
Part I

Beginnings/Endings: Complex Issues with Pregnancy, Newborns, and Young Children

End-of-life cases involving pregnancy, newborns, and young children are difficult. There are at least two patients to consider—at a minimum, a mother and child. Most often, there are other family members to consider. Birth is usually a joyous event in a hospital, but not always. The cases discussed here remind us that sometimes hospitals are sites of celebration, but more often sites of illness and dying. Death is nearly always hard to accept, but when a child is dying, the emotions, medical complexities, communication challenges, and ethical dilemmas can multiply.

The cases discussed in this section involve issues such as the biases healthcare professionals may hold about families with different lifestyles, values, or cultural traditions; appropriate decision-making roles for parents who are too young to legally make medical decisions for themselves; parents who have unreasonable expectations about what medical care might achieve for their child; and the ethics surrounding postmortem sperm retrieval. A short summary of each of the five cases in this section follows:

Case 1—Does the Nearness of Death Diminish the Value of a Life?

A sex worker who was pregnant with her fourth child was diagnosed with a fatal tongue tumor. Balancing her treatment preferences along with the needs of her unborn child was further complicated by difficult family relationships and a history of poor access to healthcare resources.

Case 2—When Cultures Collide and a Newborn Almost Dies

A graduate student studying in the U.S. from China gave birth to a baby girl with Down syndrome and an esophageal fistula. The mother refused to consent for surgery for the baby and explained that her disabled daughter would not be welcomed by extended family members when she and her husband completed their degrees and returned to China.

Case 3—When the Family Won't Decide

A teenage mother gave birth to a baby with multiple congenital abnormalities including alobar holoprosencephaly (where the brain does not develop into left and right lobes), cleft lip/palate, severe gastroesophageal reflux, failure to thrive, and seizure disorder. The baby's young parents each lived with their own parents and refused to make medical decisions or communicate with the medical team.

Case 4—Aggressive Treatment for a Child's Inoperable Tumor

A 4-year-old boy was diagnosed with an anaplastic Wilms tumor, inoperable because of its massive size and proximity to vital organs. The parents insisted on continued aggressive treatment, despite its high risks, harsh side effects, and limited efficacy. The parents' religious beliefs—one is a Jehovah's Witness and the other relied only on nonmedical approaches to health care—further complicated treatment decision-making.

Case 5—Is There Life After Death? A Case of Postmortem Sperm Retrieval

A young widow asked her late husband's physicians to retrieve his sperm posthumously so she could conceive a child in his memory, and then changed her mind when she fell in love with another man.