Fetal Deaths
Carla DeSisto
Division of Reproductive Health
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention

Joyce Martin

Elizabeth Gregory
Birth and Infant Health Team, Reproductive Statistics Branch
Division of Vital Statistics, National Center for Health Statistics
Centers for Disease Control and Prevention
ACKNOWLEDGEMENTS

Donna Hoyert
Nosology Rules and Resolution Team/Mortality statistics Branch, Division of Vital Statistics, NCHS/CDC

and

Claudia Valenzuela
Birth and Infant Health Team/Reproductive Statistics Branch
Division of Vital Statistics, NCHS/CDC
OUTLINE

Importance of fetal death and vital statistics fetal death data (Carla) → International reporting of fetal deaths (Carla) → Definitions and reporting requirements (Joyce) → History of vital statistics and fetal death reporting (Joyce)

• Revisions of the US standards and other changes

CAUSE OF FETAL DEATH (Elizabeth) → DATA AVAILABILITY (Elizabeth) → A FEW STATS (Elizabeth)
THE IMPORTANCE OF FETAL DEATH
THE IMPORTANCE OF FETAL DEATH

• Fetal deaths are part of the continuum of pregnancy outcomes

• Fetal death can be a heartbreaking tragedy for women and families

• Causes are poorly understood, but believed to be associated with:
  – Maternal infections
  – Non-communicable diseases
  – Chromosomal abnormalities
  – Obstetric complications
DISTRIBUTION OF ALL PREGNANCIES BY OUTCOME: UNITED STATES, 2010 (N = 6.2 MILLION)

- Live Births: 65%
- Induced Terminations of Pregnancy: 18%
- Fetal Deaths*: 17%

*All gestational ages

Around the world, there are an estimated 2.6 million fetal deaths of at least 20 weeks gestation each year.
INTERNATIONAL REPORTING OF FETAL DEATHS
INTERNATIONAL REPORTING: WORLD HEALTH ORGANIZATION

• WHO has long recognized the importance of international comparison of perinatal mortality and its components.

• One of the tasks of WHO is to coordinate the compilation of health statistics and to encourage member countries to rely on the same definitions to allow for the comparison of those statistics.

• Events related to birth, death, and fetal death, and the reporting requirements for the data, are defined in the *International Classification of Diseases* (ICD).
WHO recommends that, if possible, all fetuses and infants weighing at least 500 g at birth, whether alive or dead, be included in the statistics.

The inclusion in national statistics of fetuses and infants weighing between 500 g and 1000 g* is recommended both because of its inherent value and because it improves the coverage of reporting at 1000 g and over.

Dissimilar definitions and reporting methods continue to hamper international comparisons.

Despite the importance to women and infant health, fetal deaths are still not included in the major international measures of disease burden:

- Sustainable Development Goals
- Global Burden of Disease estimates

Data on fetal deaths are less frequently available than data on births and infant deaths.

Fetal death data are available for fewer countries and are less consistent than early neonatal and neonatal mortality data.

Fetal deaths are more likely underreported, especially at earlier gestational ages:

- The magnitude of underreporting likely varies by country.
IMPORTANCE OF VITAL STATISTICS
FETAL DEATH DATA
THE IMPORTANCE OF VITAL STATISTICS FETAL DEATH DATA

Vital statistics data are the most comprehensive source of US data on fetal deaths of 20 weeks of gestation and greater.
THE IMPORTANCE OF VITAL STATISTICS FETAL DEATH DATA

- The only other national source of fetal death data is the National Survey of Family Growth (NSFG).
  - However, the NSFG has important limitations that vital statistics data do not have:
    - Data - including gestational age information - are self-reported and subject to recall bias
    - Does not include information from clinicians or medical records
    - Cannot produce state-level or lower geographic-level estimates
THE IMPORTANCE OF VITAL STATISTICS FETAL DEATH DATA

- The study of fetal deaths can provide important clues on how various health conditions and risk factors can affect pregnancy outcomes.

- In Utah, fetal death records are used to send surveys to women who have recently experienced a fetal death.
  - The study is called the Study of Associated Risks of Stillbirth (SOARS) and is an adaptation of the Pregnancy Risk Assessment Monitoring System (PRAMS).
  - Surveys include questions about:
    - Women’s life experiences before and during pregnancy
    - Delivery and hospital experience
    - Health behaviors
    - Clinical testing
    - Bereavement support
  - Reliable fetal death data is the critical first step for this type of study.
POLL QUESTION

Is your state/jurisdiction currently or planning to use fetal death records to send surveys to women who have recently experienced a fetal death?

Yes, we currently have such a survey

Yes, we are planning, or are interested in planning such a survey

No, we are not planning such a survey

Don’t know
DEFINITIONS
The complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy, which, after such expulsion or extraction, breathes, or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached. Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps.

* Model State Vital Statistics Act and Regulations. Consistent with WHO definition
Fetal death is defined as **death prior to the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy** and which is **not an induced termination of pregnancy**. The death is indicated by the fact that after such expulsion or extraction, the fetus **does not breathe or show any other evidence of life** such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.

INDUCED TERMINATION OF PREGNANCY (ITOP)

The *purposeful interruption of an intrauterine pregnancy with the intention of other than to produce a live-born infant*, and which does not result in a live birth. This definition excludes management of prolonged retention of product of conception following fetal death.

* Model State Vital Statistics Act and Regulations. The WHO does not have a definition for ITOP.
<table>
<thead>
<tr>
<th>Live Birth</th>
<th>vs.</th>
<th>Fetal Death</th>
<th>vs.</th>
<th>ITOP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evidence of Life</td>
<td></td>
<td>Death prior to delivery</td>
<td></td>
<td>Purposeful interruption of an intrauterine pregnancy with the intention of other than to produce a live-born infant</td>
</tr>
<tr>
<td>- Breathing*</td>
<td></td>
<td>Not an induced termination of pregnancy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Beating of the heart**</td>
<td></td>
<td>No evidence of life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Pulsation of the umbilical cord</td>
<td></td>
<td>- No breathing*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Definite movement of voluntary muscles</td>
<td></td>
<td>- No beating of the heart**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- No pulsation of the umbilical cord</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- No definite movement of voluntary muscles</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Respirations are to be distinguished from fleeting respiratory efforts or gasps

**Heartbeats are to be distinguished from transient cardiac contractions
DEFINITIONS BY STATE

All states use definitions of live birth and fetal death that are fundamentally consistent with The Model Law.
Guidelines for Reporting Live Births, Infant Deaths, Fetal Deaths, and Induced Terminations of Pregnancy

Did infant/fetus show signs of life at delivery?

- Yes
  - Signs of life:
    - Breathing
    - Beating of the heart
    - Pulsation of the umbilical cord
    - Definite movement of voluntary muscles
  - Prepare/file Certificate of Live Birth

- No
  - Was the intent to terminate the pregnancy?
    - Yes
      - Prepare/file Intentional Termination of Pregnancy Report
    - No
      - Did the infant subsequently die?
        - Yes
          - Prepare/file Report of Fetal Death
        - No
          - STOP No further action required

Prepare/file Death Certificate

*Whether the hospital or the funeral home prepares/files the death certificate is determined by which disposes of remains.

**Refer to jurisdictional reporting requirements.

***Refer to jurisdictional requirements. Thresholds (or reporting requirements) for reporting fetal death vary by jurisdiction as to the birthweight and/or gestational age at which a Report of Fetal Death is required.
REPORTING REQUIREMENTS
RECOMMENDED REPORTING REQUIREMENTS

Both The 1992 and The 2011 Model State Regulations and Reporting Requirements (Model Law) recommend that a fetal death be reported if it is:

- 350 grams or more, OR if weight is unknown
- 20 completed weeks gestation or more, calculated from the date last normal menstrual period began to the date of delivery

✓ All live births are to be reported regardless of gestational age or viability.

GESTATIONAL AGE/BIRTHWEIGHT AT WHICH FETAL DEATH REPORTING IS REQUIRED BY STATE

Within Model Law Recommendations: 39
Outside Model Law Recommendations: 6

Gestational age/Birthweight at which reporting is required: 20 weeks or 350 grams
REPORTING REQUIREMENTS

• National fetal death data available for 20+ weeks

• Historically, reporting of fetal deaths tends to be more complete the earlier reporting is required

• Differences in state reporting requirements can affect the completeness of national reporting at 20+ weeks

• And, accordingly, comparisons of fetal mortality rates by state
  – Solution = restrict to 24 and greater weeks for state x state comparisons
RELATIVE MAGNITUDE OF FETAL DEATHS OF 20+ WEEKS OF GESTATION, AND INFANT DEATHS: UNITED STATES, 2017

Infant Deaths: 49.5% N=22,341
Fetal Deaths: 50.5% N=22,827

NOTE: Infant death is defined as death within the first year of life.
POLL QUESTION (POP QUIZ!)

A woman comes to the hospital and delivers at 29 weeks gestation. The infant does not appear to breathe or show any other evidence of life. How should this event be reported?

- Certificate of Live Birth
- Certificate of Death
- Report of Fetal Death
- Certificate of Live Birth and Certificate of Death
- Certificate of Live Birth and Report of Fetal Death
HISTORY OF FETAL DEATH REPORTING IN THE U.S.

1918
US Census begins collection and reporting*

1933
All states added to the fetal death registration area

1939
1st US Standard Fetal Death Certificate established

1946
National Office of Vital Statistics (NOVS) created

1960
NCHS created (includes NOVS)

1974
NCHS mandated by law** to collect (from states) and publish vital statistics data

*Some states report via birth and death certificates, some use stillbirth certificate.
**Health Services Research and Evaluation and Health Statistics Act of 1974 (Public Law 93–353)
REVISIONS OF US STANDARD FETAL DEATH REPORT


• Beginning with 1978, revisions designed to capture information similar to that on birth certificate (COD included from 1939)

• 2003 revision expanded medical/health info captured; concerns soon grew over the amount of data collected

• Birth Data Quality Workgroup – reviews/recommends dropping 36 items
  – Goal: to improve quality of other data items, especially COD

• Recommendations accepted by NAPHSIS & NCHS leadership; beginning with 2014 national file these items no longer included in national reporting
2003 REVISIONS ITEMS (36) DROPPED FROM NATIONAL REPORTING

- Mother ever married (not standard marital status item or on standard fetal report but part of national file)
- Mother married? (At delivery, conception or anytime between)
- Total number of prenatal visits for this pregnancy
  - Edit flag - Total number of prenatal visits for this pregnancy
- Date of last prenatal care visit*
- Mother’s weight at delivery
  - Edit flag - Mother’s weight at delivery
- Number of other pregnancy outcomes

- Date of last other pregnancy outcome
- Mother/patient transferred for maternal medical or fetal indications for delivery?
- Previous preterm birth (Risk factors for this pregnancy)
- Other previous poor pregnancy outcomes (Risk factors for this pregnancy)*
- Hysterotomy/hysterectomy (Method of delivery)
- Maternal transfusion (Maternal morbidity)
- Third or fourth degree perineal laceration (Maternal morbidity)
- Unplanned hysterectomy (Maternal morbidity)
- Unplanned operating room procedure (Maternal morbidity)
2003 REVISIONS ITEMS (36) DROPPED FROM NATIONAL REPORTING

- Infections present and/or treated during this pregnancy:
  - Gonorrhea
  - Syphilis
  - Chlamydia
  - Listeria
  - Group B strep
  - Cytomegalovirus
  - Parvovirus
  - Toxoplasmosis
  - Other (Specify)

- Congenital anomalies of the fetus:
  - Anencephaly
  - Meningomyelocele/Spina bifida
  - Cyanotic congenital heart disease
  - Congenital diaphragmatic hernia
  - Omphalocele
  - Gastrochisis
  - Limb reduction defect
  - Cleft Lip with or without Cleft Palate
  - Cleft palate alone
  - Down syndrome- karyotype confirmed/pending
  - Suspected Chromosomal disorder - karyotype confirmed/pending
  - Hypospadias
CAUSE OF FETAL DEATH
While sometimes unknown, the cause of these deaths is a critical piece of information to identify why the death occurred and factors that might influence ways to prevent such losses.

Better information on the cause of fetal death can help us to prevent these tragic events in the future.
CAUSE OF FETAL DEATH

• Cause of fetal death data was not released by NCHS prior to 2014 because of concerns with data quality and the lack of resources needed to adequately code cause of death.

• NCHS recently revised instructions on coding, developed a system for processing cause, and assumed responsibility for coding fetal cause of death for revised reporting areas starting in 2010.

• The first NCHS report on cause of fetal death was released in October 2016; a new report, with COD data through 2017 was released earlier this month.
FETAL DEATHS BY SELECTED CAUSES, 39 AREAS: 2017

- Unspecified cause (P95) 31.1%
- Placenta, cord and membranes complications (P02) 26.3%
- Maternal complications (P01) 12.5%
- Congenital malformations (Q00-Q99) 10.2%
- Maternal conditions unrelated to pregnancy (P00) 9.8%
- All other causes 10.1%

NOTES: By place of residence. Excludes CT, GA, MI, MS, ND, NY, RI, TN, VA, VT, WI, which had more than 50% of records with unspecified COD. CA was also excluded because COD data are based on the 1989 revision and are not considered comparable with the 2003 revision format.

DATA AVAILABILITY
NATIONAL FETAL DEATH DATA RELEASES

• Due to the staggered implementation of the 2003 revision, there was a lack of comparable data items for many items through 2017

• For the 2018 data year, all 50 states, the District of Columbia, and New York City have revised their fetal death reports and national data based on the 2003 revision are available

  -RELEASED THIS MONTH!

• Annual national detailed micro-data files and User Guide available at:

  https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm

• CDC WONDER
  – Data available for 2005-2017 fetal deaths
  – Cause of Death data available for 2014-2017
NATIONAL FETAL DEATH DATA RELEASES

• Annual standard reports
  – Fetal death NVSR beginning with 2018 data (includes COD!)
  – Perinatal Data Brief beginning with 2018 data

• Special reports
  – NVSRs
    • Cause-of-death data from the fetal death file, 2015-2017 (Released this month!)
    • Cause of Fetal Death: Data From the Fetal Death Report, 2014 (2016)
  – Data briefs
    • Lack of Change in Perinatal Mortality in the United States, 2014 (2018)
    • Trends in Fetal and Perinatal Mortality in the United States, 2006–2012 (2014)
A FEW STATS
FETAL MORTALITY RATE: UNITED STATES, 1970-2000

NOTES: Fetal mortality rates are the number of fetal deaths at 20 weeks of gestation or more per 1,000 live births and fetal deaths.

FETAL MORTALITY RATE: UNITED STATES, 2000-2017

NOTES: Fetal mortality rates are the number of fetal deaths at 20 weeks of gestation or more per 1,000 live births and fetal deaths. Starting with 2014 data, the obstetric estimate of gestation at delivery (OE) replaced the gestational age measure based on the date of the last normal menses (LMP).

Early and late fetal mortality: United States, 2000-2017

NOTE: Early fetal mortality rate is the number of fetal deaths at 20-27 weeks of gestation per 1,000 live births and fetal deaths at 20-27 weeks of gestation. Late fetal mortality rate is the number of fetal deaths at 28 weeks of gestation or more per 1,000 live births and fetal deaths at 28 weeks of gestation or more. Starting with 2014 data, the obstetric estimate of gestation at delivery (OE) replaced the gestational age measure based on the date of the last normal menses (LMP), introducing a discontinuity in early and late fetal mortality rates from earlier years; rates calculated using the different measures are non-comparable.

Rates range from 2.18 in New Mexico to 6.86 in Mississippi

NOTE: Rate per 1,000 live births and fetal deaths at 24 weeks or greater.
FETAL MORTALITY BY AGE OF MOTHER:
UNITED STATES, 2017

FETAL MORTALITY BY RACE AND HISPANIC ORIGIN OF MOTHER: UNITED STATES, 2017

Rate per 1,000 births and fetal deaths

Race and Hispanic origin:
- Non-Hispanic black: 10.32
- American Indian or Alaska Native: 7.22
- Hispanic: 5.01
- Non-Hispanic white: 4.89
- Asian or Pacific Islander: 4.29

PERINATAL, LATE FETAL, AND EARLY NEONATAL MORTALITY RATES: UNITED STATES, 2014-2017

NOTES: Perinatal mortality is the number of infant deaths under age 7 days and fetal deaths at 28 weeks of gestation or more per 1,000 live births and fetal deaths at 28 weeks of gestation or more. Late fetal mortality rate is the number of fetal deaths at 28 weeks of gestation or more per 1,000 live births and fetal deaths at 28 weeks of gestation or more. Early neonatal mortality is the number of infant deaths under age 7 days per 1,000 live births.

Despite efforts to improve the quality of the data collected (e.g., dropping of multiple items from national reporting), the quality of fetal death data continues to be of concern.
FETAL DEATH DATA QUALITY

• Please join us for our next webinar—July 15th.

ASSESSING AND IMPROVING THE QUALITY OF FETAL DEATH DATA
Does your state publish stats on fetal deaths at least annually?

- Yes
- No
- Plan to in the future
SUMMARY
FETAL DEATHS SUMMARY

Fetal deaths are part of the pregnancy continuum.

There are more fetal deaths of 20 and greater weeks in the US than infant deaths, but are too often overlooked.

Vital statistics data are the most comprehensive source of US data on fetal deaths of 20 weeks of gestation and greater.

National data, including COD data based on the 2003 revision now available.

Improvements in the quality of non-COD and COD data quality necessary.
CONCLUSION

Fetal death data are often overlooked in the United States and around the world.

Improved fetal death data is key for improving maternal and child health.
QUESTIONS?