Effective Review of Natural Infant Deaths

November 16, 2016



About the National Center

The National Center for Fatality Review and Prevention is a resource and data center that supports child death review (CDR) and fetal and infant mortality review (FIMR) programs around the country.

It is funded in part by Cooperative Agreement Number UG7MC28482 from the U.S. Department of Health and Human Services (HHS), Health Resources Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).



Speaker Panel

Diane Pilkey, RN, MPH Senior Nurse Consultant MCHB, HRSA





Rosemary Fournier, RN, BSN NCFRP FIMR Director



Jason Jarzembowski, MD, PhD Children's Hospital of Wisconsin



Webinar Goals:

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- Describe the impact of natural infant deaths on the overall child mortality rate for the US and why it's important for child death review teams to consider including these deaths in their review processes.
- Identify the maternal risk factors contributing to infant deaths due to conditions originating in the perinatal period.
- Describe how to conduct effective reviews of natural infant deaths, including what records are needed for successful reviews, and what to look for (risk factors) in those records.
- Understand that many of the natural infant deaths are preventable and provide guidance to teams for making recommendations on effective prevention services/actions

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Housekeeping

 The session is being recorded and archived. Slides and archive will be available at: https://www.childdeathreview.org/

Choose one of the following audio options:



- TO USE YOUR COMPUTER'S AUDIO:
 When the webinar begins, you will be connected to audio using your computer's microphone and speakers (VoIP). A headset is recommended.
 --OR—
- TO USE YOUR TELEPHONE:
 If you prefer to use your phone, you must select "Use Telephone" after joining the webinar and call in using the numbers +1 (415) 655-0052,
 Access Code: 483-332-644



Housekeeping

- All participants will be muted, listen only mode
- Questions can be typed into the Chat Window. Due to the large number of participants, we may not be able to get to all questions in the time allotted. Additional questions will be answered after the webinar and posted on the NCFRP web site:

https://www.childdeathreview.org/



Infant Mortality

 Definition: The death of any live born infant prior to his/her first birthday. • "The most sensitive index we possess of social welfare . . ."

Julia Lathrop, Children's Bureau, 1913





Infant Mortality in the United States

- 3,988,076 births in 2014
 - 8% were low birth weight (less than 5.5 pounds)
 - 9.6% preterm, (born less than 37 weeks gestation
- 23,215 infant deaths
- Rate of 5.82 deaths per 1,000 live births



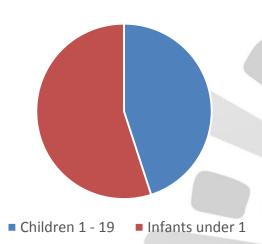
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National Vital Statistics Reports, Vol. 65 No. 4, June 30, 2016 http://www.cdc.gov/nchs/

Impact of Infant Deaths on Overall Child Mortality

- In 2014, there were 41,881 deaths of children 0 − 19.
- 23,215 of the deaths were to infants under the age of one.
- This represents 55% of overall child mortality.



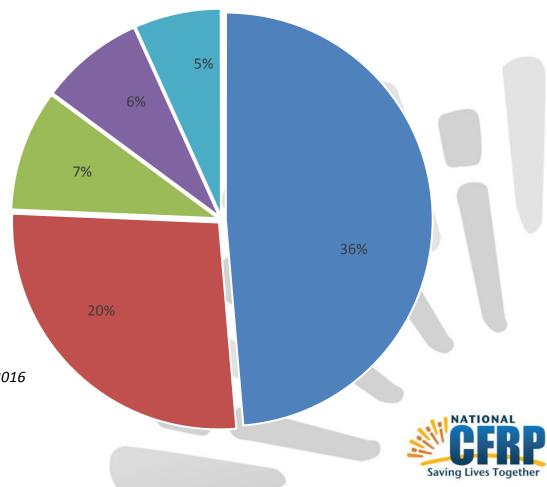


Leading Causes of Infant Deaths



- Congenital Malformations
- Maternal Complications of Pregnancy
- Sudden Infant Death Syndrome
- Accidents (Unintentional Injuries)

National Vital Statistics Reports, Vol. 65 No. 4, June 30, 2016 http://www.cdc.gov/nchs/



Fetal Mortality

 "Fetal death" means 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. Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps.



Fetal Mortality in the United States

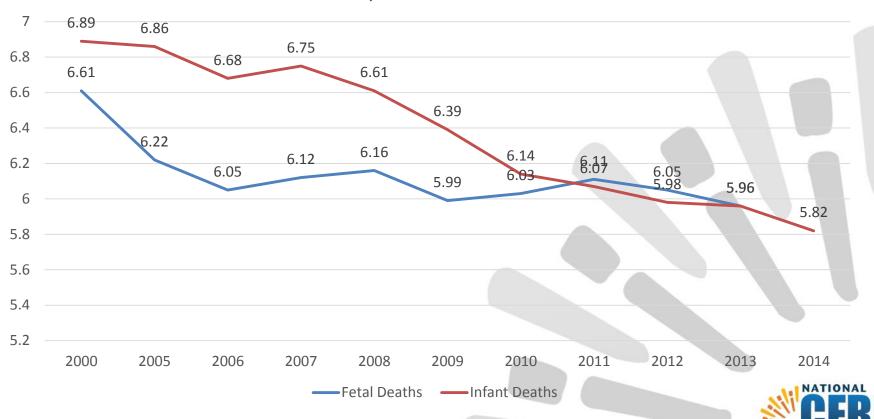
- 5.96 deaths per 1,000 live births
 - early (less than 20 completed weeks of gestation)
 - intermediate (20–27 weeks of gestation)
 - late (28 weeks of gestation or more)

MacDorman MF, Gregory ECW. Fetal and perinatal mortality: United States, 2013. National vital statistics reports; vol 64 no 8. Hyattsville, MD: National Center for Health Statistics. 2015.

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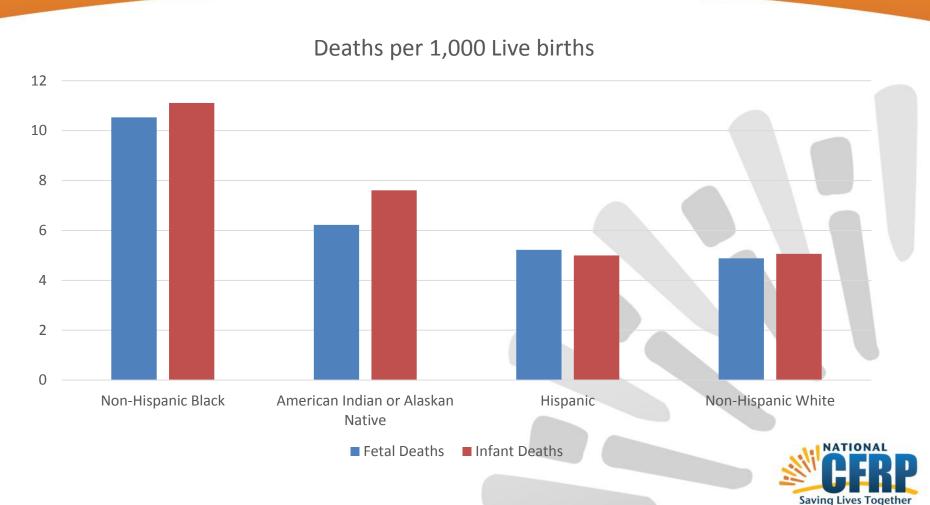
US Fetal and Infant Mortality Trends





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Disparities in Fetal and Infant Mortality Rates



Status of Reviews in the CDR-CRS

- Of the 183,145 child death cases reviewed by teams in the CDR Case Reporting System:
 - 98,477 are infants under the age of one (54%)
 - 1,329 are stillbirths or fetal deaths (less than 1%)





Effective Review of Natural Infant Deaths: Improving stillbirth and infant death reviews to enhance prevention

November 16, 2016

Jason Jarzembowski, MD, PhD
Laboratory Medical Director, Children's Hospital of Wisconsin
Associate Professor and Chief, Pediatric Pathology
Medical Advisor, Infant Death Center of Wisconsin

Background

- Each year, more than 23, 400 US infants die before their first birthday.
- Approximately 75 percent of these infants were born premature.
- Prematurity is a complex event with multiple causes/risk factors.
- Nonetheless, thorough review can identify discrete risk factors present in individual or groups of cases amenable to prevention efforts.

Definitions

Category	Gestational age
Term	40 weeks
Late premature	37-39 weeks
Moderately premature	32-37 weeks
Very premature	28-31 weeks
Extremely premature	<28 weeks

Risk factors for preterm birth

- Maternal
- Fetal
- Placental
- Biological
- Psychological
- Social



Biological risk factors

- Multiple pregnancies
- Abnormal uterine or cervical anatomy
 - Uterine fibroids
 - Incompetent cervix
- Infection UTI, placenta
- Placental abnormalities
- Alcohol / drugs / cigarettes



Biological risk factors

- Previous preterm birth
- Especially young or advanced age
- Underweight or overweight
- Fetal abnormalities
- Short time between pregnancies

Biological risk factors

- Race
- Poor nutritional status
- Chronic maternal health issues
 - High blood pressure
 - Diabetes
 - Blood clotting disorders

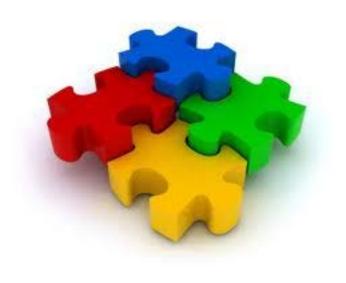
Psychological risk factors

- Stress
- Anxiety / depression
- Domestic violence or abuse

Social risk factors

- Low socioeconomic status
- □ Late / incomplete prenatal care
- Lack of social support
- Unmarried
- Long work hours / extended standing
- Environmental exposures

Putting it all together



- Historical summary
- Data collection
- Maternal interview (FIMR)
- Identifying what happened
- Identifying why it happened
- Identifying how it could have been prevented

Records & Data Sources

Case review strategies



■So how do we review these cases at CDR or FIMR in order to capture all the pertinent data with an eye towards public health and prevention?

Maternal history - sources

- Medical records
 - prepregnancy care (internist)
 - prenatal visits (OB, etc.)
 - delivery (hospital, other)
 - "face sheet"
 - laboratory reports
- Social work consult
- Mental health records (rare)
- Maternal interview (FIMR)

Maternal social history

- Age, race
- Education and employment
- ☐ Marital/family status especially FOB
- Insurance coverage
- Living situation
- Transportation
- Planned pregnancy?

Maternal mental health

- "Pre-existing conditions"
- Post-partum depression
- Pathologic grief

Maternal medical history

- Pre-pregnancy maternal health
 - Body mass index (BMI)
 - Chronic illnesses
 - Medications
 - Mental health

- Mom's prior pregnancies
 - Number, duration, outcome
 - Delivery methods
 - Interval
 - Complications



Maternal medical history

- Course of current pregnancy
 - Date of first prenatal visit
 - Unexpected OB/ED/urgent care visits
 - Ultrasound exams
 - Weight gain
 - Fetal monitoring heart rate, growth, anatomy
 - Blood pressure hypertension, pre-eclampsia
 - Labs: glucose tolerance, urinalysis, cultures

Maternal medical history

- Outcome of current pregnancy
 - Circumstances surrounding entry into labor
 - Medical interventions
 - Fetal monitoring
 - Mode of delivery
 - Initial infant assessment: weight, Apgar scores
 - NICU transfer
 - Placental pathology report

Infant history - sources

- Medical records
 - delivery (L&D, NICU)
 - pediatrician
 - laboratory reports
- ☐ Immunization records
- Child welfare records
- Maternal interview (FIMR)

Infant medical history

- Post-delivery hospital/NICU course
- Early infancy pediatrician visits, frequent illnesses, hospitalizations
- ☐ Growth & development

Circumstances of Death

- Emergency Department or hospital notes
- Hospital lab reports
- Police reports
- Medical examiner/coroner records
- Autopsy reports
- Death certificate

Circumstances of death

- Death scene investigation
- Autopsy report
- Placental pathology report
- Genetic testing
- Post-mortem laboratory testing



Prevention Opportunities

Role of CDR/FIMR in Prevention

"Reviews are intended to catalyze community action."



Role of CDR/FIMR in Prevention

- Data collection
- ☐ Finding common themes / problems
- Identifying partnerships and building relationships
- Advocacy

Prevention

- Awareness
- Analysis
- Addressing
- Advocacy

Policy Makers

How should federal, state and local governments, and corporate entities help public health, providers and agencies to reduce disparity and increase infant survival?

Health Plans Clinics/Provider Groups Private Practices

How can healthcare providers and health insurers apply Standards of Care and the concepts of Social Justice to reduce disparity and increase infant survival?

Community Agencies

How can social service providers and other community agencies address the social determinants of healthy birth outcomes?

Partnering for Solutions

Milwaukee Businesses and Community Groups

How can the community be informed? How can the community act to reduce disparity and increase infant survival?

Individuals

What actions can individuals and families take to reduce disparity and increase infant survival?

Prevention topics

- Medical / Clinical
 - Interconceptional care
 - Early and regular prenatal care
 - Weight
 - Proper control of diabetes and high blood pressure
 - Screening and treatment of infections
 - Prompt treatment of new problems
 - Ensuring placental analysis, autopsy, and appropriate testing in cases of fetal/infant death

Prevention topics

- Psychosocial
 - Referral and access to mental health services.
 - Maintenance of chronic conditions
 - Transportation and funding
 - Home visits and follow-up

- Other
 - SIDS risk reduction / promoting safe sleep practice
 - Teen pregnancy prevention

Barriers to Review & Prevention

Barriers to Review

- Inadequate/incomplete information
- Access to documents/data
- Willingness of participants/participating groups to share information
- Maintaining confidentiality
- Keeping teams engaged and motivated
- Self-care for team members

Barriers to Prevention

- Staying focused on the big picture, not individual cases
- Devoting team time to prevention work
- Breadth of team resources and experience
- Finding suitable community/government partners

Take Home Messages



- Prematurity is a major cause of infant mortality and morbidity, with multiple complex risk factors
- Case review needs to look for all these risk factors and identify possible points of intervention.
- Data must be acquired from numerous sources.
- □ Prevention efforts need to be multipronged and tailored to areas – interconceptional care and access to care are important themes.

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Effective Review of Natural Infant Deaths

Thank You!

Additional questions can be directed to info@ncfrp.org



Save the Date!



December 14, 2016, 2:00 p.m. – 3:00 p.m. ET

Fatality review is hard work! Join us to discuss taking care of ourselves. Recognizing and Responding to Vicarious Trauma

Speaker: Tammy Scheidegger, Ph.D. Associate Professor,
Mount Mary University



