledge, we also know that there is a racial disparity associated with maternal mortality.

To begin to answer the questions of who, what, when, where and how pregnant women are dying related to their pregnancy we first need a defined way to capture and review women’s cases.

This leads us first to defining maternal deaths.....
What is Maternal Mortality?

- World Health Organization (WHO) Definitions
  - **Maternal Death**: “death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes.”
  - **Pregnancy-Related Death**: “death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the cause of death.”
  - **Late Maternal Death**: “death of a woman from direct or indirect causes, more than 42 days, but less than 1 year, after termination of pregnancy.”
• World Health Organization (WHO) Definitions continued
  
  • **Maternal Mortality Ratio**: “number of maternal deaths per 100,000 live births”
  
  • **Maternal Mortality Rate**: “ratio of maternal deaths to the woman-years of exposure for women aged 15–49 years.”
    
    • Although maternal mortality is reported per 100,000 live births, it is a ratio rather than a rate because some of the deaths occur in women with nonviable pregnancies (e.g., ectopic pregnancies, miscarriages, terminations, stillbirths), which are not in the denominator of live births.
    
    • Because the proper denominator, the total number of pregnant women, is unknowable (there is no system for collecting early pregnancy losses), the countable number, live births, is used as an approximation, which leads to the correct term, a maternal mortality ratio.
    
    • Most investigators and public health agencies utilize maternal mortality ratios, and occasionally maternal mortality rates, when considering maternal deaths.
Are You Confused Yet?

Just wait, there’s more...
Sometimes maternal deaths are subdivided into direct and indirect.

- **Direct obstetric deaths** are those resulting from obstetric complications of the pregnant state
  - pregnancy, labor, and puerperium
  - consequence of interventions, omissions, or incorrect treatment or from a chain of events resulting from any of these.

- **Indirect obstetric deaths** are those resulting from previous existing disease or disease that developed during pregnancy and that was not the result of direct obstetric causes, but was aggravated by the physiologic effects of pregnancy.
  - As the US maternal population has aged and developed more underlying conditions (e.g., morbid obesity), the number of indirect deaths has increased.

- The distinction between direct and indirect is more useful for understanding causes than for clinical care.

- Deaths of unknown cause are not classified as either direct or indirect.

*Creasy and Resnik's Maternal-Fetal Medicine: Principles and Practice - Eighth Edition*
As we begin thinking about Maternal Mortality, we need to think in a systematic way.

1. We need to agree on terms defining maternal death and mortality related terms
2. We need consistent ways to measure or collect data about maternal deaths
3. We need to take time to determine why and when those deaths are occurring so that we can have an impact on preventing future maternal deaths.
• The CDC has set up a process for reviewing maternal deaths

• The cases are reviewed and placed into a database to allow for better data collection and ultimately to be able to determine system processes or education at the provider or individual level to increase prevention steps.

There are a variety of terms connected with maternal mortality

- **Maternal death**: Used by World Health Organization – death of a woman while pregnant or within 42 days of termination of pregnancy, regardless of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not for accidental or incidental causes.

- **Pregnancy-associated**: The death of a woman while pregnant or within one year of the termination of pregnancy, regardless of the cause.

- **Pregnancy-related**: The death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy
  - This is further defined as the death of a pregnant or postpartum woman was related to her pregnancy
  - In other words...if this woman was not pregnant, she would not have died.

- **Pregnancy-associated, but NOT related**: The death of a woman during pregnancy or within one year of the end of the pregnancy from a cause that is not related to pregnancy.
  - This is a woman died for a reason, but not related to the fact that she was pregnant.

- **Unable to determine if pregnancy-related or pregnancy-associated, but NOT related**

- **Not pregnancy-related or associated** (i.e., false positive, woman was not pregnant within one year of her death)

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“Severe maternal morbidity (SMM) includes unexpected outcomes of labor and delivery that result in significant short- or long-term consequences to a woman’s health.”

- Indicators from the CDC:
  - Acute myocardial infarction
  - Aneurysm
  - Acute renal failure
  - Adult respiratory distress syndrome
  - Amniotic fluid embolism
  - Cardiac arrest/ventricular fibrillation
  - Conversion of cardiac rhythm
  - Disseminated intravascular coagulation
  - Eclampsia
  - Heart failure/arrest during surgery or procedure
  - Puerperal cerebrovascular disorders
  - Pulmonary edema / Acute heart failure
  - Severe anesthesia complications
  - Sepsis
  - Shock
  - Sickle cell disease with crisis
  - Air and thrombotic embolism
  - Blood transfusion
  - Hysterectomy
  - Temporary tracheostomy
  - Ventilation

We will not focus on this topic today, but it is important to understand maternal morbidity has a very large impact on overall maternal outcomes and health.

https://www.cdc.gov/reproductivehealth/maternalinfanthealth/severematernalmorbidity.html
Maternal deaths in the United States have decreased over the last century.

- Rates went from an estimated 900 per 100,000 births in 1901 to 9 per 100,000 in 1991.

Why?
- Success for both public health programs and obstetrics providers.
- Multiple factors:
  - The movement of most births to hospitals.
  - Improved hygiene and aseptic technique.
  - Common use of prenatal care, including screening for preeclampsia.
  - The introduction of blood transfusions and antibiotics.
  - Widespread availability of obstetric anesthesia.
  - An increase in training and expertise of obstetrics providers.
  - Improvement in the overall health of the population.

This leads us to the next questions –
- “Are we happy with the amount of improvement that occurred from 1901 – 1990’s?”
- Are we done with the work?
The Maternal mortality rate (MMR) is the annual number of female deaths per 100,000 live births from any cause related to or aggravated by pregnancy or its management (excluding accidental or incidental causes).

2018 - US is # 137 from the highest maternal mortality rates with 14 per 100,000.
Maternal Mortality Rates Worldwide

The Maternal mortality rate (MMR) is the annual number of female deaths per 100,000 live births from any cause related to or aggravated by pregnancy or its management (excluding accidental or incidental causes).

Are we the worst?
No, Sierra Leone’s rate 1,360 deaths per 100,000 births

Highest rates of maternal mortality

<table>
<thead>
<tr>
<th>Rank</th>
<th>Country</th>
<th>Maternal mortality rate (deaths/100,000 live births)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sierra Leone</td>
<td>1,360</td>
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<tr>
<td>2</td>
<td>Central African Republic</td>
<td>892</td>
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<tr>
<td>3</td>
<td>Chad</td>
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<td>4</td>
<td>Nigeria</td>
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<td>5</td>
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<td>6</td>
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<tr>
<td></td>
<td>42</td>
<td>Sudan</td>
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</table>
Maternal Mortality Rates Worldwide

Highest rates of maternal mortality

2018 - US is #137 from the highest to lowest maternal mortality rates with 14 per 100,000.

https://www.indexmundi.com/g/r.aspx?v=2223
Source: CIA World Factbook - January 1, 2018

The Maternal mortality rate (MMR) is the annual number of female deaths per 100,000 live births from any cause related to or aggravated by pregnancy or its management (excluding accidental or incidental causes).

Are we the worst? No, Sierra Leone’s rate 1,360 deaths per 100,000 births

But look at the best! Finland, Greece, Iceland & Poland each with a rate of 3/100,000

Lowest rates of maternal mortality

- Lebanon
- Bahrain
- Puerto Rico
- United States
- Qatar
- Saudi Arabia
- Kazakhstan
- Korea, South
- New Zealand
- Bosnia and Herzegovina
- Bulgaria
- Portugal
- Lithuania
- Luxembourg
- Singapore
- Slovenia
- United Kingdom
- Libya
- Malta
- Estonia
- Ireland
- France
- Croatia
- Macedonia
- Netherlands
- Montenegro
- Canada
- Belgium
- Australia
- Germany
- Denmark
- Slovakia
- United Arab Emirates
- Switzerland
- Spain
- Japan
- Israel
- Norway
- Italy
- Kosovo
- Czech Republic
- Austria
- Belgium
- Sweden
- Finland
- Greece
- Iceland
- Poland

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In the U.S., 14 out of every 100,000 mothers died due to complications of pregnancy or childbirth. That puts it between Qatar (13 deaths) and Bahrain (15) in the ranking of all 184 countries for which the WHO has data. The United States is ranked 46 out of those 184 countries, barely in the top 25 percent. By contrast, in Canada only 7 out of 100,000 mothers died in pregnancy or childbirth. American women are over four times as likely to die in pregnancy or childbirth as women in Greece, Iceland or Poland, where the rate is 3 out of every 100,000...

We're one of the world's wealthiest countries, and we spend way more on healthcare than other rich nations. So how did we end up here?“

Maternal Deaths in the U.S. Are on the Rise

Maternal mortality ratio (number of maternal deaths per 100,000 live births)

- United States
- Developed Regions

<table>
<thead>
<tr>
<th></th>
<th>1990</th>
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<tr>
<td>World</td>
<td>380</td>
<td>210</td>
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<tr>
<td>Developed Regions</td>
<td>26</td>
<td>16</td>
</tr>
<tr>
<td>Developing Regions</td>
<td>430</td>
<td>230</td>
</tr>
<tr>
<td>United States</td>
<td>12</td>
<td>28</td>
</tr>
</tbody>
</table>

Source: World Health Organization

Notes


Source: The Lancet    Credit: Rob Weychert/ProPublica
When we compare maternal deaths by ethnicity, we immediately visualize the disparity between White and Other versus African American. This is not acceptable to have one ethnic group have a 3 times higher rate of mortality related to pregnancy. This should lead us to consider two questions:

1. Why are women dying in pregnancy?
2. Why is there a disparity among ethnicity?
This bar graph highlights the changes that have occurred over the last several years in reasons women are dying related to pregnancy.

Let's compare Hemorrhage. There is a steady decrease.

However, comparing thrombotic pulmonary embolism, AFE, Infection, Cardiomyopathy, CVA, Cardiovascular conditions and non-cardiovascular medical conditions, these are all steadily increasing!
Thus far we KNOW:

1. Women are dying related to pregnancy.
2. There is a change in why women are dying. (decreasing rates of hemorrhage, increasing rates of cardiovascular complications)
3. There is a very large disparity related to African-American women

How can we understand better the WHY and WHEN associated with maternal mortality? Who needs to have the conversation?
Why are women dying in pregnancy and postpartum?

Let’s look again at the overall cause of maternal deaths:

![Figure 4. Leading Underlying Causes of Pregnancy-Related Deaths*](image)

- **Hemorrhage**: 14.0%
- **Cardiovascular and Coronary Conditions**: 14.0%
- **Infection**: 10.7%
- **Cardiomyopathy**: 10.7%
- **Embolism**: 8.4%
- **Preeclampsia and Eclampsia**: 7.4%
- **Mental Health Conditions**: 7.0%

*Amniotic fluid embolism is not included in the embolism grouping due to differences in etiology and opportunities for prevention. The underlying cause of death, as defined by the World Health Organization (WHO), is “disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury.”

BUT...This question has to be further broken down into the three different time periods associated with pregnancy.
The next step in reviewing maternal mortality is to look at when pregnant or postpartum women are dying.

There are three categories:
1. During Pregnancy
2. Within 42 days Postpartum
3. 43 days to 1 year Postpartum

The next set of data comes from the CDC’s pregnancy surveillance system and “Report from Nine Maternal Mortality Review Committees”

- In order to gather the best evidence and data surrounding maternal deaths, it has been suggested that states have a team to collect or abstract de-identified data about each maternal death, then a maternal mortality review committee will review each case to determine the pregnancy relatedness that was discussed in the definitions.
When are our moms dying?

**Figure 1. Distribution of Pregnancy-Related Deaths by Timing of Death in Relation to Pregnancy**

- **38%** While pregnant
- **45%** Within 42 days
- **18%** 43 days to 1 year

- **63% of Maternal deaths occur in the postpartum time period!**
- **This data shows us the importance of the postpartum time period and the associated risk of death related to the pregnancy.**

Why are women dying in pregnancy and postpartum time periods?

When we break down the timing of the death in relation to pregnancy we can begin to see more clearly components of why women are dying and then we can begin to address issues to prevention.

- **WHILE PREGNANT:**
  1. Tied: Cardiovascular and Coronary Conditions & Hemorrhage

- **WITHIN 42 DAYS POSTPARTUM:**
  1. Infection
  2. Tied: Cardiovascular and Coronary Conditions & Hemorrhage

- **43 DAYS TO 1 YEAR POSTPARTUM:**
  1. Cardiomyopathy
  2. Mental Health Conditions
Within the overall assessment of when the deaths are occurring, Race-Ethnicity and Maternal Age demographics needs to be considered.

Non-Hispanic Black women are dying at 18% higher rate than Hispanic women and nearly 20% higher rate than non-Hispanic White women.

Clearly, pregnant/postpartum women over the age of 30 are at a higher rate of dying than women under the age of 30.
How do we compare in overall cause of pregnancy-related deaths by Race?

Non-Hispanic Black women leading causes of death are: Cardiomyopathy, Cardiovascular & Coronary Conditions, and Preeclampsia/Eclampsia

Non-Hispanic White women leading causes of death are: Cardiovascular & Coronary conditions, Hemorrhage & Infection
What does this mean to YOU & to ME as Perinatal Nurses?

We take all of the data presented and need to begin to think about how we associate maternal deaths in our daily work and how do we make an impact on these rates.

Things to think about moving forward:

1) Do I understand *when* women are dying related to pregnancy and childbirth?
2) Do I understand *why* women are dying related to pregnancy and childbirth?
3) Is there a way to prevent maternal deaths?
4) How do we address the disparities associated with maternal deaths?
Currently the CDC has a system to capture information gained from Maternal Mortality Review Committees in the US to review each maternal death and determine:

- Was the death pregnancy-related?
- How complete was the medical record information associated with the maternal death?
- What was the cause of death
  - Further assessed by Immediate/Contributing/Underlying/Other significant factors
- Then assess the relatedness of obesity, mental health, substance use, suicide/homicide.
- Preventability:
  - This is defined by the CDC for Maternal Mortality Review Boards as - “A death is considered preventable if the committee determines that there was at least some chance of the death as being averted by one or more reasonable changes to the patient, community, provider, facility, and/or systems factors
  - Then preventability is further determined
    1. Decide Yes or No – the death was preventable
    2. Determine the chance to alter outcomes with the following scale: No chance, Some chance, or Good Chance
In order to determine preventability, the Maternal Review Committees must first determine was the Death Related to the Pregnancy – as discussed previously.

Then the causation of death is looked at.

Categories of preventability

![Image of Maternal Mortality Review Committee Decisions Form](image-url)
Once the death is determined to be pregnancy-related, the review committee selects the underlying cause of death.
Then the review board determines if the following conditions contribute to the death.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>DID OBESITY CONTRIBUTE TO THE DEATH?</td>
<td>Yes</td>
</tr>
<tr>
<td>DID MENTAL HEALTH CONDITIONS CONTRIBUTE TO THE DEATH?</td>
<td>Yes</td>
</tr>
<tr>
<td>DID SUBSTANCE USE DISORDER CONTRIBUTE TO THE DEATH?</td>
<td>Yes</td>
</tr>
<tr>
<td>WAS THIS DEATH A SUICIDE?</td>
<td>Yes</td>
</tr>
<tr>
<td>WAS THIS DEATH A HOMICIDE?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

If homicide, suicide, or accidental death, list the means of fatal injury:

- Firearm
- Sharp instrument
- Blunt instrument
- Poisoning/overdose
- Hanging/strangulation/suffocation

If homicide, what was the relationship of the perpetrator to the decedent?

- No relationship
- Partner
- Ex-partner
- Other relative

- Fall
- Punching/beating
- Explosive
- Drowning
- Fire or burns
- Motor vehicle

- Intentional neglect
- Other, specify:
- Unknown
- Not applicable
Reviewing Maternal Deaths

- The review board also considers if the available records that were used to review the case were complete.
  - Meaning, was there access to a medical record to give enough information to review the case?
• After reviewing the case carefully, the review board looks to determine preventability, contributing factors and recommendations.

The BIG Question: Could the Maternal Death have been prevented?

Was there a chance that the death could have been avoided?
CONTRIBUTING FACTOR DESCRIPTIONS

DELAY OR FAILURE TO SEEK CARE
The woman was delayed in seeking or did not access care, treatment, or follow-up care/actions (e.g., missed appointment and did not reschedule).

ADHERENCE TO MEDICAL RECOMMENDATIONS
The woman did not accept medical advice (e.g., refused treatment for religious or other reasons or left the hospital against medical advice).

KNOWLEDGE - LACK OF KNOWLEDGE REGARDING IMPORTANCE OF EVENT OR OF TREATMENT OR FOLLOW-UP
The woman did not receive adequate education or lacked knowledge or understanding regarding the significance of a health event (e.g., shortage of breath as a trigger to seek immediate care) or lacked understanding about the need for treatment/follow-up after evaluation for a health event (e.g., needed to keep appointment for psychiatric referral after an ED visit for exacerbation of depression).

CULTURAL/RELIGIOUS, OR LANGUAGE FACTORS
Demonstrations that any of these factors was either a barrier to care due to lack of understanding or led to refusal of therapy due to beliefs (or belief systems).

ENVIRONMENTAL FACTORS
Factors related to weather or terrain (e.g., the advent of a sudden storm leads to a motor vehicle accident).

VIOLENCE AND INTIMATE PARTNER VIOLENCE (IPV)
Physical or emotional abuse other than that perpetrated by intimate partner (e.g., family member or stranger); IPV Physical or emotional abuse perpetrated by the woman's current or former intimate partner.

MENTAL HEALTH CONDITIONS
The woman carried a diagnosis of a psychiatric disorder. This includes postpartum depression.

SUBSTANCE USE DISORDER — ALCOHOL, ILLICIT/ PRESCRIPTION DRUGS
Substance use disorder is characterized by recurrent use of alcohol and/or drugs causing clinically and functionally significant impairment, such as health problems or disability. The committee may determine that substance use disorder contributed to the death when the disorder directly or indirectly compromised a woman's health status (e.g., acute methamphetamine intensification exacerbated pregnancy-induced hypertension, or woman was more vulnerable to infections or medical conditions).

TOBACCO USE
Women's use of tobacco directly compromised the woman's health status (e.g., long-term smoking led to underlying chronic lung disease).

CHRONIC DISEASE
Occurrence of one or more significant pre-existing medical conditions (e.g., obesity, cardiovascular disease, or diabetes).

CHILDHOOD SEXUAL ABUSE/TRAUMA
Women experienced type, maltreatment, or other sexual exploitation during childhood plus parasuicide, induction, or coercion of a child to engage in sexually explicit conduct; or woman experienced physical or emotional abuse or violence other than that related to sexual abuse during childhood.

LACK OF ACCESS/FINANCIAL RESOURCES
System issues, e.g., lack of access to healthcare insurance or other financial means, as opposed to a woman's noncompliance impacted woman's ability to care for herself (e.g., did not seek services because unable to miss work or afford postpartum visits after insurance expired). Other barriers to accessing care: insurance non-eligibility, provider shortage in woman's geographical area, and lack of public transportation.

UNSTABLE HOUSING
Women lived on the street or in a homeless shelter or lived in transitional or temporary circumstances with family or friends.

SOCIAL SUPPORT/ Isolation - LACK OF FAMILY/ FRIEND SUPPORT SYSTEM
Social support from family, partner, or friends was lacking. Inadequate, and/or dysfunctional (e.g., domestic violence, no one to rely on to ensure appointments were kept).

INADEQUATE OR UNAVAILABLE EQUIPMENT/ TECHNOLOGY
Equipment was missing, unavailable, or not functional, (e.g., absence of blood tubing connector).

LACK OF STANDARDIZED POLICIES/PROCEDURES
The facility lacked basic policies or infrastructure germane to the woman's needs (e.g., response to high blood pressure or a lack of or outdated policy or protocol).

POOR COMMUNICATION/LACK OF CASE COORDINATION OR MANAGEMENT/ LACK OF CONTINUITY OF CARE (SYSTEM PERSPECTIVE)
Care was fragmented (i.e., uncoordinated or not comprehensive) among or between healthcare facilities or units, (e.g., records not available between inpatient and outpatient or among units within the hospital, such as Emergency Department and Labor and Delivery).

LACK OF CONTINUITY OF CARE
Care providers did not have access to women's complete records or did not communicate women's status sufficiently. Lack of continuity can be between prenatal, labor and delivery, and postpartum providers.

CLINICAL SKILL/QUALITY OF CARE
Personnel were not appropriately skilled for the situation or did not exercise clinical judgment consistent with current standards of care (e.g., error in the preparation or administration of medication or unavailability of translation services).

INADEQUATE COMMUNITY OUTREACH/RESOURCES
Lack of coordination between healthcare system and other outside agencies/organizations in the geographic/cultural area that work with maternal child health issues.

INADEQUATE LAW ENFORCEMENT RESPONSE
Law enforcement response was not in a timely manner or was not appropriate or thorough in scope.

LACK OF REFERRAL OR CONSULTATION
Specialists were not consulted or did not provide care; referrals to specialists were not made.

FAILURE TO SCREEN/INADEQUATE ASSESSMENT OF RISK
Factors placing the woman at risk for a poor clinical outcome recognized, and the woman was not transferred/transported to a provider able to give a higher level of care.

LEGAL
Legal considerations that impacted outcome.
Recall the leading underlying causes of pregnancy related deaths...

When the Question of Preventability is considered, Maternal Mortality review committees found the following data:
Now you have a better understanding of the depth of the problem...

What is Next?
Everyone needs to begin to see this as a problem and look at the prevention steps.

- The following slides are from the World Health Organization (WHO).
- They highlight through infographics the significance of maternal mortality at a global level.
Every day, approximately 830 women die from preventable causes related to pregnancy and childbirth.

99% of all maternal deaths occur in developing countries.

Maternal mortality is higher in women living in rural areas and among poorer communities.

Young adolescents face a higher risk of complications and death as a result of pregnancy than other women.

Skilled care before, during and after childbirth can save the lives of women and newborn babies.

Between 1990 and 2015, maternal mortality worldwide dropped by about 44%.

Between 2016 and 2030, as part of the Sustainable Development Goals, the target is to reduce the global maternal mortality ratio to less than 70 per 100,000 live births.

https://www.who.int/news-room/fact-sheets/detail/maternal-mortality
Obtained 02/15/2019
Maternal – Child Infographics
WHO

ENDING PREVENTABLE NEWBORN DEATHS & STILLBIRTHS

**EVERY YEAR:**

- **2.6 million** babies die in the first 28 days of life. Most in the first week.

**THE TOP CAUSES:**
1. Prematurity
2. Complications during birth
3. Severe infections

**AN ADDITIONAL:**

- **2.6 million** stillbirths occur each year
- **50%** after labour has begun

**BUT:**

- **75%** of newborn deaths CAN be prevented with high-quality care. So can the majority of maternal deaths and stillbirths.

Healthy mother + Healthy birth + Good health in the first days of life = The start of a healthy childhood

NEARLY 3 MILLION NEWBORNS AND MOTHERS COULD BE SAVED EACH YEAR BY:

1. Investing in maternal and newborn care during labour, birth and the first week of life
2. Improving the quality of maternal and newborn care
3. Reaching every woman and newborn to reduce inequalities
4. Harnessing the power of parents, families and communities
5. Counting every newborn with measurement, programme-tracking and accountability

Investing just $1.15 USD more per person WILL save women and newborns.
Maternal – Child Infographics
WHO

Better Data to Save Mothers’ and Babies’ Lives

The day of birth can be a dangerous time for mothers and babies.

Every year:
- 303,000 mothers die during childbirth
- 2.7 million babies die during the first 28 days of life
- 2.6 million stillbirths occur

These are only estimates. They do not tell the whole story.

~60% of countries lack adequate systems for counting births and deaths

Many deaths are unreported

Most death reviews focus on medical causes and overlook solutions

The majority of maternal deaths and stillbirths, and 75% of newborn deaths, are preventable.

In order to prevent future deaths, WHO is helping countries to:
- Produce a birth and death certificate for everyone, including stillbirths
- Form death review committees
- Create policies to report and review all deaths

For more information check out:
https://www.who.int/news-room/fact-sheets/detail/maternal-mortality
Let’s bring this a little closer to home.

Initiatives at work at US and State of South Carolina levels.
Council on Patient Safety in Women’s Health Care – Safe Healthcare for Every Woman
https://safehealthcareforeverywoman.org

• Resources for individuals and hospitals to work on Patient safety initiatives.
• Through this council, the AIM Program information is housed.
What is AIM?
The Alliance For Innovation On Maternal Health Program

Details:
• Multiple partners with a vested interest in improving maternal outcomes.
• National data-driven maternal safety and quality improvement initiative based on proven implementation approaches to improving maternal safety and outcomes in the U.S. Our end goal is to eliminate preventable maternal mortality and severe morbidity across the United States.
• The states in Green have been established as AIM states
• South Carolina is in the application process
• Initiatives are set through adoption and implementation of Patient Safety Bundles. Here is a list of the current bundles.
  • A bundle is a collection of 10-13 best practices for improving safety in maternity care that have been vetted by experts in practice.
• **GOAL OF THE BUNDLES:** *Move established guidelines into practice with a standard approach.*

For More Information:
https://safehealthcareforeverywoman.org
https://safehealthcareforeverywoman.org/aim-supported-patient-safety-bundles/
Sample Safety Bundle

READINESS

Every unit
- Hemorrhage cart with supplies, checklist, and instruction cards for intrauterine balloons and compression stitches
- Immediate access to hemorrhage medications (kit or equivalent)
- Establish a response team—who to call when help is needed (blood bank, advanced gynecologic surgery, other support and tertiary services)
- Establish massive and emergency transfusion protocols (type-O negative/un-crossmatched)
- Unit education on protocols, unit-based drills (with post-drill debriefs)

RECOGNITION & PREVENTION

Every patient
- Assessment of hemorrhage risk (prenatal, on admission, and at other appropriate times)
- Measurement of cumulative blood loss (formal, as quantitative as possible)
- Active management of the 3rd stage of labor (department-wide protocol)

RESPONSE

Every hemorrhage
- Unit-standard, stage-based, obstetric hemorrhage emergency management plan with checklists
- Support program for patients, families, and staff for all significant hemorrhages

REPORTING/SYSTEMS LEARNING

Every unit
- Establish a culture of huddles for high risk patients and post-event debriefs to identify successes and opportunities
- Multidisciplinary review of serious hemorrhages for systems issues
- Monitor outcomes and process metrics in perinatal quality improvement (QI) committee

https://safehealthcareforeverywoman.org/patient-safety-bundles/obstetric-hemorrhage/
New Legislation – National

Preventing Maternal Death Act

- Introduced: Mar 2, 2017
- 115th Congress, 2017–2019
- Status: Enacted — Signed by the President on Dec 21, 2018
  - This bill was enacted after being signed by the President on December 21, 2018.

https://www.congress.gov/115/bills/hr1318/BILLS-115hr1318enr.pdf
Summary of the Bill – Now called Maternal Deaths Act of 2018

Preventing Maternal Deaths Act of 2017

• This bill directs the Department of Health and Human Services (HHS) to establish a program under which HHS may make grants to states for the purpose of:
  1) reviewing pregnancy-related and pregnancy-associated deaths (maternal deaths);
  2) establishing and sustaining a maternal mortality review committee to review relevant information;
  3) ensuring that the state department of health develops a plan for ongoing health care provider education in order to improve the quality of maternal care, disseminate findings, and implement recommendations;
  4) disseminating a case abstraction form to aid information collection for HHS review and preserve its uniformity; and
  5) providing for the public disclosure of information included in state reports.

• The bill defines "pregnancy-associated death" as the death of a woman while pregnant or during the one-year period following the date of the end of pregnancy, irrespective of the cause of death.

• It defines "pregnancy-related death" as the death of a woman while pregnant or during the one-year period following the date of the end of pregnancy, irrespective of the pregnancy's duration, from any cause related to, or aggravated by, the pregnancy or its management, excluding any accidental or incidental cause.

• States shall develop procedures for mandatory reporting to their departments of health by health facilities and professionals concerning maternal deaths and for voluntary reporting of such deaths by family members.

• States shall investigate each case and prepare a case summary for each case, to be reviewed by the committee and included in applicable reports.

• The bill amends the Public Health Service Act to direct HHS to take specified steps to eliminate disparities in maternal health outcomes.

https://www.govtrack.us/congress/bills/115/hr1318/summary
What does the new law provide?

• The new law will establish and support Maternal Mortality Review Committees at the state level and provides $12 million a year in new funds for 5 years for states. The committees will be required to review every pregnancy-related death as well as develop recommendations to prevent future deaths. (https://www.contemporaryobgyn.net/legislation/major-maternal-health-legislation-signed-law)

• “The Preventing Maternal Deaths Act authorizes federal funding for multidisciplinary entities known as maternal mortality review committees (MMRCs) that review individual cases of maternal death. MMRCs are key to developing locally relevant strategies to eliminate maternal mortality.” (https://www.acog.org/About-ACOG/News-Room/Statements/2018/US-House-Passes-Landmark-Legislation-to-Prevent-Maternal-Deaths)
MATERIAL MORTALITY IN SOUTH CAROLINA 2011-2015

Daniela K. Nitcheva¹ and Michael G. Smith²

¹Division of Biostatistics, Public Health Statistics and Information Services, SC DHEC; ²Division of Research and Planning, Maternal and Child Health Bureau, SC DHEC

Introduction

- Maternal mortality has been increasing in SC and across the United States in recent years.
- In 2018 a bill was passed to create a maternal mortality review process for pregnancy-related deaths in SC.

Objective

- The purpose of this analysis is to use SC vital records data to provide some basic incidence and demographic estimates related to maternal mortality and more detailed data are available from the maternal mortality review process.

Methods

- South Carolina birth certificate and death certificate data were linked to the pregnancy-related death occurring from 2011-2015.
- The World Health Organization's definition of maternal deaths was used.
- Calculations included all maternal deaths occurring within 42 days of delivery with an SDM.

Results

- There were a total of 66 maternal deaths meeting the World Health Organization's maternal mortality definition in South Carolina from 2011-2015.
- The rate of maternal mortality, increased from 14.2 deaths per 100,000 live births in South Carolina in 2011 to 31.0 deaths per 100,000 live births in 2015 before dropping to 25.5 deaths per 100,000 live births in 2015.
- Of those 66 deaths, 44 (67%) occurred during pregnancy or the six weeks following delivery.
- The rate was highest for women 35 years or older (36 deaths per 100,000 live births).
- Non-Hispanic Black women had a rate of maternal mortality that was 3.5 times greater than the rate among non-Hispanic White women (34.4 deaths per 100,000 live births compared to 10.9 deaths per 100,000 live births, respectively).
- While the majority of the women died at a hospital, 17.2% of the deaths occurred outside of a hospital.

Conclusion & Future Directions

- Maternal mortality continues to be a substantial public health concern in South Carolina as well as across the United States.
- Demographic disparity in maternal mortality exist in South Carolina, including a substantial racial disparity.
- The ongoing work of the South Carolina maternal mortality review process will be essential in improving understanding of the causes of maternal deaths and the development of strategies to improve maternal health outcomes in the future.

References:

AN ACT TO AMEND THE CODE OF LAWS OF SOUTH CAROLINA, 1976, BY ADDING SECTION 44-1-310 SO AS TO REQUIRE THE DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL TO ESTABLISH THE MATERNAL MORBIDITY AND MORTALITY REVIEW COMMITTEE TO REVIEW AND STUDY MATERNAL DEATHS AND TO REPORT THE FINDINGS TO THE GENERAL ASSEMBLY.

Legislative findings

SECTION 1. The General Assembly finds that:

1. The South Carolina rate of maternal death is higher than the United States average;

2. Maternal deaths are a serious public health concern and have a tremendous family and societal impact;

3. Maternal deaths are significantly underestimated and inadequately documented, preventing efforts to identify and reduce or eliminate the causes of death;

4. No processes exist in this State for the confidential identification, investigation, or dissemination of findings regarding maternal deaths;

5. The federal Centers for Disease Control and Prevention and the American College of Obstetricians and Gynecologists have determined that maternal deaths and severe maternal morbidity should be investigated through state-based maternal morbidity and mortality reviews in order to institute the systemic changes needed to decrease maternal mortality; and

6. There is a need to establish a program to review maternal deaths and maternal morbidity to develop strategies for the prevention of maternal deaths in South Carolina.
The Department of Health and Environmental Control shall establish a Maternal Morbidity and Mortality Review Committee to review maternal deaths and to develop strategies for the prevention of maternal deaths. The committee must be multidisciplinary and composed of members deemed appropriate by the department. The committee also may review severe maternal morbidity. The department may contract with an external organization to assist in collecting, analyzing, and disseminating maternal mortality information, organizing and convening meetings of the committee, and performing other tasks as may be incident to these activities, including providing the necessary data, information, and resources to ensure successful completion of the ongoing review required by this section.

The committee shall:

1. identify maternal death cases, as defined as a death within one year of pregnancy with a direct or indirect causation related to the pregnancy or postpartum period;
2. review medical records and other relevant data;
3. contact family members and other affected or involved persons to collect additional data;
4. consult with relevant experts to evaluate the records and data;
5. make determinations regarding the preventability of maternal deaths;
6. develop recommendations for the prevention of maternal deaths; and
7. disseminate findings and recommendations pursuant to subsection (F).

Health care providers and pharmacies licensed pursuant to Title 40 shall provide reasonable access to the committee to all relevant medical records associated with a case under review by the committee.

A health care provider, health care facility, or pharmacy providing access to medical records pursuant to this subsection are not liable for civil damages or subject to criminal or disciplinary action for good faith efforts in providing the records.
Maternal Morbidity and Mortality Review Committee

SECTION 2. Chapter 1, Title 44 of the 1976 Code is amended by adding: "Section 44-1-310.

(D) Information, records, reports, statements, notes, memoranda, or other data collected pursuant to this section are not admissible as evidence in any action of any kind in any court or before another tribunal, board, agency, or person. The information, records, reports, statements, notes, memoranda, or other data must not be exhibited nor their contents disclosed, in whole or in part, by an officer or a representative of the department or another person, except as necessary for the purpose of furthering the review of the committee of the case to which they relate. A person participating in a review may not disclose the information obtained except in strict conformity with the review project.

(2) All information, records of interviews, written reports, statements, notes, memoranda, or other data obtained by the department, the committee, and other persons, agencies, or organizations authorized by the department pursuant to this section are confidential.

(E) All proceedings and activities of the committee, opinions of members of the committee formed as a result of the proceedings and activities, and records obtained, created, or maintained pursuant to this section, including records of interviews, written reports, and statements procured by the department or another person, agency, or organization acting jointly or under contract with the department in connection with the requirements of this section, are confidential and are not subject to the provisions of Chapter 4, Title 30 relating to open meetings or public records, or subject to subpoena, discovery or introduction into evidence in any civil or criminal proceeding. However, this section must not be construed to limit or restrict the right to discover or use in any civil or criminal proceeding anything that is available from another source and entirely independent of the committee's proceedings.

(2) Members of the committee must not be questioned in a civil or criminal proceeding regarding the information presented in or opinions formed as a result of a meeting or communication of the committee. However, this section must not be construed to prevent a member of the committee from testifying to information obtained independently of the committee or which is public information.

(F) Reports of aggregated nonindividually identifiable data for the previous calendar year must be compiled and disseminated by March first of the following year in an effort to further study the causes and problems associated with maternal deaths. Reports must be distributed to the General Assembly, the Director of the Department of Health and Environmental Control, health care providers and facilities, key governmental agencies, and others necessary to reduce the maternal death rate.

(G) Members shall serve without compensation, and are ineligible for the usual mileage, subsistence, and per diem allowed by law for members of state boards, committees, and commissions."
SC Legislative Brief 2017 - From the SC Maternal Mortality and Morbidity Review Committee

The South Carolina Maternal Mortality and Morbidity Review (MMMR) Committee, established by state law in 2001, investigates the death of mothers associated with pregnancy to determine which ones can be prevented. A pregnancy-related death occurs when a woman dies while pregnant or within 1 year after the pregnancy. The cause must be related to or made worse by her pregnancy or its management. This does not include accidental or incidental causes.

Across the United States, approximately 700 women die each year from the result of pregnancy or delivery complications. Some groups of women in South Carolina experience this tragic event at a much higher rate than other groups.

During 2016, the maternal death rate in South Carolina was higher than the Healthy People 2020 goal of 11.4 maternal deaths per 100,000 live births.

Goals of the South Carolina MMMR Committee

1. Determine the annual number of pregnancy-associated deaths that are pregnancy-related.
2. Identify trends and risk factors among preventable pregnancy-related deaths in South Carolina.
3. Develop actionable strategies for prevention and intervention.

2016-2017 MMMR Committee Accomplishments

Established the Committee
- Members include stakeholders from multiple disciplines.

Best Practices
- Trained members on the mission, goals, best practices, and data structure.

Began Data Review
- Identified cases through voluntary hospital reporting.
- Collected and reviewed data on 6 deaths.

Scope of Case Review

pregnancy-associated deaths

Primary Focus
preventable pregnancy-related deaths

MMMR Committee Findings

During 2016-2017, 7 of the 8 maternal deaths reviewed in S.C. were determined to be pregnancy-related.

87.5%

As reported nationally, the findings from South Carolina’s MMMR Committee show that the common causes of maternal death include cardiovascular and coronary conditions, hemorrhage, infections, and embolism.

Once access to vital records is gained, a complete, more robust analysis will be possible. Review of all pregnancy-related deaths will provide the committee with the ability to see trends in contributing factors and make recommendations for prevention.

MMMR Committee Recommendations

Since 2016, the committee has identified actions that could improve South Carolina’s ability to understand causes of pregnancy-related death.

Remove Barriers to Accessing Data
- Allow linkage to vital records to improve case identification. This information would provide the true burden of maternal deaths in S.C. and would enable a more representative number of cases to be reviewed.

Identify Funding
- Identify funding that would provide resources for the review of all pregnancy-related deaths.

Improve Reporting of Maternal Deaths
- Establish routine hospital and birthing center reporting, which would allow more cases to be reviewed.

South Carolina’s Contribution to National Efforts

In partnership with the Centers for Disease Control and Prevention (CDC), South Carolina recently contributed its aggregate data to national surveillance efforts in the 2018 “Report from Nine Maternal Mortality Review Committees”. This effort allows the committee to better understand trends in maternal deaths, contributing factors, and recommendations for prevention in our state.

South Carolina's partnership with the CDC has led the state to the deployment of the Maternal Mortality Review Information Application (MMRIA), a comprehensive database that can be used for surveillance, monitoring, and research of maternal mortality. MMRIA will support the work of the committee and improve case investigation efforts.

• South Carolina Birth Outcomes Initiative (SC BOI) meets monthly to work on a variety of perinatal safety, quality and evidence-based practice initiatives.

• Patient safety bundles are being implemented in delivery hospitals around the state

• Simulation education provided with the SimCOACH™ gives opportunities for hospital staff to prepare for common and rare obstetric and neonatal emergencies

• South Carolina working to officially become an AIM state
Neonatal/Infant Mortality
• Neonatal Death
  • Neonatal death is when a baby dies in the first 28 days of life
  • Neonatal death happens in about 4 in 1,000 babies each year in the United States
  • Non-Hispanic black women are more likely to have a baby die than women of other races or ethnicities

• Infant Death
  • Death of an infant before his or her first birthday

https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm
The infant mortality rate is the number of infants deaths for every 1,000 live births.

The infant mortality rate is an important marker of the overall health of a society.

Lack of access to health care, poor maternal health, and prenatal and postnatal care all contribute to infant mortality.
Infant mortality is higher in the U.S. than in comparable countries

### Infant mortality per 1,000 live births, 2014

<table>
<thead>
<tr>
<th>Country</th>
<th>Infant Mortality Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>5.8</td>
</tr>
<tr>
<td>Canada</td>
<td>4.8</td>
</tr>
<tr>
<td>Switzerland</td>
<td>3.9</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>3.9</td>
</tr>
<tr>
<td>Netherlands</td>
<td>3.6</td>
</tr>
<tr>
<td>France</td>
<td>3.5</td>
</tr>
<tr>
<td>Comparable Country Average</td>
<td>3.4</td>
</tr>
<tr>
<td>Australia</td>
<td>3.4</td>
</tr>
<tr>
<td>Belgium</td>
<td>3.4</td>
</tr>
<tr>
<td>Germany</td>
<td>3.2</td>
</tr>
<tr>
<td>Austria</td>
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</tr>
<tr>
<td>Sweden</td>
<td>2.2</td>
</tr>
<tr>
<td>Japan</td>
<td>2.1</td>
</tr>
</tbody>
</table>

Comparable countries are defined as those with above median GDP and above median GDP per capita in at least one of the past 10 years. Canada data estimated from 2012.


Infant Mortality Rate in U.S.

Neonatal mortality in the U.S. is higher than in comparable countries

Neonatal mortality per 1,000 live births, 2014

<table>
<thead>
<tr>
<th>Country</th>
<th>Neonatal Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
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</tr>
<tr>
<td>Canada</td>
<td>3.6</td>
</tr>
<tr>
<td>Switzerland</td>
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<td>United Kingdom</td>
<td>2.7</td>
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<tr>
<td>Australia</td>
<td>2.4</td>
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<tr>
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<td>2.4</td>
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<tr>
<td>Austria</td>
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<tr>
<td>Belgium</td>
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<td>Germany</td>
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<td>Netherlands</td>
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<tr>
<td>Sweden</td>
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<tr>
<td>Japan</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Comparable countries are defined as those with above median GDP and above median GDP per capita in at least one of the past 10 years. In cases where 2014 data were unavailable, data from the best available year are shown.

Leading Causes of Infant Deaths in U.S.

Figure 5. Infant mortality rates for the 10 leading causes of infant death in 2016: United States, 2015 and 2016

1Statistically significant decrease in mortality rate from 2015 to 2016 (p < 0.05).
NOTES: A total of 23,161 deaths occurred in children under age 1 year in the United States in 2016, with an infant mortality rate of 587.0 infant deaths per 100,000 live births. The 10 leading causes of infant death in 2016 accounted for 67.5% of all infant deaths in the United States. A total of 23,455 infant deaths occurred in 2015, with an infant mortality rate of 599.5 infant deaths per 100,000 live births. Rankings for 2015 data are not shown. Causes of death are ranked according to number of deaths. Access data table for Figure 5 at: https://www.cdc.gov/nchs/data/databriefs/db293_table.pdf#5.

https://www.cdc.gov/nchs/images/databriefs/251-300/db293_fig5.png
• The infant mortality rate in South Carolina decreased from 7.0 infants deaths per 1,000 live births in 2016 to 6.5 deaths per 1,000 births in 2017. Thirty fewer infants died in 2017 than in the previous year.

• From 2016 to 2017, there was a 24.7 percent decrease in infant deaths from birth defects. Preterm/low birthweight deaths decreased by 8.8 percent.

• The number of infant deaths due to maternal complications of pregnancy increased 70 percent, from 20 in 2016 to 34 in 2017.

Figure 2.
Five Year Infant Mortality Rates<sup>1</sup> by County
South Carolina
2013-2017
(Residence Data)

Above State Average indicates a rate greater than 7.2.
State Average indicates a rate between 5.8 and 7.2 inclusive.
Below State Average indicates a rate lower than 5.8.

<sup>1</sup>Rate per 1,000 live births. Rates calculated with 20 or fewer deaths are unreliable and should be used cautiously.

Causes of Infant Mortality

- The leading causes of infant mortality are:
  - Birth Defects
  - Preterm Birth/Low Birth Weight
  - SIDS
  - Maternal Pregnancy Complications
  - Injuries

- The US infant mortality rate is 5.87 deaths per 1000 live births
- The South Carolina infant mortality rate is 6.7 deaths per 1000 live births
- Birth Defects remained the leading cause for infant mortality in 2015 and 2016

https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm
• CDC estimates that birth defects occur in about 1 in every 33 infants born in the United States each year

• Birth defects can occur in any pregnancy but there are some factors that increase a pregnant woman's risk
  • Lack of folic acid: Recommended dose for women who are pregnant or planning a pregnancy is 400 micrograms per day. Folic acid is recommended to help prevent neural tube defects. According to the CDC, only 2 out of every 5 women of childbearing age take the recommended dose of folic acid
  • Drinking alcohol: Drinking alcohol during pregnancy can lead to a variety of problems. Fetal Alcohol Syndrome is characterized by intellectual or developmental disability, physical challenges, and behavioral problems
  • Smoking cigarettes: Smoking can lead to certain birth defects with the heart and intestines
  • Drug Use: Can lead to birth defects, pregnancy loss and stillbirths
• **Medication use:**
  - Certain medications taken during pregnancy can lead to birth defects. Thalidomide, is currently used to treat certain cancers. This drug was once used to treat morning sickness until it was found to cause severe birth defects. The defects ranged from structural and functional problems, misshapen ears and shortened limbs. Majority of medications currently used by pregnant women have not been tested for safety or efficacy in pregnant women. NICHD Obstetric-Fetal Pharmacology Research Units Network is focusing on addressing this issue.

• **Infections:**
  - Some of the most common infections that are linked to birth defects such as cytomegalovirus, a common virus that spreads through body fluids and usually causes no symptoms. Toxoplasmosis, a parasitic infection that spreads through contact with cat feces, raw meat, and contaminated food and water. Zika Virus is linked to microcephaly in newborn babies.

• **Obesity and uncontrolled diabetes:**
  - Obesity has been linked to heart and neural tube defects.
There are two main categories of birth defects:

- Structural Birth Defects
  - Defects related to a problem with the structure of body parts:
- Functional or Developmental Birth Defects
  - Defects related to a problem with how a body part or body system works or functions

https://www.nichd.nih.gov/health/topics/birthdefects/conditioninfo/types
Structural Birth Defects
- Defects related to a problem with the structure of body parts:
  - Cleft lip or Cleft palate
  - Heart Defects
  - Abnormal limbs
    - Clubfoot
  - Neural Tube Defects
    - Spina Bifida

https://www.nichd.nih.gov/health/topics/birthdefects/conditioninfo/types
### Structural Birth Defects in South Carolina

<table>
<thead>
<tr>
<th>Birth Defect</th>
<th>Birth Year 2016</th>
<th>Birth Year 2017</th>
<th>Birth Year 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ventricular Septal Defect</td>
<td>238</td>
<td>223</td>
<td>186</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>76</td>
<td>69</td>
<td>45</td>
</tr>
<tr>
<td>Atrial Septal Defect</td>
<td>40</td>
<td>55</td>
<td>52</td>
</tr>
<tr>
<td>Microcephaly</td>
<td>64</td>
<td>41</td>
<td>28</td>
</tr>
<tr>
<td>Coarctation of Aorta</td>
<td>37</td>
<td>25</td>
<td>21</td>
</tr>
<tr>
<td>Atrioventricular Septal Defect</td>
<td>35</td>
<td>23</td>
<td>25</td>
</tr>
<tr>
<td>Renal Agenesis, Unilateral</td>
<td>22</td>
<td>31</td>
<td>29</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>27</td>
<td>26</td>
<td>21</td>
</tr>
<tr>
<td>Congenital Pulmonary Valve Stenosis</td>
<td>28</td>
<td>23</td>
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Structural Birth Defects in South Carolina

- Ventricular Septal Defect is the number one structural birth defect seen in South Carolina. Ventricular septal defect is one of the most common congenital heart defects and the cause is unknown. It occurs in nearly half of all children with congenital heart disease.

- Let’s do a quick review of how the heart works:
  - The heart has two sides, separated by the septum. With each heartbeat, the right side of your heart receives oxygen-poor blood from your body and pumps it to your lungs. The left side of your heart receives oxygen-rich blood from your lungs and pumps it to your body.

- The Ventricular septal defect is a hole in the wall (septum) of the two lower chambers (ventricles) of the heart.
  - This defect allows blood to pass from the left side of the heart to the right side. This means that oxygen-rich blood can mix with oxygen-poor blood. As a result, some oxygen-rich blood is pumped to the lungs instead of out to the body.

https://www.cdc.gov/ncbddd/heartdefects/ventricularseptaldefect.html
Types of Ventricular Septal Defect

- Listed below are common locations and names of VSD’s
  - Membranous Ventricular Septal Defect
    - Located near the heart valves. These VSD’s can close at any time
  - Muscular Ventricular Septal Defect
    - Located in the lower part of the septum. They are surrounded by muscle and most close on their own during early childhood
  - Inlet Ventricular Septal Defect
    - Located close to where the blood enters the ventricles. They are less common than membranous and muscular VSD’s.
  - Outlet Ventricular Septal Defect
    - Found in the part of the ventricle where blood leaves the heart. These are the rarest type of VSD’s.
• Murmur is usually present at birth and may be the only sign or symptom. Infants who have medium or large sized VSD’s are at risk for heart failure.

• Signs and symptoms of heart failure
  • Failure to thrive
  • Difficulty feeding

• Signs and symptoms are rare after infancy because the defect either decreases in size on its own or is repaired
Diagnosing and Treatment of Ventricular Septal Defect

- Diagnosing
  - Referral to Pediatric Cardiologist
  - Echocardiogram
  - EKG
  - Chest X-Ray
  - Cardiac Catheterization

- Treatment will depend on our the infant is doing. More than half of VSD’s eventually close, usually by the time a child is in preschool.

- Surgery may be recommended if the infant’s VSD:
  - Is large
  - Causing symptoms
  - Is medium-sized and causing enlarged heart chambers
  - Affects aortic valve

- Most VSD’s that require surgery are repaired in the first year of life
Types of Birth Defects:
FUNCTIONAL / DEVELOPMEMENTAL

- Functional or Developmental Birth Defects are defects related to a problem with how a body part or body system works or functions:
  - Nervous System
    - Down Syndrome
    - Fragile X Syndrome
  - Sensory
    - Hearing loss
    - Visual problems
  - Metabolic Disorders
    - Phenylketonuria
    - Hypothyroidism
  - Degenerative Disorders
    - Muscular
  - Degenerative Disorders
    - Muscular Dystrophy
    - X-linked Adrenoleukodystrophy
The most common functional or developmental birth defect we see in South Carolina is hearing loss. Hearing loss occurs in newborn infants more frequently than any other condition for which newborn infant screening is required. Studies show hearing loss occurs in approximately 2-4 out of 1,000 babies. Hearing is very important with development of language skills. Infants begin developing speech and language at birth. 80% of language ability is established by the age of 18 months.
• The top four newborn screening conditions identified in South Carolina in 2016 were:
  • Congenital Hypothyroidism
  • Sickle C Disease
  • Sickle Cell Disease
  • Cystic Fibrosis

• The top four newborn screening conditions identified in South Carolina in 2017 were:
  • Sickle Cell Disease
  • Sickle C Disease
  • Congenital Hypothyroidism
  • Cystic Fibrosis
Sickle cell disease is a group of disorders that affects hemoglobin.
The hemoglobin molecule is atypical and are called hemoglobin S, which can distort red blood cells into a sickle, or crescent shape.
Signs and symptoms usually begin in early childhood. Characteristic features include anemia, repeated infections, and periodic episodes of pain.
- The signs and symptoms are caused by the sickling of red blood cells. When red blood cells sickle, they break down prematurely, which can lead to anemia.
- Painful episodes can occur when sickled red blood cells, which are stiff and inflexible, get stuck in small blood vessels. These episodes deprive tissues and organs of oxygen rich blood and can lead to organ damage.
- A serious complication of sickle cell disease is pulmonary hypertension (high blood pressure in the blood vessels that supply the lungs). Pulmonary hypertension may lead to heart failure and affects one-third of adults with sickle cell disease.

https://medlineplus.gov/ency/article/002052.htm
Sickle cell disease is the most common inherited blood disorder in the United States, affecting 70,000 to 80,000 Americans. The disease is estimated to occur in 1 in 500 African Americans and 1 in 1,000 to 1,400 Hispanic Americans. The condition is inherited and is autosomal recessive.
Autosomal recessive disorder means two copies of an abnormal gene must be present in order for the disease or trait to develop.

- If an infant is born to parents who carry the same autosomal recessive mutation, the infant has a 1 in 4 chance of inheriting the abnormal gene from both parents and developing the disease. The infant has a 50% chance of inheriting one abnormal gene, this would make them a carrier.

- An infant is born to a couple who both carry the gene (but do not have signs of disease), the expected outcome for each pregnancy is:
  - 25% chance the infant is born with two normal genes (normal)
  - 50% chance the infant is born with one normal and once abnormal gene (carrier, without disease)
  - 25% chance infant is born with two abnormal genes (at risk for the disease)
Hemoglobin SC disease is the second most common type of sickle cell disease.

The SC variant is when one gene is mutated to the S form (sickled form) and the other is mutated to the C variant, which is also abnormal.

For people with one S and one C mutation, they have less episodes of their blood cells clumping together compared to people with SS disease, so they have less pain crises. Sickle Cell C disease is also autosomal recessive.

https://www.healthline.com/health/sickle-cell-anemia#types
Congenital Hypothyroidism

- Congenital hypothyroidism is a partial or complete loss of function of the thyroid gland that affects infants from birth. The thyroid gland makes iodine-containing hormones that play an important role in regulating growth, brain development, and metabolism.

- Two Types of Congenital Hypothyroidism
  - Thyroid Dysgenesis is when the thyroid gland is absent, severely reduced in size or abnormally located.
  - Thyroid Dyshormonogenes is when the thyroid gland is normal in size or enlarged thyroid gland (goiter) is present. Production of thyroid hormones are decreased or absent.

Signs and symptoms of Congenital Hypothyroidism appear secondary to the shortage of thyroid hormone. Some infants have no symptoms and some are less active and sleep more than other infants. Infants may also have difficulty feeding and experience constipation. If untreated, congenital hypothyroidism can lead to intellectual disability and slow growth. If infants receive treatment in the first two weeks after birth, they usually develop normally.

Diagnosing and Treatment:
- The Newborn State Screening test will show a low T4 (low level of thyroid hormone) and a high TSH (thyroid stimulating hormone). The infants physician will be contacted and confirmation lab testing will be done.
- Treatment: The infant will be started on a medication called Levothyroxine.
Cystic Fibrosis

- Cystic Fibrosis is an inherited disease caused by mutations in a gene called cystic fibrosis transmembrane conductance regulator (CFTR) gene.
  - This gene provides instructions for the CFTR protein. CFTR protein is located in every organ of the body that makes mucus, including the lungs, liver, pancreas, intestines and sweat glands.
  - The mutations in the CFTR gene cause the CFTR protein to not work properly by causing thick, sticky mucus and blockages in the lungs and digestive system. Normally mucus coats the cilia in the airways of the lungs, which sweep the mucus particles up to the nose and mouth where the body can rid of them. People with cystic fibrosis, this process does not work properly.

- Screening:
  - Every infant in the United States are screened for Cystic Fibrosis by their Newborn State Screening test. Genetic testing may also look for carriers or the CFTR mutation gene.

- Diagnosing can be done by genetic testing or sweat test

- Treatment:
  - While there is no cure for Cystic Fibrosis, advancements in treatment are allowing people to live longer, healthier lives
The number one cause of neonatal death is prematurity.

Respiratory distress syndrome is the leading cause of death with the premature infant

- About 380,000 babies are born prematurely in the United States each year
- The premature birth rate has increased for the third year in a row. The United States has the highest rates of premature birth in the industrial world
2018 Premature Birth Report Card

2018 PREMATURE BIRTH REPORT CARDS

Moms and babies face higher risks than ever before. The preterm birth rate in the United States has worsened for a third year, rising to 9.93 percent in 2017. Premature birth and its complications are the largest contributors to infant death in this country and globally. March of Dimes is working to solve this problem, and the most serious health threats to moms and babies, so all families can get the best possible start.

Choose your state to see how it ranks on this year’s Report Card.

Source: Preterm birth rates are from the National Center for Health Statistics, 2017 final natality data. Grades assigned by March of Dimes Perinatal Data Center.
Prematurity in South Carolina

- In South Carolina, 1,118 infants are born per week. Of these infants, 123 were born preterm, 85 were born late preterm, and 22 were born very preterm
  - Preterm is less than 37 weeks
  - Late Preterm is 34 to 36 weeks
  - Very Preterm is less than 32 weeks

- In 2017, there were 6,396 preterm births in South Carolina, representing 11.2% of live births
  - 1 in 9 babies were born preterm in South Carolina in 2017

What is Respiratory Distress Syndrome?

- Respiratory Distress Syndrome is caused by pulmonary surfactant deficiency in the neonate's lungs.
- It is more commonly seen in infants that are less than 37 weeks gestation.
- Surfactant production begins at 25 weeks gestation but adequate amounts of surfactant are not produced until 34-36 weeks gestation.
  - Pulmonary surfactant is needed to decrease the surface tension of the water film that lines the alveoli.
  - It is needed to help prevent the alveoli from collapsing and decrease the work required to inflate the alveoli.
  - When the lungs are surfactant deficient, greater pressure is needed to open the alveoli. Without adequate airway pressure, the lungs become diffusely atelectatic.
Infant’s who have respiratory distress syndrome or RDS will typically be symptomatic at birth or a few hours after birth.

- They may present with nasal flaring, retractions, grunting and tachypnea.
- As the atelectasis worsen, signs and symptoms will worsen.
- Infant will become apneic, lethargic and have cyanosis.
- Neonates weighing less than 1000 grams may have lungs that are so stiff they are unable to initiate or sustain respirations in the delivery room
Diagnosis of respiratory distress syndrome is by clinical presentation. Arterial blood gases will show hypoxemia and hypercapnia. Chest x-ray will show diffuse atelectasis with visible air bronchograms.
Respiratory Distress Syndrome

- Specific treatment of respiratory distress syndrome is endotracheal surfactant therapy. This therapy requires endotracheal intubation which also may be necessary to achieve adequate ventilation and oxygenation.

- Respiratory Support:
  - CPAP (Continuous Positive Airway Pressure) with the combination of surfactant therapy, the goal is to prevent the infant with respiratory distress syndrome from requiring mechanical ventilation.
  - Mechanical ventilation may be necessary especially for the very low birth weight infant’s (VLBW).
    - The goal is to monitor these infant’s closely and wean the oxygen and ventilator settings whenever possible.
    - The concerns when using mechanical ventilation is the long term damage that can occur such as chronic lung disease.

Before Surfactant
After Surfactant
What Is Being Done To Improve Mortality Rates?

- Improving birth outcomes requires public health agencies working together with health care providers, communities, and partners to reduce infant deaths in the United States. CDC is committed to improving birth outcomes and listed below are programs they are using to help understand and reduce infant mortality.
  - Perinatal Quality Collaborative are state or multi-state networks of teams working to improve the quality of care for mothers and babies. Perinatal Quality Collaborative have contributed to improvements in health care and outcomes for mothers and babies, including:
    - Reductions in deliveries before 39 weeks of pregnancy without a medical reason
    - Reductions in healthcare associated bloodstream infections in newborns
    - Reductions in severe pregnancy complications
  - SUID is the sudden and unexpected death of an infant less than 1 year old without an obvious cause of death before investigation. The CDC has SUID monitoring programs in 16 states and 2 jurisdictions. Participating states and jurisdictions use data about SUID and circumstances to develop strategies to reduce future deaths
  - Pregnancy Risk Assessment Monitoring System (PRAMS) was established in 1987 to reduce infant morbidity and mortality. PRAMS data can be used to identify groups of women and infants at high risk for health problems, and to measure progress toward goals in improving the health of mothers and infants
  - National Center on Birth Defects and Developmental Disabilities. The CDC works to identify causes of birth defects, find opportunities to prevent them, and improve the health of those living with birth defects
What Is Being Done To Improve Mortality Rates?

• The March of Dimes aims to reduce preterm birth rates across the United States to 8.1 percent of live births by 2020. Every baby in South Carolina deserves the chance to be born healthy.

• Prematurity Research Initiative: In 2004, the PRI began and it funds research into the causes of prematurity. The PRI are exploring how genetics or a combination of genetic and environmental factors may influence a woman’s chances of going into premature labor.

• The Processes of Development: Some of March of Dimes grantees are studying basic biological processes of development. This research should improve our understanding of how genes and other factors direct the transformation from a single cell into a complete being.

• Genetic Causes: Genetics has been a main theme of March of Dimes research. Grantees have discovered genes that cause or contribute to a number of common birth defects, including fragile X-syndrome, cleft lip and palate and heart defects.
Conclusion/Wrap-Up
Congratulations!
You have finished the module.

Last Step: Complete the Post-Test & Evaluation

• All participants must complete the Post-Test and Evaluation.
• New This Year – Online Post-Test and Evaluation (Preferred Methods)
  • Please click on the following link https://www.surveymonkey.com/r/PKHHQMJ or open your I-Phone Camera and scan the QR Code located to the right to access the online Post-Test and Module Evaluation
  • Alternate option, please complete the paper version of the post-Test utilizing the Answer Sheet and Evaluation
    • Return Answer sheet/Evaluation Form to Perinatal Systems:
      • Fax: (803)434-4309
      • E-mail: PerinatalSystems@prismahealth.org

• Questions?
  Contact Cathy White (Cathy.White@prismahealth.org) or Michelle Flanagan (Michelle.Flanagan@prismahealth.org)

Thank you!