

NEBRASKA CHILD DEATH REVIEW TEAM

Glossary

Births

Apgar Score

Newborn viability is most often assessed by the Apgar score. The Apgar score is a widely used assessment of the physical condition of a newborn infant based on heart rate, muscle tone, breathing effort, color and reflex responsiveness. Scores are assessed at 1, 5 and 10 minutes after birth. A score of 10 suggests the healthiest infant, and scores below 5 indicate that the infant needs immediate assistance in adjusting to his or her new environment. The Apgar test is non-invasive and does not involve risk to the newborn.

Birth Defect / Congenital Anomaly

A birth defect is an abnormality of structure, function or metabolism (body chemistry) that is present at birth. Birth defects may be caused by chromosomal or “hereditary” errors or by other influences on the fetus during gestation. They are the leading cause of death for infants. The March of Dimes groups birth defects in three main categories:

- Structural/metabolic (e.g., neural tube defects, missing organs),
- Congenital infections (e.g., Rubella (German measles), syphilis), and
- Other (e.g., Fetal Alcohol Syndrome (FAS)).

For this report, birth defects are only categorized as such if there was no known cause for their occurrence. For example, defects resulting from congenital infections are considered under Maternal Complications; defects resulting from FAS are under Maternal Substance Use.

Gestation

The gestational age of the newborn is the interval between the first day of the mother’s last normal menstrual period (LMP) and the date of birth. It is typically determined by maternal recall, but can also be determined by clinical examination if the mother’s information is not available or is

inconsistent with the fetus' or newborn's size.

Live Birth

The state of Nebraska defines a live birth as “The complete expulsion or extraction of a product of conception from its mother, irrespective of the period of gestation, which, after such separation, 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, and is reportable.”

Premature birth

Premature birth is a leading cause of infant mortality, yet little is known on how to prevent it. A normal gestation is defined as 37 to 41 weeks; an infant born at 37 or fewer weeks of gestation is considered premature. Through 37 weeks, major systems and organs are still developing. However, babies with at least 28 weeks of gestation are considerably more likely to survive; each additional week of gestation improves the likelihood of survival and decreases the probability of lifelong disabilities. Multiple gestation pregnancies (twins, triplets, etc.) are more likely to deliver prematurely. The prematurity rate is the number of live births of 37 weeks or less gestation divided by the total number of live births.

Viable

Capable of living; born alive and with such form and development of organs as to be capable of living.

Death / Mortality

Cause of Death

The *immediate* cause of death is the disease (condition) or complication occurring closest to the time of death that leads to or contributes to death, and is classifiable according to the International Classification of Diseases (ICD) system. The State of Nebraska used the Ninth Revision for deaths up until 1998, and the Tenth Revision since 1999. However, the immediate cause of death does not necessarily reflect the complete set of reasons for the death. The *underlying* cause of death is the disease or condition that

initiated the train of morbid events leading directly to death, and may be many years removed from the actual occurrence of death.

Although immediate causes of death are often preventable, underlying causes are more informative for primary prevention purposes as defined by the Team. For example, pneumonia deaths are largely preventable. However, when pneumonia is the immediate cause of death in a child who is ventilator dependent due to cerebral palsy, prevention of infantile or childhood cerebral palsy becomes the larger, long-term focus. Similarly, while massive head trauma may be an immediate cause of death, prevention of the motor vehicle crash that caused the trauma is as important as improved emergency medical care.

Manner of Death

The manner of death is important and distinct from the cause of death. Manner of death is typically classified as:

- Natural
- Accidental
- Homicide
- Suicide
- Undetermined
- Unknown / No Answer

Fetal Death

The state of Nebraska follows the National Center for Health Statistics' definition of a fetal death as "... death prior to¹ 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."

Neonatal Death

¹ Emphasis added.

Death of a live born infant under 28 days of age.

Perinatal Death

Death of a fetus after 28 weeks or more of gestation or of a live born infant within seven days of life.

Medical Conditions

Cancer / Malignant Neoplasms

Cancer begins in cells, the building blocks that make up [tissues](#). Normally, cells grow and divide to form new cells as the body needs them. When cells grow old, they die and new cells take their place. When new cells form that the body does not need and old cells do not die when they should, these extra cells can form a mass of tissue called a growth or [tumor](#). Not all tumors are cancer. Tumors can be [benign](#) or [malignant](#):

- Benign tumors are not cancer
 - Benign tumors are rarely life-threatening.
 - Usually, benign tumors can be removed, and they seldom grow back.
 - Cells from benign tumors do not spread to tissues around them or to other parts of the body.
- Malignant tumors are cancer
 - Malignant tumors generally are more serious than benign tumors. They may be life-threatening.
 - Malignant tumors often can be removed, but they can grow back.

Hypoxia / Asphyxia

Hypoxia is an insufficient supply of oxygen to the brain. The American Academy of Pediatrics states that an infant who has had "asphyxia" or hypoxia immediately prior to or during delivery that is severe enough to result in acute neurologic injury should demonstrate all of the following: (a) profound metabolic or mixed acidemia (ph <7.00) on an umbilical arterial blood sample, if obtained, (b) an Apgar score of 0 to 3 for longer than 5 minutes, (c) neurologic manifestation, e.g., Seizure, coma, or hypotonia, and

(d) evidence of multiorgan dysfunction. Because this level of detail was rarely available for this report, the physician's or pathologist's assessment was accepted.

Neural tube defect(s)

The neural tube is the part of the developing fetus that becomes the spinal cord and brain. Neural tubes close within the first four weeks of gestation, often before a woman knows she is pregnant; neural tube defects (NTD) occur when the tube only closes partially or not at all. NTDs are among the most common of all serious birth defects.

The two major types of NTDs are anencephaly and spina bifida. Anencephaly is the partial or complete absence of the baby's brain. This defect causes extensive damage, and most of these babies are stillborn or die soon after birth. Spina bifida occurs when an opening remains in the spine. These babies need surgery soon after birth to close the spine and prevent further damage. They also may need a shunt or a drain to prevent a build-up of spinal fluid in the brain called hydrocephalus. Babies with spina bifida may lack feeling in their legs and later develop problems with walking. In addition, these children may develop problems with their bowel and bladder control. They may also have learning problems, and some have mental retardation.

Sudden Infant Death Syndrome (SIDS)

SIDS is officially defined as the sudden death of an infant less than one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history. In Nebraska, only the autopsy is required.² Major risk factors for SIDS are pre- or post-natal exposure to tobacco smoke, low birth weight, not breast-feeding, and the baby not sleeping on his/her back. SIDS is intended to be a diagnosis of exclusion, when no legitimate cause of death can be determined by autopsy or other means.

Trisomy

² Nebr. Rev. Stat. §71-605.

Trisomies are genetic conditions present at birth where cells contain three copies of specific chromosomes instead of the normal two copies. For example, the presence of three copies of chromosome 21 is called Trisomy 21. A partial trisomy occurs when part of an extra chromosome is attached to one of the other chromosomes. A mosaic trisomy occurs when not all cells contain the extra chromosomal material. Trisomies can result in birth defects, miscarriage or early infant death.

Other Terms

Bed sharing vs. Co-sleeping

These terms are often used interchangeably, which adds confusion to an already complex subject. The CDRT follows the general public health consensus that bed-sharing refers to sleeping on the same surface with a person or animal, whereas co-sleeping refers to being in the same room but not the same surface. The surface involved might be a bed, but could also be a futon, mattress, sofa, chair and so on. The dangers of sudden infant death are applied to bed sharing, not co-sleeping.

Preventability

The Team focuses on identifying deaths that could have been prevented under Nebraska's definition:

“Preventable child death shall mean the death of any child which reasonable medical, social, legal, psychological, or educational intervention may have prevented. Preventable child death shall include, but not be limited to, the death of a child from (a) intentional and unintentional injuries, (b) medical misadventures, including untoward results, malpractice, and foreseeable complications, (c) lack of access to medical care, (d) neglect and reckless conduct, including failure to supervise and failure to seek medical care for various reasons, and (e) preventable premature birth; Reasonable shall mean taking into consideration the condition, circumstances, and resources available.”§71-3405 Neb. Rev. Stat.

While preventability is often a straightforward assessment, it can also be quite challenging. For example, if a seizure disorder has been controlled

with medications yet causes a 17-year old driver to have a fatal motor vehicle crash, preventability becomes problematic. As a result, the Nebraska Child Death Review Team uses a 5-point Likert Scale of preventability. For each case reviewed, reviewers assessed whether they:

Strongly Disagree	Somewhat Disagree	Neutral / Undecided	Somewhat Agree	Strongly Agree
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with the statement

- This death was preventable - standard-of-care medical management would have changed the circumstances that led to death (Medical cases);
or,
- This death was preventable - an individual or community could reasonably have done something that would have changed the circumstances that led to death (Non-medical cases).

Race and Ethnicity

Nebraska assigns infant race and ethnicity at birth as that of the mother as reported on the birth certificate. Ethnicity and race are overlapping categories and are thus reported separately. For the time period of these data (2005-2006), Nebraska recognized four racial categories: White, African-American, American Indian and Asian / Pacific Islander.

Risk Factor

There is a distinct difference between a “risk factor” for a disease and a “cause” of that disease. A “cause” refers to something that leads to something else with some degree of certainty through a recognized series of normal or abnormal events. For some diseases or conditions, however, such causes remain unknown and possible chains of events are only hypotheses or theories. Therefore public health workers talk about “risk factors,” factors that are found more frequently in a group of people with a certain problem than in a group of people without that particular problem. The connection between the risk factor and the problem is not always obvious. Some risk

factors are not at all modifiable, such as sex and birth year. Others are categorized as such because, for instance, once an infant is born its birth weight and gestational age cannot be changed even though they may place the infant at risk for other diseases. However, some risk factors can be modified, for example, sleeping position, use of car restraints, vaccination status.

Questions or comments regarding the report or the Nebraska Child Death Review Team should be directed to:

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