Neonatal Death in the Emergency Department: When End-of-Life Care Is Needed at the Beginning of Life

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Abstract:
The death of a neonate is devastating for all involved. Each year, critically ill neonates present to emergency departments across the United States. These infants require acute medical interventions with a goal of stabilization. Despite these efforts, hundreds of infants die every year in emergency departments across the United States. Emergency care providers, unaccustomed to providing neonatal end-of-life care, may feel unsure about how to best care for families during resuscitative measures and after neonates die. There is literature to suggest that increased knowledge and advance preparation can calm fears of providers caring for patients in such tragic situations. We aim to provide in this article a broad overview of a variety of topics related to neonatal death and bereavement care.

Keywords:
neonatal death; neonatal bereavement; palliative care; emergency department

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The death of a neonate, no matter in what setting or circumstance, is devastating for all involved. The birth of a child is rightly expected to be a joyous event. Neonates and their families who instead require emergency treatment demand immediate expert care from medical teams in several forms: quick diagnostic assessment, procedural skills, clear communication, and intensive psychosocial support. Balancing these tasks is difficult but critically important for involved patients, families, and staff.

For the purpose of this article, we will focus on emergency care providers' experiences immediately after the death of a neonate. We will present definitions of perinatal death, describe death of a neonate after resuscitation, discuss the role of palliative care, and explore the needs of families after neonatal death. Much has been written about providers' experiences after the death of a child in the emergency department (ED).[1–3] Many of these concepts apply to the neonatal patient and will be reviewed. However, neonatal loss can be viewed by providers and families as different from the loss of an older child. We will try to address differences in what families may need from providers and what providers may feel.

We hope that, by highlighting unique aspects of neonatal end-of-life care, we can improve awareness, competence, and skill of emergency providers in this area.

DEMOGRAPHICS OF NEONATAL DEATH

Dying patients present to EDs during various stages of the perinatal period—from a fetus with evidence of in utero distress to a neonate decompensating at home. Infant mortality, including perinatal mortality, remains a significant measure of health in modern society.[4] It is important to understand the terminology of these deaths to accurately report them and gather information on vital statistics. Table 1 lists commonly used definitions related to birth and death as adapted from the American Academy of Pediatrics Committee on Fetus and Newborn.[5]

Most neonatal deaths happen in inpatient units, such as neonatal or pediatric intensive care units. Between 1999 and 2013, 268 225 neonatal deaths were reported in the United States. A total of 249,871 (93%) of these occurred in inpatient medical facilities. Of the remaining, 9842 (3.7%) were recorded as either occurring in an outpatient medical facility/ED or presenting dead on arrival to a facility.[6] These statistics indicate that emergency care providers irregularly attend to dying neonates and their families. Because the vast majority of neonates die in inpatient units, it is likely that inpatient staff have more experience in this area. Emergency providers may appreciate this difference and feel ill prepared to care for dying neonates. Advance preparation, including acquiring knowledge of various issues surrounding neonatal death, may help to alleviate discomfort and improve care.

TABLE 1. Commonly used definitions of birth and death in the perinatal period.

Live birth: Complete expulsion or extraction from the mother of a product of human conception, irrespective of the duration of pregnancy, which, after such expulsion or extraction, breathes or shows any other signs of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, regardless of whether umbilical cord has been cut or placenta is attached.
Fetal death: Death before complete expulsion or extraction from the mother of a product of human conception, 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 sign of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.
Infant death: Live birth that results in death within the first year.
Neonatal death: Live birth that results in death within the first 28 d.

Data from Ahrens and Hart.[3]

HOW AND WHY NEONATES DIE

There are 3 mechanisms through which infants who will die arrive in EDs. First, these infants may be born in EDs. This could include pregnancies affected by stillbirth as well as infants who are born alive with conditions causing physiologic instability. Examples of such conditions include prematurity, congenital anomalies, and birth asphyxia. Next, infants may be born outside of hospitals and present to EDs for acute care. This accounts for precipitous births outside of the hospital setting as well as planned out-of-hospital deliveries. It merits mention that out-of-hospital birth has been identified as an independent risk factor for neonatal mortality.[7] Finally, neonates who were born in hospitals and discharged home may subsequently become acutely ill or injured and present for emergency care.

The causes of neonatal death are many[7–11] and have changed over time with changing care practices.[9] We offer that differential diagnoses for a particular neonate can be thought of as related to age after birth. Numerous studies have described how neonates die in the setting of neonatal intensive care.[7–11] A parallel can be drawn between how neonatal intensive care unit infants die shortly after birth (immediately to hours) and conditions emergency care providers might encounter in an infant's first moments of life. Although causes of early death are numerous, they generally belong to 1 or more of the following categories: complications of prematurity, congenital anomalies (genetic and/or structural), respiratory failure, asphyxia, shock/anemia, infection, or malignancy.

Causes of death for neonates who were discharged home after birth may be different than those described above. It is likely that causes of acute neonatal decompensation at home resemble the etiologies of postdischarge death for low–birth weight infants and the etiologies of sudden unexpected death in infancy.[12,13] There may be some overlap, but understanding history and timing of neonatal decompensation can focus the set of possible diagnoses (Table 2).

One cause of both early and late neonatal mortality which deserves separate discussion is

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