REFERENCES

- Ahluwalia J, Lees C, Paris J: Decisions for life made in the perinatal period: who decides and on what standards? Arch Dis Child Fetal Neonatal Ed 93:F332, 2008.
- Ajayi-Obe M, Saeed N, Cowan FM, et al: Reduced development of cerebral cortex in extremely preterm infants, *Lancet* 356:1162, 2000.
- Allmark P, Mason S, Gill AB, et al: Obtaining consent for neonatal research, Arch Dis Child Fetal Neonatal Ed 88:F166, 2003.
- American Academy of Pediatrics, Committee on Bioethics: Ethics and the care of critically ill infants and children, *Pediatrics* 98:149, 1995.
- American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care: Palliative care for children, *Pediat*rics 106:2, 2000.
- American Academy of Pediatrics, Committee on Fetus and Newborn: Noninitiation or withdrawal of intensive care for high-risk newborns, *Pediatrics* 119:401, 2007.
- American Academy of Pediatrics, Committee on Fetus and Newborn: Perinatal care at the threshold of viability, *Pediatrics* 96:974, 1995.
- American Academy of Pediatrics, Section on Hospice and Palliative Medicine and Committee on Hospital Care: Pediatric palliative care and hospice care commitments, guidelines, and recommendations, *Pediatrics* 132:5, 2013.
- American College of Obstetricians and Gynecologists, Committee on Ethics: Patient choice: maternal-fetal conflict (ACOG committee opinion 55), Washington, DC, 1987, ACOG.
- American Hospital Association, Report of the Special Committee on Biomedical Ethics: Values in conflict: resolving ethical issues in hospital care, Chicago, 1985, American Hospital Publishing.
- 11. Angell M: The Baby Doe rules, N Engl J Med 314:642, 1986.
- 12. Arras JD: Toward an ethic of ambiguity, Hastings Cent Rep 14:25,
- Bancalari E: Corticosteroids and neonatal chronic lung disease, Eur J Pediatr 157:S31, 1998.
- Beauchamp T, Childress J: Principles of biomedical ethics, ed 6, New York, 2008, Oxford University Press.
- Berlinger N, Raymond B, Fleischman AR: Facing persistent challenges in pediatric decision-making: new Hastings Center guidelines, *Pediatrics* 152:5, 2013.
- Bhatia J: Palliative care in the fetus and newborn, J Perinatol 26(suppl 1):524, 2006.
- Board R, Ryan-Wenger N: State of the science on parental stress and family functioning in pediatric intensive care units, Am J Crit Care 9:2, 2000.
- Boss RD, Hutton N, Sulpar IJ, et al: Values parents apply to decision-making regarding delivery room resuscitation for high risk newborns, *Pediatrics* 122:3, 2008.
- Breeze AC, Lees CC: Antenatal diagnosis and management of life-limiting conditions, Semin Fetal Neonatal Med 18:68, 2013.
- Bruner J: Intrauterine surgery in myelomeningocele, Semin Fetal Neonatal Med 12:471, 2007.
- 21. Buus-Frank ME: Sometimes a time to be born is also a time to die, *Adv Neonatal Care* 6:1, 2006.
- Canadian Pediatric Society and Society of Obstetricians and Gynecologists of Canada: Management of the woman with threatened birth of an infant with extremely low gestational age, Can Med Assoc J 155:547, 1994.

- Caplan AL, Murray TH, editors: Which babies shall live? Humanistic dimensions of the care of imperiled newborns, Clifton, NJ, 1985, Humana Press.
- Carroll KW, et al: Influences on decision making identified by parents of children receiving pediatric palliative care, Am J Bioeth Prim Res 3:1, 2012.
- Carter B, Wocial L: Ethics and palliative care: which consultant and when? Am J Hospice Palliat Med 29:146, 2012.
- Carter BS, Bhatia J: Comfort/palliative care guidelines for neonatal practice: development and implementation in an academic medical center, J Perinatol 21:279, 2001.
- Carter BS, Hubble C, Weise KL: Palliative medicine in neonatal and pediatric intensive care, *Child Adolesc Psychiatr Clin North Am* 15:759, 2006.
- Carter BS, Jones PM: Evidence-based comfort care for neonates towards the end of life, Semin Fetal Neonatal Med 18:88, 2013.
- Catlin A: Transition from curative efforts to purely palliative care for neonates, Adv Neonatal Care 11:3, 2011.
- Catlin A: Thinking outside the box: prenatal care and the call for a prenatal advance directive, J Perinatal Neonatal Nurs 19:2, 2005.
- Catlin A, Armigo C, Volat D, et al: Conscientious objection: a potential neonatal nursing response to care orders that cause suffering at the end of life? Neonatal Netw 27:101, 2008.
- Congress of the United States, Office of Technology Assessment: Neonatal intensive care for low birth weight infants: costs and effectiveness, Washington, DC, 1987, U.S. Government Printing Office.
- Costeloe K, Hennessy E, Gobson AT, et al: The EPICURE study: outcomes to discharge from hospital for infants born at the threshold of viability, *Pediatrics* 106:659, 2000.
- Doroshow RW, Hodgman JE, Pomerance JJ, et al: Treatment decisions for newborns at the threshold of viability: an ethical dilemma, J Perinatol 20:379, 2000.
- Duff R, Campbell AGM: Moral and ethical dilemmas in the special care nursery, N Engl J Med 289:890, 1973.
- ECHO: Extreme Care, Human Options: Community recommendations for appropriate, humane medical care for dying or irreversibly ill patients, Carmichael, Calif, 1997, Sacramento Health Care Decisions.
- 37. Eisenberg L:The human nature of human nature, *Science* 176:123, 1972.
- Engelhardt HT Jr:Viability and use of the fetus. In Bondeson WB, editor: Abortion and the status of the fetus, Dordrecht, Netherlands, 1983, D Reidel Publishing.
- English NK, Hessler KL: Prenatal birth planning for families of the imperiled newborn, J Obstet Gynecol Neonatal Nurs 42:3, 2013.
- Ferrell B: Understanding the moral distress of nurses witnessing medically futile care, Oncol Nurs Forum 33:922, 2006.
- Field MJ, Behrman RE: When children die: improving palliative and end-of-life care for children and their families (Report of the Institute of Medicine Task Force), Washington, DC, 2003, National Academy Press.
- Finer NN, Craft A, Vaucher YE, et al: Postnatal steroids: shortterm gain, long-term pain? J Pediatr 137:9, 2000.
- Fleischman A, Murray T: Ethics committees for Infants Doe? Hastings Cent Rep 13:5, 1983.
- 44. Fletcher J: Humanhood: essays in biomedical ethics, Buffalo, NY, 1979, Prometheus Books.
- Francoeur R.T: From then to now. In Harris CC, Snowden F, editors: Bioethical frontiers in perinatal intensive care, Natchitoches, La, 1985, Northwestern State University Press.
- Gale G, Brooks A: Implementing a palliative care program in a newborn intensive care unit, Adv Neonatal Care 6:37, 2006.

- Gardner S, Hauser P, Merenstein G: Grief and perinatal loss. In Merenstein G, Gardner S, editors: Handbook of neonatal intensive care, ed 6, St Louis, 2006, Mosby.
- Hack M, Taylor G, Klein N, et al: Functional limitations and special health care needs of 10- to 14-year-old children weighing less than 750 grams at birth, *Pediatrics* 106:554, 2000.
- Hack M, Wilson-Costello D, Friedman H, et al: Neurodevelopment and predictors of outcomes of children with birth weights of less than 1000 g, Arch Pediatr Adolesc Med 154:725, 2000.
- Hudson KL, Guttmacher AE, Collins FS: In support of SUP-PORT—a view from the NIH, N Engl J Med 368:2349, 2013.
- Kesselheim J, Johnson J, Joffe S: Ethics consultation in children's hospitals: results from a survey of pediatric clinical ethicists, *Pediatrics* 125:742, 2010.
- Kodish E: Informed consent for pediatric research: is it really possible? J Pediatr 142:89, 2003.
- Koogler TK, Wilfond BS, Ross LF: Lethal language, lethal decisions, Hastings Cent Rep 3:37, 2003.
- Koops BL, Morgan LJ, Battaglia FC: Neonatal mortality risk in relation to birth weight and gestational age: update, *J Pediatr* 101:969, 1982.
- Kuhse H, Singer P: Should the baby live?, New York, 1985, Oxford University Press.
- Lantos JD: SUPPORTing premature infants, Pediatrics 132:e1661, 2013.
- 57. Lantos JD: Lessons from the controversy over the SUPPORT study, *Arch Dis Child Fetal Neonatal Ed* 99:F4, 2014.
- Lantos JD, Singer PA, Walker RM, et al: The illusion of futility in clinical practice, Am J Med 87:81, 1989.
- 58a. Larcher V: Ethical considerations in neonatal end-of-life care, Semin Fetal Neonatal Med 18:105, 2013.
- Leiken S: Children's hospital ethics committees, Am J Dis Child 141:954, 1987.
- Liggins GC, Howie RN: A controlled trial of antepartum glucocorticoid treatment for prevention of the respiratory distress syndrome in premature infants, *Pediatrics* 50:515, 1972.
- Lorber J: Results of treatment of myelomeningocele, Dev Med Child Neurol 13:279, 1971.
- Lorber J: Early results of selective treatment of spina bifida cystica, BMJ 4:201, 1973.
- Mason SA, Allmark PJ: Obtaining informed consent to neonatal randomized controlled trials: interviews with parents and clinicians in the Euricon study, *Lancet* 356:2045, 2000.
- 64. Meert KL, Eggly S, Pollack M, et al; the National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network: Parents' perspectives regarding a physician-parent conference after their child's death in the pediatric intensive care unit, J Pediatr 151:50, 2007.
- Mitchell C: Care of severely impaired infant raises ethical issues, *Am Nurse* 16:9, 1984.
- National Institute of Health: NIH consensus statement: antenatal corticosteroids revisited—repeat courses, Bethesda, Md, 2000, The Institute.
- 67. Nelson JE, Bassett R, Boss RD, et al: Models for structuring a clinical initiative to enhance palliative care in the intensive care unit: a report from the Improving Palliative Care in the ICU (IP-AL-ICU) Project and the Center to Advance Palliative Care, Crit Care Med 38:1765, 2010.
- Nelson-Marten P, Braatan J, English NK: Critical caring: dying in the intensive care unit, Crit Care Nurs Clin North Am 13:577, 2001.

- 69. O'Shea TM, Kothadia JM, Klinepeter KL, et al: Randomized placebo-controlled trial of a 42-day tapering course of dexamethasone to reduce the duration of ventilator dependency in very-low-birthweight infants: outcome of study participants at 1-year adjusted age, *Pediatrics* 104:15, 1999.
- Pellegrino ED: The anatomy of clinical ethical judgments in perinatology, Semin Perinatol 11:202, 1987.
- Peterson BS, Vohr B, Staib LH, et al: Regional brain volume abnormalities and long-term cognitive outcome in preterm infants, *JAMA* 284:1939, 2000.
- 72. Pless JE: The story of Baby Doe, N Engl J Med 309:663, 1983.
- 73. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: *Deciding to forego life-sustaining treatment*, Washington, DC, 1983, U.S. Public Health Service, Health and Human Services.
- Ramsey P: Ethics at the edges of life, New Haven, Conn, 1978, Yale University Press.
- 75. Rasmussen SA: Population-based analysis of mortality in trisomy 13 and trisomy 18, *Pediatrics* 111:4, 2003.
- Rhoden NK: Treating Baby Doe: the ethics of uncertainty, Hastings Cent Rep 16:34, 1986.
- Robertson JA: Involuntary euthanasia of defective newborns. In Mappes TA, Zembaty JS, editors: *Biomedical ethics*, ed 2, New York, 1986, McGraw-Hill.
- Schneiderman LJ, Jecker NS, Jonsen AR: Medical futility: its meaning and ethical implications, Ann Intern Med 112:949, 1990.
- Shelp EE: Born to die? Deciding the fate of critically ill newborns, New York, 1986, The Free Press.
- Shurtleff D: Care of the myelodysplastic patient. In Green M, Haggerty R, editors: Ambulatory pediatrics, Philadelphia, 1986, Saunders.
- Siegler M: Ethics committees: decisions by bureaucracy, Hastings Cent Rep 16:22, 1986.
- Solomon MZ, Dokken DL, et al, for IPPC: The Initiative for Pediatric Palliative Care (IPPC): background and goals. Newton, Mass, Education Development Center, Inc.
- Stark AR, Waldemar AC, Tyson JE, et al: Adverse effects of early dexamethasone treatment in extremely-low-birth-weight infants, N Engl J Med 344:95, 2001.
- Stenson BJ, Becher J-C, McIntosh N: Neonatal research: the parental perspective, Arch Dis Child Fetal Neonatal Ed 89:F321, 2004.
- Thomasma DC: Training in medical ethics: an ethical workup, Forum Med 1:33, 1978.
- Tooley M: Abortion and infanticide, New York, 1983, Oxford University Press.
- Victoroff M:The ballad of Baby Doe: parental discretion or medical neglect? *Prim Care* 13:271, 1986.
- Walters JW: Approaches to ethical decision making in the neonatal intensive care unit, Am J Dis Child 142:825, 1988.
- Weil WB: Issues associated with treatment and nontreatment decisions, Am J Dis Child 138:519, 1984.
- Weiner J, Sharma J: Lantos J, Kilbride H: How infants die in the neonatal intensive care unit; trends from 1999 through 2008, Arch Pediatr Adolesc Med 165:630, 2011.
- Weir RF: Selective nontreatment of handicapped newborns, New York, 1984, Oxford University Press.
- 92. Williams C, Cairnie J, Fines V, et al, for the With Care Team: Construction of a parent-derived questionnaire to measure endof-life care after withdrawal of life-sustaining treatment in the neonatal intensive care unit, *Pediatrics* 123:e87, 2009.

- 93. Wisconsin Association for Perinatal Care: Position statement: guidelines for the responsible utilization of neonatal intensive care, Madison, Wisc, 1997, Lawrence University.
- 94. Wolfe J: Suffering in children at the end of life: recognizing an ethical duty to palliate, *J Clin Ethics* 11:157, 2000.
- Wood NS, Marlow N, Costeloe K, et al: Neurologic and developmental disability after extremely preterm birth, N Engl J Med 343:378, 2000.
- Young EWD: Caring for disabled infants, Hastings Cent Rep 13:15, 1983.
- Zachary R: Ethical and social aspects of treatment of spina bifida, Lancet 2:274, 1968.

RESOURCE MATERIALS

Books and Journals

- Carroll K, et al: Influences on decision making identified by parents of children receiving pediatric palliative care, *Am J Bioethics* 3(1), January-March 2012.
- Carter B, Hubble C, Weise K: Palliative medicine in neonatal and pediatric intensive care, *Child Adolesc Psychiatr Clin North Am* 15:759–777, 2006. A complete outline of the issues involved in implementing palliative care for infants and children in an intensive care setting. It also describes select programs that have a palliative care service in intensive care.
- Carter B, Levetown M, Freibert S: Palliative care for infants, children, and adolescents: a practical handbook, ed 2, Baltimore, Md, 2011, Johns Hopkins University Press. Excellent chapter on decision making in the pediatric setting.
- Committee on Fetus and Newborn: Noninitiation or withdrawal of intensive care for high-risk newborns, *Pediatrics* 119:401, 2007.
- Gale G, Brooks A: A parent's guide to palliative care, Adv Neonatal Care 6(1):54, 2006. Directed to parents, this article describes what palliative care is, who it may benefit, and where and how long it may be provided for babies.
- Johnson A, Siegler M, Winslade WJ: Clinical ethics: a practical approach to ethical decisions in clinical medicine, ed 5, New York, 2002, McGraw-Hill.

- Leuthner S, Jones EL: Fetal concerns program: a model for perinatal palliative care, MCN Am J Matern Child Nurs 32(5):272, 2007.
- National Association of Neonatal Nurses: NAAN position statement: palliative care for neonates and infants #3051, Adv Neonatal Care 10:6, 2012.
- Neonatal Netw 27(6), 2008. This entire issue addresses the needs of infants on the margin of viability, 23 to 27 weeks of gestation.

Websites

- British Association of Perinatal Medicine (BAPM): A framework for clinical practice in prenatal medicine, www.bapm.org/publications/documents/guidelines/palliative_care-report-final
- Center for the Advancement of Palliative Care (CAPC): Pediatric palliative care referral criteria, www.capc.org/tool-for-palliative-care-program/clinical-tools/consult-triggers/pediatric-palliative-care-referral-criteria
- End-of-Life Nursing Education Consortium pediatric palliative care training program, from the American Association of Colleges of Nursing, www.aacn.nche.edu/ELNEC/Pediatric.htm.
- End-of-Life Physicians Education Resource Center: Educational resources for physicians (includes pediatrics), www.eperc.mcw.edu
- Ian Anderson continuing education program in end-of-life care with a pediatric module on decision making and more in development, www.cme.utoronto.ca/endoflife.edu
- Initiative for Pediatric Palliative Care: A comprehensive resource on educational resources including videotapes and other resources, www.ippcweb.org
- Palliative Care for Neonates, www.capc.org/tool-for-palliative-careacrossthecontinuum/pediatricpathway
- Resolve Through Sharing (RTS), www.bereavementservices.org/ resolve-through-sharing/conferences-and-workshops/perinataldeath-training
- Together for Short Lives ACT—clinical pathways for perinatal/ neonatal palliative care, www.togetherforshortlives.org.uk/professionals/external_resources/3862_perinatal_palliative_care_ framework