Care of the Dying Infant

A ccording to the Centers for Disease Control and Prevention’s National Vital Statistics Reporting System, 15,013 infants younger than 7 days old and 3,769 infants between 7- and 28-days-old died in 2005. More than 25,000 fetal deaths occurred in the same year. These statistics, including the cause of death, have been relatively unchanged for the past 10 years in the United States.1

Some of the deaths are anticipated, and some are unexpected. Although preparing for an unexpected death is not realistic, families can be prepared and counseled regarding an anticipated death of an infant. For these babies who are expected to die, where and how they die can make a great difference in the short- and long-term emotional outcome for the family.

In this article, care of the dying infant is discussed, but perhaps just as important are the challenges and possible solutions involved in anticipating and preparing for an infant’s death.

Scott M. Klein, MD, MHSA, FAAP, FAAHPM, is Senior Medical Director for Visiting Nurse Service of New York (VNS-NY) Hospice.

Address correspondence to: Scott M. Klein, MD, MHSA, FAAP, FAAHPM, Senior Medical Director, VNS-NY Hospice, 1250 Broadway, 7th Floor, New York, NY 10001; email: smklein20@gmail.com.

Dr. Klein has disclosed no relevant financial relationships.

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Scott M. Klein, MD, MHSA, FAAP, FAAHPM
Baby Doe Regulations: An Amendment to the Child Abuse Prevention and Treatment Act of 1984

Caregivers may withhold treatment if any one of the following conditions is met:

- The infant is chronically and irreversibly comatose;
- The treatment would merely prolong dying;
- The treatment would not be effective in ameliorating or correcting all of the infant’s life-threatening conditions;
- The treatment would be futile in terms of survival;
- The treatment would be virtually futile in terms of survival, and the treatment itself under such circumstances would be inhumane.

CASE EXAMPLES

Case 1

Baby S was born to a mother with little prenatal care. In the delivery room, he was noted to have severe respiratory difficulties and clinical features consistent with Trisomy 13 (Patau syndrome). He was rushed from the delivery room to the neonatal intensive care unit (NICU), where he received resuscitation and stabilization. His mother was given little information at the delivery.

Many meetings were held over subsequent days with the mother, with regard to her son’s prognosis and her wishes for him. Eventually, Baby S succumbed to his underlying conditions and died in his mother’s arms in the NICU.

Case 2

Baby J was diagnosed by prenatal ultrasound at 17 weeks gestation with bilateral agenesis of the kidneys. Consultation with pediatric nephrology and pulmonology, as well as the family’s pediatrician, allowed for discussions about the likelihood of pulmonary hypoplasia. The family was well prepared for the extremely poor prognosis and likely rapid death of their son.

Through the work of a local hospice team, the family (parents, siblings, and grandparents) developed detailed birth plans and goals of care. In addition, the delivery room and neonatal staff were well aware of the family’s wishes. The parents decided to have oxygen and oral/mucosal-absorbed morphine available for comfort of respiratory distress, with no other resuscitative measures planned. Family photographs were taken during the infant’s 45 minutes of life, while he was held and comforted by his parents.

These two cases each ended with an infant dying within a short period after birth and are illustrative of different prenatal preparations. Variables included key knowledge before birth; willingness to address difficult and potentially painful outcomes; openness by health providers to grant family wishes; and the ability to capture important mementos to provide a legacy of the infant.

CAUSES OF DEATH

Among the annual 19,000 US neonatal deaths (ie, occurring with the first within 28 days of life), congenital malformations; low birth weight, sudden infant death syndrome (SIDS); and maternal complications of pregnancy and complications of the placenta, cord, and membranes are the most common causes. The US has been criticized for higher than expected infant mortality rates compared with the rest of the world. This has been mostly due to gaps in health status between upper and lower socioeconomic groups rather than due to poor medical care.

One group that has made great strides in outcome are infants born at low birth weight (less than 1,500 g). These low birth weight (LBW) infants had a 20% survival rate in 1960; in recent years, infant survival approaches 80%. Approximately half of LBW infants have a normal neurological outcome, but 20% of infants will suffer severe neurological deficits as a result of prematurity.

Advances in treatment and technology, such as use of antenatal steroids and surfactant, as well as extracorporeal membrane oxygenation, nitric oxide, and improvements in mechanical ventilation have greatly contributed to the improved survival of infants. In addition, basic supportive care, such as nutrition, anti-reflux medications, and more reliable yet simpler oxygen delivery methods have helped more infants survive than in the past. Despite these measures, fragile infants may survive longer in the NICU before, ultimately, dying.

DIFFICULTIES IN PROGNOSTICATION

Among the greatest barriers to providing effective palliative care for infants is the difficulty in providing accurate prognostic information to families. Unlike adults dying of cancer, most pediatric fatal illnesses do not take a normal trajectory toward death. In fact, even pediatric cancers often fail to follow the adult trajectory. Furthermore, much of the literature describing life expectancy for genetic syndromes is based upon outdated information, as well as on very small numbers of patients. This leaves practitioners with a significant level of uncertainty when counseling families.

In the past, infants with fatal conditions may have been given little supportive care. Today, infants receive enteral feedings, gastroesophageal reflux medications, and effective seizure control. As a result of better nutrition and prevention of aspiration, life expectancy figures have extended well beyond that projected even 20 years ago. Also, parents have information resources, such as the Internet, to research genetic syndromes with untraditional or “miracle” outcomes. There are several prominent online cases of patients with so-called “fatal” conditions living 10 to 20 years beyond prediction.

Health care providers may complicate the problem by framing bias. When
prognostic information is framed as a positive outcome (survival with little disability), families are more likely to choose more aggressive measures, including resuscitation. Ideally, parental decision-making should be based upon unbiased, nondirective counseling. Even when families have acknowledged that their child will die, they sometimes struggle with the uncertainty of when the death will occur. Waiting for what seems to be an interminable time, parents often ask, “How long can this last?” The family may grieve the loss of the normal birth and newborn infant, even while waiting for their child to die. The emotional dichotomy of the joy of birth and bonding with the newborn child while confronting the grief process can be unfathomable. This stressful situation can be overwhelming, invoking anger, helplessness, and extreme sorrow in the family.

LEGAL ISSUES OF NEONATES

When addressing decisions regarding infants, legal issues are sometimes of concern. Three of the most common cases utilized to guide legal obligations regarding infants are the Baby Doe regulations, the case of Baby K, and the case of Saikewicz. Several important ethical considerations are relevant in neonatal end-of-life care. Because neonates are never considered competent, similar to adults who have never been competent, the concepts of substituted judgment and best interest standards apply. Parents are assumed to be making decisions for the infant in line with the family’s overall cultural and health care beliefs. The assumption is that the infant would adopt the family’s beliefs, and therefore approach his/her own health care decisions in the same way (a substituted judgment).

The case of Baby K involved a child with anencephaly for whom the hospital wished to terminate respiratory support, and the child’s mother objected. The hospital went to court to request withdrawal of the ventilator. The court rejected the hospital’s request, arguing that respiratory failure could be reversed, although anencephaly could not; the treatment was considered neither futile nor inhumane.

The case of Saikewicz involved an adult patient who was mentally retarded and developed leukemia. The patient’s mother, acting as his surrogate, felt treatment with chemotherapy would induce a great burden on her son and requested to withhold treatment. The court sided with the mother, arguing that the treatment needed to be placed in the overall context of the patient; the burden on his quality of life would outweigh any benefits from chemotherapy.

Other court cases have refined the obligations of the medical team as well as the parents in decision-making regarding infants. In general, the court looks to answer what treatment is in the best interest of the infant.

ETHICAL CONSIDERATIONS

Several important ethical considerations are relevant in neonatal end-of-life care. Because neonates are never considered competent, similar to adults who have never been competent, the concepts of substituted judgment and best interest standards apply. Parents are assumed to be making decisions for the infant in line with the family’s overall cultural and health care beliefs. The assumption is that the infant would adopt the family’s beliefs, and therefore approach his/her own health care decisions in the same way (a substituted judgment).

The best interests of the infant can be a source of conflict among family members, as well as among family members and health care providers, because the definition of what is in the best interest of the infant is less clearly defined. It is important to consider best interest within the entire context of the infant’s situation, as illustrated in the Saikewicz case.

The concepts of withholding versus withdrawing care and medical futility are no different in infants than in older children and adults. Ethical standards approach the withholding of treatment no differently than later withdrawing the same treatment: if a decision is made to withhold a therapy, then that same therapy could be later be withdrawn using the same criteria. Medical futility can be viewed in quantitative and qualitative terms. Quantitative futility would use the standard of a less than 1% chance of a hoped for outcome succeeding. Qualitative futility, rather, is based upon quality of life and is very dependent upon subjective values.

THE ROLE OF GRIEF

Although grief is not a concept unique to the death of infants, practitioners need to understand some key issues in order to provide the greatest support for families. First, due to the nature of infant mortality, parents may
Planning for an Infant’s Death

Little planning can be performed when an infant dies unexpectedly. Conversely, prenatally there is the opportunity to anticipate and plan for an infant likely to die, followed by support of the family, with a memory box and bereavement resources. The specific timeline will depend upon the prognosis and an understanding of likely symptoms leading up to death.21

Developing goals of care with a family is a very useful step in planning the infant’s comfort. An emphasis should be made on the most important tenets of care. All interventions, invasive or not, may be appropriate if aligned with the overall goals or mission of the family (see Sidebar 2, page 255). When in utero diagnosis occurs, the goals of care may include birth plans, who will be in delivery room and what interventions will be performed.22 In addition, team discussions should make these plans clear before delivery; the delivery room is not a good place for long-term decision-making.23-26

Beyond the delivery room, planning starts with open discussions.27 Communication between families and staff can be strained by mixed messages and varying predictions of outcome. Discussions are best held in quiet, relaxed settings rather than at the bedside in a busy NICU.28 Relationship building is necessary to be able to have clear and open discussions. The strength of the relationship depends upon many factors but is often greatly affected by the amount of time available and may be compromised by the health of the mother post-partum.19,29-31 Again, the family pediatrician may play an important role as a trusted source and bridge to the primary team.

Location of Death

Most dying infants are managed within a hospital and usually an ICU (see Sidebar 3).32 However, for many cases, a more peaceful death can occur out of the ICU and, in certain cases, in the home. There are many benefits and a few barriers to discharging an infant to die at home.33 The benefits include privacy; family unity; fewer interventions; quieter environment; and usually increased family satisfaction.34

However, home-based care may not be viable in all situations.35 For example, infants who have specific, high-skill care needs, are receiving costly medications that are difficult to obtain from community pharmacies, or living in areas with little available skilled pediatric nursing, may be served best within a hospital. Other barriers to a home death include the difficulty in obtaining follow-up subspecialty care, if needed. Also, families view the benefits of an infant dying at home differently; thus their wishes are to be respected. Some siblings will benefit from a home death while others may be negatively affected by the experience.

Symptoms Management Concepts

Regardless of the location of death, management of the infants’ symptoms is critical. Expected symptoms at the end of life are variable depending upon the diagnosis and comorbid conditions. In general, there are certain symptoms that are most common and should be anticipated.36

Pain management is often of great concern to families and practitioners. Although it is often difficult to differentiate the irritable infant from one in pain, it is best to assume that the infant is in pain and to treat accordingly. The World Health Organization (WHO) ladder utilizes three steps for pain control. The first step utilizes pain medications, acetaminophen and a non-steroidal anti-inflammatory agents (NSAIDs), such as ibuprofen, along with adjunctive or complementary care (ie, swaddling, sucrose sucking). Subsequent steps utilize more powerful opioid agents;36 ketamine37 and gabapentin have shown promise in infants with irritability or refractory pain at the end of life.38

Pain medications can be administered in many different forms. Infants with intravenous access can receive opioids and sedative agents intermittently or as a continuous infusion. Medications also can be administered subcutaneously and intramuscularly; however, these routes are best avoided to minimize painful injections. Many effective pain medications, especially

SIDEBAR 3.
Creating a Supportive Hospital Environment for the Family of a Dying Infant

- Provide a separate room
- Reduce external noise
- Play soothing music
- Allow family to choose visitors
- Offer clergy support
- Minimize invasive measures unless needed for comfort (eg, suctioning)
- Turn off alarms and monitors

Source: Klein SM.
morphine and fentanyl, are available in concentrated liquid forms to allow enteral, sublingual, and buccal administration. Methadone and lorazepam are also available in liquid formulations.36

Other than pain, seizure control is also an important aspect of care. Many genetic syndromes are associated with increased seizure activity as death approaches, and frequent or continuous seizure activity can cause distress to parents and family members. There are many anticonvulsant medications, which can be titrated in the hospital or at home. Anticipatory guidance for the parents about expectations regarding seizure activity can help avoid emergency department visits.

Infants with hydrocephalus are another group who require consideration. Although the placement of a ventriculoperitoneal (VP) shunt is invasive, there may be an indication for its use if the shunt provides symptomatic relief.36 Ideally, all interventions should align with the family’s overall goals of care; procedures that some families may desire for their infant may be refused by other families.

Similarly to the VP shunt, a tracheostomy tube may be considered palliative treatment by some families if it improves quality of life and meets the goals of care of the infant. Comfort measures for the control of dyspnea could include use of supplemental oxygen; humidification; non-invasive positive pressure ventilation; and opioid medications.

Agonal breathing is a brain stem effect near the end of life; it is unlikely to cause discomfort to the infant, but may be quite distressing to observers. Therefore, comfort measures at the very end of life are beneficial to the family and the infant.36

Feeding is another challenge for the dying infant. Intestinal motility slows during the dying process, making feedings potentially more detrimental than helpful. On the other hand, withholding feedings from an infant may generate a high level of anxiety to the family and health care provider.36 Anticipating and counseling about the expected loss of interest in eating and possible weight loss by the infant may require many conversations with distressed families, as the loss of the ability to feed and nurture an infant may be one of the most distressing moments for a family. Reduction or removal of feeding may be the first visible sign that the infant is no longer normal and will die soon. If the mother has been breast-feeding her infant, guidance with obstetrical consultation is important to aid in cessation of milk production.

ACKNOWLEDGING BEREAVEMENT
Even with the best preparation, an infant’s death can be devastating to the family and the entire health care team. Burial and funeral arrangements may be foreign to families who have not faced the death of a loved one. Cultural awareness is needed to make sure that family beliefs are upheld. Bereavement support for families is critical to help a family cope with their loss. Grief is not measured as an amount of time, but rather as the intensity and level of dysfunction induced.

Most hospice care providers offer at least 13 months of bereavement support to include the anniversary of the infant’s death. Support is needed not only for the parents, but also for siblings and extended family members. Siblings may feel unheard and should not be overlooked. Although clinical effectiveness has not been thoroughly proven, providing bereavement support seems intuitively correct.20

THE IMPORTANCE OF MEMORIES
Creating a legacy of the infant is made possible through the collection of memory items. Hair clippings, hand-, ear-, and footprints, and photographs/videos all help capture the essence of the infant (see Sidebar 4). Bereavement photography has documented the beauty inherent in an infant even after death.19,20 Families treasure these mementos; staff often benefit from being involved in the process of creating these memories.

CONCLUSION
Infant mortality rates have changed very little in the past decade, yet the palliative approach to the dying infant has made great strides. Challenges of prognostication, as well as legal and ethical concerns, are important but not insurmountable barriers. Communication is important in developing goals of care that satisfy family wishes; symptoms should be controlled, regardless of the infant’s location at the time of death.

SIDEBAR 4.
Creating Memories for a Family
The following measures have been shown to be extremely helpful in providing closure to the extended families of dying infants:
- See, touch, or hold their baby
- Dress and bathe their baby
- Name their baby
- Take photographs, videos
- Keepsakes of the baby in a special memory box:
  - Hand, foot, ear prints
  - Locks of hair
  - Identification band from the hospital
  - Card with full name, weight, length, head circumference
  - Ultrasound pictures
  - A special outfit, blanket
  - Stuffed animal
  - Poems, letters, songs, written message to the baby
  - Pictures drawn or created by siblings
  - Allow enough time to be with the baby (pre- and post-death)
  - Appropriate transport box to the funeral home

Source: Klein SM.

Creating Memories for a Family
Bereavement support can begin before an infant’s death, followed by direction to effective grief counseling. Unfortunately, intensive care of all infants does not avoid or prevent death in the neonatal period. However, proper palliative care for the infant and family allows control over where and how these infants will die.

REFERENCES