

Questions for Reading Groups

(Also suitable as points of discussion for classes in medical humanities, the social sciences, nursing, public health, and healthcare policy.)

1. The costs to care for a premature baby, such as Jacob Jenner, in the newborn period alone may be half a million dollars or more, and lifetime costs can be far greater. If “rationing” were to be instituted in the U.S. health care system, do you think it should be applied to any aspects of NICU care, and if so, how?
2. The United States has one of the highest rates of premature birth of any developed country in the world. Did you find that any of the stories shed light on why this is so? Did reading the stories give you any ideas for how premature birth could be prevented?
3. The technology to save babies’ lives has improved greatly over time. In the story about Josi, some neonatologists’ opinions that “because we can (save lives), we should (save them all)” was voiced. Can you think of any situations in which technology should not be applied to save a baby’s life?
4. Jaxon and Jacob are babies who were born prematurely to teenage mothers. After reading their stories, how do you think teen pregnancies could be better prevented, or how could teen mothers be better supported?
5. The stories about Samantha and Grace demonstrated how far both medical professionals and the public have come in their willingness to talk openly about babies born with birth defects, instead of shunning them as being “abnormal” and not worthy of care. How do you think that societal change came about, and does it need to go further? Do you know individuals who went through an experience where they felt as if they could not talk about their child who had a birth defect? How did it affect them?
6. The lower age limit for resuscitation of babies has continually dropped over the years, and now even babies born as early as the twenty-third or twenty-fourth week out of a normal forty-week gestation (such as Josi and Devon) may survive. It seems that current techniques in medicine may have reached their limits, and the next step to lower the gestational age at which babies can survive might be to go to creation of an artificial womb, in which embryos or fetuses could be nurtured in aquatic chemical environments outside the uterus. Already researchers are working to develop this possibility. Is this a positive and desirable step? Why?

7. Jesús and Tiffany are two babies who began their lives under the influence of maternal drugs. What do you think are reasonable criteria drug-using mothers should meet to take their babies home with them? Why?
8. Since a doctor's prognosis about an individual baby's outcome may be wrong, do you think doctors should share their opinions about a baby's prognosis with the parents? Under what circumstances should they, and when should they not? What duty do they have to inform parents of possible consequences of their choices for ongoing care of their babies?
9. Neonatologists work long hours in a high-stress environment, often twenty-four hours or more at a time, as in the stories about Preston and Devon. Do you think their work hours should be limited? Why?
10. In Charlie's story, the topic of "informed consent" was brought up. Do you agree that doctors should inform patients/parents about all possible complications, no matter how remote? Or, is their duty limited to informing patients/parents of major, more common complications? What would you want to be told if you were undergoing an invasive procedure or operation?
11. Were there any stories in which you thought the doctors and/or nurses should have responded to a baby's family differently, and why?
12. Was there any baby you found you had particular empathy for? What was it about the baby's story that resonated with you?
13. What was the most surprising thing you learned from reading this book?
14. Grace's mother held on to hope that her daughter would live a reasonably normal life even when evidence suggested otherwise. Oliver Wendell Holmes said to "beware how you take away hope from another human being." How should a health care professional best walk the fine line between hope and reality when a patient is facing difficult circumstances? Have you ever had an experience in which holding on to hope made a difference in your life?