



# *Bioethics References*

Applicable to the Care of Pediatric Patients



## FOREWORD

The program requirements for residency education in pediatrics stipulate that training include a structured curriculum in medical ethics that addresses the ethical principles of medical practice and the ethical aspects of a physician's relationship to patients, other physicians, and society.

The Ethics Committee of the American Board of Pediatrics (ABP), which was dissolved in 2015, compiled this list of bioethics references applicable to the care of pediatric patients. The annotated bibliography contains journal references, books, and book chapters that cover the topics outlined in the table of contents.

This bibliography has not been updated since 2015 but remains available for those who want a starting point.

The primary intent in the development of the bibliography was to promote familiarity with ethical principles and concepts (theories) and to provide published guidelines for problem solving via ethical analysis. It is hoped that these publications will increase physician awareness around moral ambiguities and emphasize the need to pursue educational opportunities in this area.

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## AUTONOMY, BENEFICENCE, AND RIGHTS

### I. Critical Care, End of Life, and Limitations on Medical Intervention

#### A. *Decisions to withdraw/withhold life-sustaining medical intervention*

#### JOURNALS

**American Academy of Pediatrics Committee on Bioethics. Guidelines on foregoing life-sustaining medical treatment. *Pediatrics* 1994;93:532-536**

This policy statement provides a framework for making decisions about life-sustaining medical treatment (LSMT) on behalf of pediatric patients, summing up with the idea that the relative benefits and burdens of further LSMT and its likely outcomes (as perceived by the patient and family) should be the ultimate deciding factor. Factors that should be considered in weighing such benefits and burdens are reviewed. The statement begins by defining LSMT. Guidance regarding who may have authority to decide and how to determine capacity is provided. The special situations of permanently unconscious patients, adolescents, mature minors, and patients with waxing and waning capacity are also discussed. Legal and ethical analyses of the principles involved in the decision-making process are presented, including the best interest standard, beneficence, nonmaleficence, self-determination, and the use of advance directives. Application of these principles to the right to full information, refusal of intervention, care after decisions to continue LSMT, physician obligation, and dispute resolution are provided. Finally, guidance on writing orders that reflect the decisions reached is provided. This is an essential article for all clinicians providing pediatric care.

**American Academy of Pediatrics Committee on Bioethics and Committee on Child Abuse and Neglect. Forgoing life-sustaining medical treatment in abused children. *Pediatrics* 2000;106:1151-1153**

This policy statement gives guidance about the criteria for decision-makers' roles and the unchanged role of the benefit-burden calculus for all children who have been seriously injured by abuse. The role of a guardian ad litem, the medical examiner, and the possibility of organ donation, as well as the need to provide family support, are described. This statement provides excellent guidance for PICU personnel, consultants, ethics committees, guardians ad litem, and judges.

**Carter BS, Hubble C, Weise KL. Palliative medicine in neonatal and pediatric intensive care. *Child Adolesc Psychiatr Clin N Am* 2006;15:759-777**

This article defines pediatric palliative care and justifies its role in the care of critically ill children of all ages. It defines barriers to the effective implementation of such programs and provides examples of successful programs from four academic centers.

**Munson D. Withdrawal of mechanical ventilation in pediatric and neonatal intensive care units. *Pediatr Clin North Am* 2007;54:773-785**

This essay addresses the circumstances in which it is morally permissible to withdraw mechanical ventilation in either a PICU or NICU and includes specific medical advice about how this ought to be done to minimize suffering in the infant or child. The essay also includes practical guidance regarding how these issues ought to be addressed with a family as a matter of communication and attentiveness to the psychosocial dimensions of medicine.

**Paris JJ, Graham N, Schreiber MD, Goodwin M. Has the emphasis on autonomy gone too far? Insights from Dostoevsky on parental decision making in the NICU. *Camb Q Healthc Ethics* 2006;15:147-151**

This paper, using literature as a backdrop, argues that the “respect” demonstrated by asking parents of dying infants to choose their child’s fate is an unwanted burden. It challenges current notions of modern Western bioethics, requiring thoughtful reevaluation of the current approach to decision-making for critically ill children. This paper is recommended for providers caring for children in ICU settings.

**Pellegrino ED. Decisions to withdraw life-sustaining treatment: a moral algorithm. *JAMA* 2000;283:1065-1067**

Pellegrino provides a framework with which to analyze end-of-life decision-making from an ethical standpoint, reviewing who the decision-makers are and the limits of authority, as well as how to distinguish effectiveness from benefit and burden, as the latter are patient dependent. The author constructs his framework around the case of a gentleman requesting that his pacemaker be turned off. This is a succinct review of critical issues.

**Reynolds S, Cooper AB, McKneally M. Withdrawing life-sustaining treatment: ethical considerations. *Surg Clin North Am* 2007;87:919-936**

An up-to-date discussion of a common and difficult clinical situation, this article improves on previous versions by addressing cultural, philosophical, ethical, and practical aspects of forgoing no-longer-beneficial treatments in the ICU setting. The case examples are adult, but the information is universally applicable.

**Sharman M, Meert KL, Sarnaik AP. What influences parents’ decisions to limit or withdraw life support? *Pediatr Crit Care Med* 2005;6:513-518**

This prospective study of ten families of children dying in the PICU indicates that issues that usually receive little attention are major factors in parents’ decision-making process. These factors are 1) their previous experience with death and end-of-life decision-making for others, 2) their personal observations of their child’s suffering and their perceptions of their child’s will to survive, 3) their need to protect and advocate for their child, and 4) the family’s financial resources and concerns regarding lifelong care. Parents in this study expressed the desire to do what is best for their child

but struggled with feelings of selfishness, guilt, and the need to avoid agony and sorrow. Physician recommendations, review of options, and joint formulation of a plan helped parents gain a sense of control over their situation. This article should be required reading for all who work in the ICU.

**Tripp J, McGregor D. Withholding and withdrawing of life sustaining treatment in the newborn. *Arch Dis Child Fetal Neonatal Ed.* Jan 2006;91(1):F67-71**

This is a great review article as well as a basic guide for end-of-life decision-making in pediatrics. Though the subject is neonatology, the guidance provided for handling "uncertain" cases can be applied to any pediatric scenario. The bibliography also offers a wealth of additional references should more information be desired.

**Truog RD, Burns JP, Mitchell C, Johnson J, Robinson W. Pharmacologic paralysis and withdrawal of mechanical ventilation at the end of life. *N Engl J Med* 2000;342:508-511**

This article reviews the prevalence of the use of pharmacologic paralysis in patients undergoing withdrawal of life support. Arguments based on ethical principles as well as physical and social considerations are reviewed, with the conclusion that pharmacologic paralysis should be used in rare instances and then only by experienced physicians with proper training. The article presents a concise and well-crafted argument that should be discussed in residency programs and critical care, neonatal, surgical, and some additional subspecialty fellowships.

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## **B. Decisions to withdraw/withhold artificial hydration/nutrition**

### **JOURNALS**

**Diekema DS, Botkin JR, and the American Academy of Pediatrics Committee on Bioethics. Forgoing medically provided nutrition and hydration in children. *Pediatrics* 2009;124:813-822**

There is broad consensus that withholding or withdrawing medical interventions is morally permissible when requested by a competent patient or, in the case of patients without decision-making capacity, when the interventions no longer confer a benefit to the patient or when the burdens associated with the interventions outweigh the benefits received. This clinical report reviews the medical, ethical, and legal issues relevant to withholding and withdrawing medically provided fluids and nutrition in children. It argues that medically provided fluids and nutrition are not fundamentally different from other medical interventions and that they can be withheld or withdrawn for similar reasons. The committee recommends ethics consultation when difficult or controversial decisions are being considered.

**Nelson LJ, Rushton CH, Cranford RE, Nelson RM, Glover JJ, Truog RD. Foregoing medically provided nutrition and hydration in pediatric patients. *J Law Med Ethics* 1995;23:33-46**

This is a thorough review of the ethical arguments and relevant case law regarding artificial nutrition



and hydration (ANH) in pediatric patients. Emotional and social constructs that interfere with professional and parental willingness to consider this option are acknowledged. Case studies illustrate practical application of arguments. Finally, guidance is provided for clinicians and ethics committees to consider the merits of foregoing ANH in an individual patient. This is an essential resource for all pediatric medical and surgical practitioners, as well as members of ethics committees that serve pediatric patient populations.

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### **C. Cardiopulmonary resuscitation and "do not resuscitate" (DNR) orders**

#### **JOURNALS**

**American Academy of Pediatrics Committee on Bioethics and Committee on School Health. Honoring do-not-resuscitate requests in schools. *Pediatrics* 2010;125:1073-1077**

This paper addresses, from the perspective of school officials, pediatricians, and families, the practical issues associated with the school attendance of chronically and terminally ill children who prefer not to have a resuscitation attempt in the event of an arrest. It provides valuable guidance for pediatricians who will be or are caring for medically fragile and terminally ill patients.

**American Medical Association Council on Ethical and Judicial Affairs. Guidelines for the appropriate use of do-not-resuscitate orders. *JAMA* 1991;265:1868-1871**

This paper reviews the success rate of cardiopulmonary resuscitation (CPR) and the situations in which it should not be performed. These situations are patient or surrogate refusal of the intervention and physician estimation of the futility of CPR in achieving the patient's clinical care goals. Reasons for the infrequency of discussions regarding resuscitation are reviewed, as well as evidence of the mismatch between physician assumptions regarding patient preferences and what the patient actually wants. Guidance is provided on how to facilitate these discussions, as well as how to write the orders. This is a classic and thoughtful paper exhorting patient autonomy in end-of-life decisions and should be familiar to all physicians.

**Clark JD, Dudzinski DM. The culture of dysthanasia: attempting CPR in terminally ill children. *Pediatrics* 2013;131:572-80.**

The authors argue that there is a moral, social, psychological, and most importantly a professional obligation not to offer CPR to the parents of imminently dying children. They discuss the reasons parents "ask for" CPR to be done, highlighting the special nature and obligations associated with the child-parent relationship that interfere with upholding the child's best interests and acknowledging medical evidence. In addition, the authors review how CPR came to have the unique status of requiring "informed refusal" and how inconsistent this is with other health care decisions, such as ECMO and surgery, when these interventions are deemed to be nonbeneficial by health care providers. Finally, the authors provide numerous references from other medical philosophers about the role of the physician in medical decision-making, enabling the student to compare and contrast approaches to this thorny issue.

**Ditillo BA. Should there be a choice for cardiopulmonary resuscitation when death is expected? Revisiting an old idea whose time is yet to come. *J Palliat Med* 2002;5:107-116**

This paper reviews the efficacy of CPR and, in the context of practical, interpersonal, institutional, philosophical, legal and ethical considerations, advocates not offering CPR or any other therapy when it will be ineffective.

**Fallat ME, Deshpande JK, et al. Do not resuscitate orders for the pediatric patients who require anesthesia and surgery. *Pediatrics* 2004;114:1686-1692**

What should be done with a child's do-not-resuscitate (DNR) order if the child needs to go to the operating room for a procedure? The article advocates "required reconsideration" of the DNR order as part of the informed consent/permission process. Options for such patients include full resuscitation, a goal-directed approach, or a procedure directed approach. "Active listening" to the concerns of the patient, family, or surrogate and communication among the health care team are essential.

**Friedman SL. Parent resuscitation preferences for young people with severe developmental disabilities. *J Am Med Dir Assoc* 2006;7:67-72**

Similar to a study of octogenarians, this study of the guardians of children with severe developmental disabilities finds that, with accurate information about the process and outcomes of CPR and reassurances that other interventions will be continued, substantially more decision-makers prefer forgoing CPR in the event of an arrest. Although ethical issues are not specifically addressed and the study is single site and relatively small, the ethical implication of the need for informed consent is clear.

**Henderson DP, Knapp JF. Report of the national consensus conference on family presence during pediatric cardiopulmonary resuscitation and procedures. *Pediatr Emerg Care* 2005;21:787-791**

This is a thorough review of studies to date, concluding that, with education and direct supervision, parents should be offered the opportunity to be present with their children during invasive procedures, including CPR, because patients and families benefit, do not interfere, and staff are not harmed.

**Loertscher L, Reed DA, Bannon MP, Mueller PS. Cardiopulmonary resuscitation and do-not-resuscitate orders: a guide for clinicians. *Am J Med* 2010;123:4-9**

DNR is the only order requiring patient consent to withhold a specific intervention. This article describes the history of the DNR order, provides an outline for a model DNR discussion with the patient/family, and discusses the controversy over DNR orders in the OR. Although not specific to pediatrics, the information contained is useful to all physicians who may have to have this conversation with a patient and/or family.

**Meyer EC, Ritholz MD, Burns JP, Truog RD. Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics* 2006;117:649-657**

This three-institution retrospective study identifies six elemental needs of parents facing the death of their child in an intensive care unit. Parents were disproportionately white and Catholic. The six priorities for pediatric end-of-life care, many of which are not adequately honored, are 1) honest and complete information, 2) ready access to staff, 3) communication and care coordination, 4) emotional expression and support by staff, 5) preservation of the integrity of the parent-child relationship, and 6) faith.

**Morrison LJ, Kierzek G, Diekema DS, et al. Part 3: ethics: 2010 American Heart Association guidelines for cardiopulmonary resuscitation and emergency cardiovascular care. *Circulation* 2010;122(18 Suppl 3):S665-S675.**

This article accompanies the American Heart Association's revised Guidelines for Cardiopulmonary Resuscitation and reviews the ethical principles and legal and cultural issues associated with decisions for resuscitation in patients of all ages, including neonates and children. Among the topics discussed are advanced directives, Do-Not-Attempt-Resuscitation Orders, futility, providing emotional support for families, family presence during resuscitation attempts, organ and tissue donation, resuscitation research, and practicing procedures on the newly dead. The manuscript also reviews criteria for terminating or not initiating cardiopulmonary resuscitative efforts in both the out-of-hospital and in-hospital settings, including a summary of the literature on prognostication in pediatric and adult patients following cardiac arrest.

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#### **D. Futility**

### **JOURNALS**

**Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. *N Engl J Med* 2000;343:293-295**

The authors describe the 10-year history of the struggle to define and apply the concept of futility to medical care. The bibliography is comprehensive, allowing a student of the futility movement and students of attempts to drive social change to easily access the full range of articles dealing with this subject. The conclusion is that the best approach is a local one involving clinicians talking with individual patient's families, explaining their discomfort with continuing the present plan of care, using conflict resolution, aided by interdisciplinary ethics committees and the courts as needed, and transferring the patient if resolution cannot be accomplished. This process, according to the authors, has obviated the need to invoke futility at a policy level.

**Moseley KL, Silveira MJ, Goold SD. Futility in evolution. *Clin Geriatr Med* 2005; 21(1):211-222**

This article succinctly describes the difficulties inherent in attempting to override patient/family requests for treatment by defining certain medical treatments as futile. The authors give a brief history of the use of the term in medical care, review the most common definitions of medical futility, and point out the flaws in each construct. The article ends with a strong note of caution to the reader about using futility as a justification for overriding patient/family wishes. This article would be helpful for all residents, especially those beginning an intensive care rotation.

**Nelson LJ, Nelson RM. Ethics and the provision of futile, harmful, or burdensome treatment to children. *Crit Care Med* 1992;20:427-433**

This paper serves as a guide to pediatricians faced with parents who wish to pursue medical interventions that are nonbeneficial or are unduly burdensome given the expected outcome of care. It proposes a conflict resolution process, but then asserts that the pediatrician has a moral duty to self and the child not to allow such interventions to continue. Several illustrative cases clarify the authors' viewpoint. The term "disproportionate burden" is introduced as a more honest one than "futility" for many situations. Finally, the authors present an analysis of the legal risks involved in acting on their advice, including relevant case law. This article should be required reading for all physicians who treat children.

**Paris JJ, Schreiber MD. Physicians' refusal to provide life-prolonging medical interventions. *Clin Perinatol* 1996;23:563-571**

Another review of the futility debate, concluding with the assertion that there is a role for clinical judgment and that clinical decisions should be made openly and honestly. References to important medical society statements are provided. This article is recommended because it is concise and clear and is published in a pediatric journal.

**Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. *Ann Intern Med* 1990;112:949-954**

The authors present two concepts. The first is the effect of an intervention contrasted with its benefit, with benefit as to the whole person rather than merely anatomic healing. They assert that effective but nonbeneficial therapies should not be offered. A lengthy discussion of the origins and meanings of the word "futility" is presented, as well as how to recognize and operationalize futility in modern medical care. The second concept is that of "quantitative" and "qualitative" futility. The authors propose quantitative futility to be a threshold of not working in the last 100 cases. For qualitative futility, the notion of merely prolonging a vegetative state or dependence on intensive care is proposed. This is a provocative article to initiate discussion among thoughtful health care practitioners regarding the meaning of futility, the limitations of medicine, and how to communicate about these issues with each other and with patients and families.

**Tomlinson T, Brody H. Futility and the ethics of resuscitation. *JAMA* 1990;264:1276-1280**

In this paper, the authors present arguments to support the idea that autonomy is best supported by not offering futile therapies such as cardiopulmonary resuscitation. The obligation of the physician is

to do more good than harm to the patient, and this inherently requires professional knowledge and value judgments. Such value judgments are invoked daily, as there is no absolute certainty in the vast majority of medical practice, and to assert otherwise is unrealistic. To not allow for moral agency and judgment on the part of physicians is to undermine the profession. Further discussion considers the relative merits of informing the patient about the judgment that a therapy is being withheld versus not doing so, as well as the need for broad social dialogue about moral, practical, and financial limitations of medical interventions. This is a thought-provoking article for all physicians, providing tools to analyze some of the most frequently frustrating aspects of the practice of moral medicine.

**Truog RD, Brett AS, Frader J. The problem with futility. *N Engl J Med* 1992;326:1560-1564**

The authors provide yet another perspective on futility, ultimately concluding that it is an unhelpful concept to assist in medical decision-making. However, they do agree that patients do not have an unlimited authority, in the name of autonomy, to insist on medical interventions that may be judged by health care professionals as interfering with their obligation to provide compassionate care that minimizes suffering. Moreover, health care providers also have a legitimate right to ensure that their training and skills are used wisely and effectively. Finally, the authors call for wide public discussion of this topic, allowing for the development of public policy and legislation regarding such issues. This article should be read with the two articles immediately above as an exercise in thinking through such weighty and difficult moral questions. It is unfortunate that, more than a decade later, these arguments are still relevant and that society is no closer to resolution on this issue, which is daily a pressing matter for most hospital-based caregivers.

**Weil MH, Weil CJ. How to respond to family demands for futile life support and cardiopulmonary resuscitation. *Crit Care Med* 2000;28:3339-3340**

This brief paper asserts that "consumerism does not extend to medically futile care." A graphic algorithm is presented for approaching such situations. The algorithm can be a useful teaching tool for residents and fellows.

## **BOOKS AND BOOK CHAPTERS**

**Zucker MB, Zucker HD. *Medical Futility and the Evaluation of Life-Sustaining Interventions*. Cambridge, England: Cambridge University Press, 1997**

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### ***E. Persistent/permanent vegetative state***

## **JOURNALS**

**Ashwal S, Bale JF Jr, Coulter DL et al. The persistent vegetative state in children: report of the Child Neurology Society Ethics Committee. *Ann Neurol* 1992;32:570- 576**

This is the report of the results of a survey of pediatric neurologists regarding their opinions (not hard data) of the ability to reliably diagnose persistent vegetative state in infants and children, as well as their approach to the management of such patients. There are a number of definitional, logical, and ethical inconsistencies among their answers and in comparison to definitions applied to adult patients (and compared to the multi-society task force consensus [see below], which applies to adults and children and was endorsed by the AAP), which must be borne in mind when counseling families.

**Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state (Part 1). *N Engl J Med* 1994;330:1499-1508**

Two representatives from each of five medical societies, including the AAP, as well as a host of legal, ethics, and medical consultants collaborated to create this comprehensive medical review of the condition of the persistent vegetative state for adults and children, including anencephalic infants. This first article addresses the definition, epidemiology, causes, pathologic features, and diagnostic studies. This article should be required reading for all practitioners.

**Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state (Part 2). *N Engl J Med* 1994;330:1572-1579**

This article reviews the prognosis for recovery, long-term survival, economic implications and implications for decision-making regarding treatment for patients with persistent vegetative state, including a discussion of withdrawing artificial nutrition and hydration.

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***F. Palliative care and pain management***

**JOURNALS**

**American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics* 2000;106:351-357**

This position statement outlines an approach to caring for children living with life-threatening conditions, which incorporates attention to the whole child and the impact of the illness on him or her as well as the rest of the family and community, throughout the lifetime and after the death of the child. It synthesizes and operationalizes a number of ethical principles, including respect for autonomy, nonmaleficence, beneficence, and distributive justice. The importance of the benefit-burden calculus in approaching the care of these patients is implicit throughout the discussion. Parts of this article are applicable to trainees, though it is targeted more to those interested in policy, finance, and education.

**American Academy of Pediatrics Committee on Fetus and Newborn and Section on Surgery; Canadian Paediatric Society Fetus and Newborn Committee, Batton DG, Barrington KJ, Wallman C. Prevention and management of pain in the neonate: an update. *Pediatrics* 2006;118:2231-2241**

This article reviews the ethical obligations to neonates vis-à-vis pain, reviewing the lifelong adverse consequences of pain in this population. It provides concrete advice including policies, training, and nonpharmacologic preventive and interventional measures, as well as pharmacologic means of controlling pain, while acknowledging the incomplete database for evidence-based care.

**Anand KJ, Craig KD. New perspectives on the definition of pain. *Pain* 1996;67:3-6**

This paper is a philosophical discussion with practical import on the topic of how to assess pain in the nonverbal patient. The authors challenge the notion that a *verbal* self-report is the only legitimate form of self-report and that experience is necessary for the sensation of pain; their target is to validate treatment of pain in premature infants, neonates, infants, and never sentient humans.

**Fleischman AR, Nolan K, Dubler NN et al. Caring for gravely ill children. *Pediatrics* 1994;94(4):433-439**

This article reports the results of a consensus conference regarding the treatment of and decision-making for children with life-threatening conditions. The authors discuss standards for decision-making, determination of best interests, an approach to assessing benefits and burdens in the face of uncertainty, and the roles in these decisions of the parents, child, and professionals. The issue of "futility" is also addressed. This is one of the few papers that specifically considers the issue of adolescents and is recommended for all pediatric care providers.

**Kenny NP, Frager G. Refractory symptoms and terminal sedation of children: ethical issues and practical management. *J Palliat Care* 1996;12:40-45**

Practical and ethical issues involved in the resolution of symptoms at the end of life in children are addressed, including who the decision-makers are, who is affected, ethical and practical distinctions between terminal sedation and euthanasia, and means of discussing and accomplishing symptom control. This article also explores the justification of treatment of symptoms to benefit onlookers and is recommended for all pediatric specialists who care for children who die.

**Levetown M. Ethical aspects of pediatric palliative care. *J Palliat Care* 1996;12(3):35-39**

This essay addresses the roles of uncertainty, consent, legal climate, and research in access to palliative care for children. Using case examples, the author concisely illustrates solutions for these ethical dilemmas.

**Mack JW, Grier HE. The Day One Talk. *J Clin Oncol* 2004;22:563-566**

This paper succinctly reviews the practical implementation of ethically pristine and compassionate disclosure of an unwelcome diagnosis. The paper discusses how to communicate effectively with

the family, including the child; means to increase the likelihood of informed consent and the elements of that discussion; and how to individualize the discussion to best meet the needs of a specific family. It should be required reading for every pediatric physician.

**Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000;132:825-832**

The authors of this qualitative study of healthcare providers, patients and family members conclude that there are six domains that are of importance and that must be considered when death approaches in order to more routinely enable a "good death." The domains are pain and symptom management; clear decision-making (in advance); preparation for death; completion; contributing to others; and affirmation of the whole person. Physicians recognized the medical domains, but rarely acknowledged the others, all of which were endorsed by the other groups. This article is recommended for educators and clinicians.

**Walco GA, Cassidy RC, Schechter NL. Pain, hurt, and harm. The ethics of pain control in infants and children. *N Engl J Med* 1994;331:541-544**

This paper reviews the myths and facts about pediatric pain, including the evidence that long-term or permanent nervous system changes can result from untreated pain, that children can accurately report their pain, that children do not have a greater likelihood of respiratory depression compared with adults, that adequate monitoring can prevent serious complications, that the risk of addiction is minimal to nonexistent, and that unrelieved pain has short-term consequences such as refusal to participate in rehabilitation, as well as long-term complications such as not seeking health care when needed. The authors conclude that failure to provide adequate pain management is substandard and unethical medical practice.

**Wolfe J, Grier HE, Klar N et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000;342:326-333**

This paper documents the prevalence of severe symptoms at the end of life for 103 children who died of cancer at one institution. In this retrospective interview, parents reported that physicians and other caregivers did not effectively assess for symptoms and that the interventions made did not effectively control the symptoms. Data were validated by chart reviews. Lack of continued involvement by the treating oncologist at the time of death and conflicting information from caregivers had significant correlations with the perception of suffering. This paper should be read by all physicians, nurses, pharmacists, and respiratory and physical therapists involved in the care of children with oncologic diseases. It should also serve as a wake-up call for greater vigilance to monitor for and attempt to treat symptoms and to relieve avoidable suffering for all pediatric patients.

**Wolfe J, Klar N, Grier HE et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA* 2000;284:2469-2475**

This study documents that inadequate or ineffective communication of physicians and parents



regarding prognosis frequently results in ongoing disease-directed treatment for terminally ill children with cancer, and that better communication results in less suffering for the child and family, as well as a perception of a better quality of care. These findings challenge the notion that parents and children are best served by ongoing attempts to cure despite overwhelming odds. This article can be used as a springboard for fruitful discussions regarding the physician's obligation to prevent and relieve suffering and the role that communication plays in accomplishing these goals.

## **BOOKS AND BOOK CHAPTERS**

Bluebond-Langner, M. *The Private Worlds of Dying Children*. Princeton University Press, 1980

Levetown M, Carter MA. Child-centered care in terminal illness: an ethical framework. In Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine (2nd ed)*. Oxford, England: Oxford University Press, 1998:1107- 1117

Mondragon D, ed. *Religious Values of the Terminally Ill: A Handbook for Health Professionals*. Las Cruces, NM: New Mexico State University Department of Health Science, 1997

Schechter NL, Berde CB, Yaster M, eds. Pain in infants, children, and adolescents: an overview. In *Pain in Infants, Children, and Adolescents*. Baltimore: Williams and Wilkins, 1993:3-9

The Cross Cultural Health Care Program. *Death and Dying in Ethnic America: A Research Study*. Seattle: The Cross Cultural Health Care Program, 2000

Walco GA, Cassidy RC. The ethics of pain control in neonates and infant. In Anand KJ, Stevens BJ, McGrath PJ, eds. *Pain in Neonates (2nd ed)*. The Netherlands: Elsevier, 2000:229-235

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## **G. Physician-assisted suicide and euthanasia**

## **JOURNALS**

Miller FG, Quill TE, Brody H, Fletcher JC, Gostin LO, Meier DE. Regulating physician-assisted death. *N Engl J Med* 1994;331(2):119-123

The authors present arguments in favor of state legislation allowing physician- assisted suicide (PAS) and voluntary euthanasia, proposing safeguards to prevent inappropriate use of these options, including improved access to palliative care. They argue that lack of regulation and sanction of the act "compromises professional integrity and undermines respect for the law" by ignoring the needs of suffering patients and leaving physicians to grapple with attempting to meet those needs versus taking on legal risks. Those interested in the arguments for and against PAS may wish to read this opinion piece to see if they agree.

Verhagen E, Sauer PJ. The Groningen protocol – euthanasia in severely ill newborns. *N Engl J Med* 2005;10:959-962

This Perspectives article discusses the Dutch view regarding euthanasia for infants with "an extremely poor prognosis for whom death may be more humane than continued life." The requirements for the controversial Groeningen protocol are listed. This article will stimulate discussion and thought as the counterpoint to the current American management of such patients.

## BOOKS AND BOOK CHAPTERS

Wolf SM. Facing assisted suicide and euthanasia in children and adolescents. In Emanuel LL, ed. *Regulating How We Die: The Ethical, Medical, and Legal Issues Surrounding Physician-Assisted Suicide*. Cambridge, Mass: Harvard University Press, 1998

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### ***H. Declaration of death: By neurologic criteria***

## JOURNALS

The President's Council on Bioethics. Controversies in the Determination of Death: a white paper by the President's Council on Bioethics. 2008.

This lengthy collection of essays explores the origins of the concept of brain death, whole brain death, persistent vegetative state and current controversies. It presents supporting and opposing positions to the current definitions of death and associated organ procurement strategies, but ultimately supports the current definition. This paper is important for thoughtful health care providers who engage in the declaration of death and who participate in the transplantation of organs.

Banasiak KJ, Lister G. Brain death in children. *Curr Opin Pediatr* 2003;15:288-293

An excellent, succinct review discussing the currently accepted definition and diagnosis of brain death in children, when to use corroborative testing, and exploration of remaining controversies in determining death by brain criteria.

Lazar NM, Shemie S, Webster GC, Dickens BM. Bioethics for clinicians: 24. Brain death. *CMAJ* 2001;164:833-836

In addition to concise review of determination of brain death, the authors consider the imposition of values on biological data, distinguish between loss of function of the whole brain and the higher brain, recognize that cultural and religious diversity influences acceptance of the occurrence of death, and highlight the importance of public trust in the medical community, particularly in its impact on the process of organ donation. The relationship between brain death and the legal

determination of death is explored, and practical management of the brain-dead patient is outlined thoughtfully.

**Truog RD. Brain death – too flawed to endure, too ingrained to abandon. *J Law Med Ethics* 2007;35:273-281**

This article is a very provocative discussion of the concept of brain death and organ transplantation. The author argues that the concept of brain death is incoherent and counterintuitive to our understanding of death. In order to abandon the concept of brain death and yet retain our practices in organ transplantation, we need to either change the definition of death or no longer maintain a commitment to the dead donor rule, which is an implicit prohibition against removing vital organs from individuals before they are declared dead. After exploring these two options, the author argues that although new definitions of death are problematic, alternatives to the dead donor rule are both ethically justifiable and potentially palatable to the public. Even so, the author concludes that neither of these approaches is likely to be adopted and that resolution will most probably come when technological advances in immunology simply make the concept of brain death obsolete. This article is very useful for discussions of brain death and organ transplantation with residents.

**Wijdicks EF. The diagnosis of brain death. *N Engl J Med* 2001;344:1215-1221**

The author discusses several neurologic states that resemble brain death, presents a systematic approach to the clinical examination and the use, as well as many of the intricacies, of confirmatory tests to determine brain death in children and adults, and briefly mentions management of possible organ donation. The author also supports the recommendations in the Special Task Force report on guidelines for the determination of brain death in children, published in *Pediatrics* 1987;80:298-300 and *Arch Neurol* 1987;44:587-588.

## **BOOKS AND BOOK CHAPTERS**

**Youngner SJ, Arnold RM, Schapiro R, eds. *The Definition of Death: Contemporary Controversies*. Baltimore: The Johns Hopkins University Press, 1999**

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### ***I. Declaration of death: By circulatory criteria***

## **JOURNALS**

**Bernat JL. Are organ donors after cardiac death really dead? *J Clin Ethics* 2006;17:122-132**

The Uniform Determination of Death Act defines death as the irreversible cessation of heartbeat and respiration or the irreversible cessation of the function of the entire brain including the brain stem. It is only when an individual is declared dead that a vital organ can be harvested for transplantation. There are some individuals, however, who are being kept alive by technology but for

whom it is determined that the technology should be removed, knowing that the individual will die. Is there a possibility for such an individual to donate organs? Donation after cardiac death may provide such a possibility. The author reviews this concept in relation to how death is determined in clinical practice and discusses the distinction between permanence and irreversibility.

**Bernat JL. The boundaries of organ donation after circulatory death. *N Engl J Med* 2008;359:669-671**

This is one of three perspective pieces in the same issue of the New England Journal of Medicine commenting on a report in that issue regarding three cases of heart transplantation from infants who were pronounced dead on the basis of cardiac criteria.

**Truog RD, Cochrane TI. The truth about “donation after cardiac death.” *J Clin Ethics* 2006;17:133-136**

In this article the authors argue that the dead donor rule is a poor basis by which to obtain organs, that patient prognosis and wishes should be the focus, and that donation after cardiac death does not serve the interests of those who wish to donate. This is a nice companion article to Bernat's article entitled “Are organ donors after cardiac death really dead?”

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## **II. Maternal/Fetal Conflicts**

### **JOURNALS**

**American College of Obstetricians and Gynecologists Committee on Ethics and American Academy of Pediatrics Committee on Bioethics. Maternal-fetal intervention and fetal care centers. *Pediatrics* 2011;128:e473-e478.**

This policy statement, a joint effort between the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists, addresses the issues that arise with prenatal diagnosis and fetal intervention. Although fetal interventions are generally intended to improve fetal and neonatal outcomes, the pregnant woman has interests that are separate from those of the fetus. Optimizing outcomes for the fetus and respecting maternal autonomy and decision-making can lead to disagreement and conflict. In addition, ethical issues are raised when fetal care may involve interventions that are innovative or even investigative, and organizational aspects within institutions in the development of fetal care centers can lead to other ethical issues. This policy statement makes recommendations regarding informed consent, the role of research subject advocates and other independent advocates in fetal care centers, the availability of support services to pregnancy women, the multidisciplinary nature of fetal intervention teams, the oversight of centers, and the need to accumulate maternal and fetal outcome data.

**American College of Obstetricians and Gynecologists Committee on Ethics. Maternal decision making, ethics, and the law. *Obstet Gynecol* 2005;106:1127-1137**

This ethics committee opinion reviews the ethical issues that arise when a woman makes decisions during pregnancy that may harm a fetus, summarizes notable legal cases related to maternal and fetal interests, and considers six objections to punitive and coercive legal approaches to maternal decision-making. The committee argues that pregnant women are entitled to informed consent and bodily integrity, and that efforts to use the legal system to protect the fetus by constraining pregnant women's decision-making authority erode a woman's basic right to privacy and bodily integrity and should not be used. Rather, efforts should focus on promoting the health of women and their fetuses through advocacy of healthy behavior, referral for mental health and substance abuse services when indicated, and development of safe, available, and efficacious services for women and families.

**Chervenak FA, McCullough LB, Skupski D, Chasen ST. Ethical issues in the management of pregnancies complicated by fetal anomalies. *Obstet Gynecol Surv* 2003;58:473-483**

This article provides an excellent survey of the ethical issues involved with making decisions about pregnancies complicated by fetal anomalies. It includes discussion of the basic ethical principles of autonomy and beneficence; the ethical concept of the fetus as a patient before and after viability; and practical guidelines for decision-making before and after viability. Also included is a discussion of the intrapartum management of hydrocephalus and fetal research. This article includes an excellent analysis of principle-based ethical reasoning, although it can be interpreted to regard mother and fetus as potential adversaries. Augmenting this reading with the Harris article (below) on traditional adversarial construct could be helpful.

**DeVille KA, Kopelman LM. Moral and social issues regarding pregnant women who use and abuse drugs. *Obstet Gynecol Clin North Am* 1998;25:237-254**

This article summarizes the rationale behind the differing responses to maternal drug abuse, reviews the moral obligations of the mother to a fetus that she has decided to carry to term, and then lists the difficulties in formulating a fair social policy to deal with the maternal drug abuse problem, including the issues of determining how much harm is the result of drug abuse rather than other environmental factors, the differential impact of drugs and poverty on poor and minority women, and the issue of gender bias inherent in the fact that fathers are not held culpable for encouraging a drug-abusing environment for the mother. The authors favor voluntary, non-coercive policies, since they are respectful of a woman's liberty and because coercive policies have not been shown to be more effective. This article is a good companion to the more traditional construct of the maternal/fetal conflict or can stand alone as an overview of the problem of maternal drug abuse.

**Harris LH. Rethinking maternal-fetal conflict: gender and equality in perinatal ethics. *Obstet Gynecol* 2000;96:786-791**

Harris proposes an alternative to the traditional adversarial maternal-fetal conflict model, a "win-win" model in which maximizing maternal well-being maximizes fetal well-being and emphasizes the need to look at relationships in the mother's life beyond the "mother-fetus-physician" triangle. Physicians and other caregivers are also advised to examine the ways in which their personal value

system may cause the caregiver to devalue the pregnant mother's concerns. Rejecting the punitive and coercive methods often resulting from the adversarial model, Harris correctly points out that moral obligations are not synonymous with legal obligations. This is an excellent article that stands as a counterpoint to the traditional construct of maternal- fetal conflicts. It clearly describes the issues of how current drug policies have an inequitable impact on poor women and women of color.

**Townsend SF. Ethics for the pediatrician: obstetric conflict: when fetal and maternal interests are at odds. *Pediatr Rev* 2012;33:33-37**

The interests of a mother and fetus usually align with one another. But when there is a conflict, Townsend argues that the physician must accept the informed consent or refusal of treatment. Respect must be accorded to a woman's autonomy and bodily integrity, as well as her values regarding the outcome of a pregnancy. Townsend contends that coercion to force treatment is never justified, even if there is a risk of harm to the fetus.

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### **III. Patient–Parent–Pediatrician Relationship**

#### **A. *Obligations: veracity, fidelity, and confidentiality***

#### **JOURNALS**

**American Academy of Pediatrics Committee on Adolescence. Counseling the adolescent about pregnancy options. *Pediatrics* 1998;101:938-940**

Pregnancy diagnosis and management options are reviewed. Physicians must be familiar with local resources (adolescent pregnancy programs, adoption agencies, abortion facilities, social services) and local laws (confidentiality, suspected abuse, suspected statutory rape, abortion laws) and should support the adolescent as she considers her pregnancy options. If unable to support the adolescent because of personal values and beliefs, the physician should refer her to another health care professional. This AAP statement is useful in outlining key areas to consider when caring for pregnant adolescents.

**American Academy of Pediatrics Committee on Bioethics. Pediatrician-family- patient relationships: managing the boundaries. *Pediatrics* 2009;124:1685-1688**

Trust and objectivity are key elements in the therapeutic relationship. These elements may be compromised by personal relationships with patients and their family members; by confusing or offensive words, body language, or touching; and by non-monetary payments and gifts. Romantic and/or sexual relationships with patients are always inappropriate. This AAP statement is an excellent overview of the potential conflicts when appropriate boundaries in the pediatrician– family–patient relationship are not in place.

**Answering parents' questions. *J Clin Ethics* (special section) 2003;14:59-87**

Have you ever been asked: "Doctor, if this were your child, what would you do?" How did you respond? Should such a question be ignored, or should you freely reveal what you would do for your child based not only on the medical facts but also on your personal and family values? What is the true meaning behind such a question, and how would you go about exploring that meaning? This special section of *The Journal of Clinical Ethics* contains commentaries by leading ethicists that explore the many facets of this question. This is a must read for all clinicians, generalists as well as subspecialists.

**Cummings CL, Mercurio MR. Ethics for the pediatrician: autonomy, beneficence, and rights. *Pediatr Rev* 2010; 31:252-255**

Although this article is very basic, it provides a good foundation in understanding ethical reasoning for a learner who has not had prior exposure.

**Hammes BJ, Klevan J, Kempf M, Williams MS. Pediatric advance care planning. *J Palliat Med* 2005;8:766-773**

This paper documents that parents of children with progressive, fatal illnesses feel more assured their children will get good and consistent care if they are given the opportunity for advance care planning. This paper provides food for thought regarding how often parents of such children are given these opportunities and why it is not offered more frequently.

**Levinson W. Doctor-patient communication and medical malpractice: implications for pediatricians. *Pediatr Ann* 1997;26:186-193**

Quality of care is not the major determinant of decisions to initiate malpractice litigation; in 70% of cases it is issues of communication and caring. Usual communication problems leading to litigation are deserting the patient, devaluing patient's views, delivering information poorly, and failing to understand patients' or families' perspectives. Adequate, unrushed explanations about diagnosis and treatment and close, trusting, respectful relationships are protective. Emotions must be dealt with directly; the process is therapeutic, does not lengthen the interview time, and enhances health outcomes as it invites the expression of concerns. Patient/family beliefs, experiences, and expectations must be elicited in order to tailor therapy to meet the needs of children and parents. Nonjudgmental inquiries of the child and parents about expected difficulties following the proposed treatment plan enhances the development of appropriate options and compliance. Explanations must be developmentally appropriate and may include written, play, and drawing communication, but this does not replace physician-patient discussion. In situations of bad news, one should prepare families in advance when possible, keep medical information to a minimum immediately after revealing the diagnosis (since it is difficult for such information to be processed at that time), and discuss treatment options at a subsequent interview. Indicate and demonstrate compassion and nonabandonment. Communication with adolescents must emphasize respect for confidentiality of the information and encourage the sharing of appropriate information with parents. This paper concludes with resources to develop improved communication skills.

**Sigman GS, Kraut J, La Puma J. Disclosure of a diagnosis to children and adolescents when parents object: a clinical ethics analysis. *Am J Dis Child* 1993;147:764-768**

Telling someone the truth is one way of respecting that person. However, there may be times when willfully hiding the truth from someone is morally justified. This article reviews the factors (physician, disease-specific, patient, family) that should be considered when deciding to disclose information to a pediatric patient. It provides a reasonable, systematic approach to responding to a parent's request not to tell his/her child the truth about the child's diagnosis.

**Vaught W. Parents, lies and videotape: covert video surveillance in pediatric care. *J Clin Ethics* 2004;15:161-175**

The use of covert video surveillance to diagnose Munchausen syndrome by proxy (MSBP) is controversial. One must balance the issues of invasion of privacy and breach of trust in the doctor-patient/family relationship with the protection of the innocent child. The author examines the fiduciary relationship between physician and parents as well as physician and pediatric patient and makes a cogent argument for the use of covert video surveillance as a diagnostic tool in the treatment of MSBP.

## **BOOKS AND BOOK CHAPTERS**

**Katz J. *The Silent World of Doctor and Patient*. Baltimore: Johns Hopkins University Press, 2002 (originally published in 1984, now with a foreword by Alexander Morgan Capron)**

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### ***B. Informed consent/dissent/assent***

## **JOURNALS**

**Alderson P, Sutcliffe K, Curtis K. Children's competence to consent to medical treatment. *Hastings Cent Rep* 2006;36:25-34**

A child's ability to meaningfully participate in medical decision-making is less dependent on the age of the child than on the experience of the child with the medical issue. The authors investigated the ability of children 3 to 12 years old to make competent informed decisions regarding treatment for insulin-dependent diabetes. They found that children, beginning at about 4 years of age, were capable of making a decision about their diabetes care that was in their own best interest. The authors conclude that: "Protecting these children from their disease means involving them in their treatment as much as possible, helping them to understand it and take responsibility for it so that they can navigate the multitude of daily decisions that become part of the diabetes medical regimen." This article highlights the importance of including children with a chronic illness at an early age in the decision-making process and of fostering their ability to make autonomous decisions.



**American Academy of Pediatrics Committee on Pediatric Emergency Medicine and Committee on Bioethics. Consent for emergency medical services for children and adolescents. *Pediatrics* 2011;128:427-433**

This is an update on the 2003 guidelines regarding emergency treatment of children and adolescents. The two most important points are: (1) It is morally obligatory and legally permissible to treat children or adolescents lacking a parent or guardian in the ED if their immediate medical condition is threatening to life or limb, if the child is in severe pain, or the condition could result in serious impairment or dysfunction if left untreated; (2) Ordinarily parental refusal of medical treatment for a child is respected, but parents are obligated to act in the best interests of a child, especially if an intervention is necessary to save a child's life or prevent serious harm. If they fail in that obligation, then physicians may call the police and enlist their assistance in placing the child in temporary protective custody. These guidelines are intended to apply to both an in-hospital and out-of-hospital setting.

**American Academy of Pediatrics Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 1995;95:314-317**

Over the last 40 years there has been a shift from a paternalistic approach to medical decision-making ("the physician knows best") to a shared decision-making approach where the patient has increasing authority to make decisions. This policy statement from the AAP is an excellent overview of the informed consent and informed permission processes. In addition, this policy statement addresses when and how the minor patient might participate in decisions.

**American Academy of Pediatrics Committee on Bioethics. Religious objections to medical care. *Pediatrics* 1997;99:279-281**

Religion plays an important role in the lives of many individuals and families. Religious freedom guaranteed by the Constitution is freedom of belief and freedom of practice as long as the practice does not harm innocent individuals. The AAP supports efforts to hold parents legally accountable for denying to their children in the name of religion medical care that would likely prevent death, substantial harm, or suffering. All pediatricians should be familiar with this very important policy statement.

**Bostick NA, Sade R, McMahon JW, Benjamin R. Report of the American Medical Association Council on Ethical and Judicial Affairs: withholding information from patients: rethinking the propriety of "therapeutic privilege." *J Clin Ethics* 2006;17:302-306**

Intentionally withholding medical information from a patient because of fear of physical or psychologic harm is known as therapeutic privilege. The Council on Ethical and Judicial Affairs of the American Medical Association discusses the role of therapeutic privilege in clinical practice and concludes that the permanent withholding of medical information from a patient is a violation of patient trust and a violation of the physician's obligations to promote benefit to the patient and respect patient autonomy. A physician should determine what and how much information the patient wants, and to whom the information can be released, prior to acquiring the information.

**Brody H. Transparency: informed consent in primary care. *Hastings Cent Rep* 1989;19(5):5-9**

Little is known about the informed consent process in primary care, yet informed consent is a part of good patient care. Disclosure of information is normally based on a community practice standard and/or a reasonable person standard. Brody proposes a different model based on talking with and making the physician's thinking transparent to the patient. This article is an important contribution to the informed consent process discussion.

**Campbell AT. Consent, competence, and confidentiality related to psychiatric conditions in adolescent medicine practice. *Adolesc Med Clin* 2006;17:25-47**

Respect for the adolescent, parental responsibility toward their child's best interests, and the family unit generally are paramount. Respect – coupled with caution, greater disclosure and cultural sensitivity, and a participatory approach to decision-making that seeks the least restrictive and least coercive options – can help avoid potential legal traps. How best to proceed? Law and ethics should be the start (not end) of discussion and analysis.

**Chervenak FA, McCullough LB, Brent RL. The perils of the imperfect expectation of the perfect baby. *Am J Obstet Gynecol* 2010;203:101.e1-5**

The authors do an excellent job of addressing the ethical issues inherent in patients' desire to have complete control over the human body. Although they speak to obstetrical issues such as detailed birth plans, this desire for control often continues after birth, affecting the parent-pediatrician relationship. The comment that “sometimes implicit in these expressions of patients' rights is the belief that laypersons can set the standard of care for clinical practice” should resonate with pediatricians. Using a preventive ethics approach, the authors argue for informing parents of the limitations of medical technology and the “background” risks of normal pregnancy and provide tables detailing such risks. Their approach could be very useful for pediatricians dealing with parental concerns about vaccination and other interventions.

**Diekema DS and Committee on Bioethics, American Academy of Pediatrics. Clinical report: responding to parental refusals of immunization of children. *Pediatrics* 2005;115(5):1428-1431**

The goal of this technical report is to assist pediatricians in understanding the reasons parents may have for refusing to immunize a child, review the limited circumstances under which parental refusals should be referred to child protective services agencies or Public health authorities, and provide practical guidance to assist the pediatrician faced with a parent who is reluctant to allow immunization of a child.

**Eder ML, Yamokoski AD, Wittmann PW, Kodish ED. Improving informed consent: suggestions from parents of children with leukemia. *Pediatrics* 2007;119:e849-e859**

This study summarizes the results of interviews with 140 parents of children who had been offered participation in a randomized clinical trial for the treatment of acute leukemia. Although the

interviews involved parents enrolling in a clinical trial, the authors argue that their findings can be generalized to the informed consent process in general, can improve the informed consent process, and can be applied to most adult and pediatric populations. The article provides a detailed summary of the suggestions parents had for improving the informed consent process. It includes a model of informed consent called the PAGIC model, developed during a meeting with an advisory group of parents. The PAGIC model of consent includes suggestions for timing, a sequence of information presentation, and a checklist of major topics to be covered. It also provides guidance on checking for understanding and guidance about what will happen next, and it emphasizes that parents have a choice.

**Jones JW, McCullough LB, Richman BW. A comprehensive primer of surgical informed consent. *Surg Clin N Am* 2007;87:903-918**

This document is useful for its discussion of the evolutionary history and the elements of truly informed consent (individually tailored disclosure, understanding, and mutual decision-making). In particular, the authors emphasize that informed consent is a process, not an event, and is certainly not about signing a piece of paper. There is a relatively small but adequate section devoted specifically to pediatric cases. Unfortunately, none of the authors is a surgeon. This paper should be read by surgeons as well as pediatric residents and fellows.

**Kodish E, Post SG. Oncology and hope. *J Clin Oncol* 1995;13:1817-1822**

This essay summarizes the role of hope in ancient and modern medicine and examines the moral dynamics of hope in the care of patients with cancer. The paper reviews the need to balance hope with honest disclosure and emphasizes the ethical distinction between diagnostic and prognostic disclosure. These issues are discussed as they relate to a paradigmatic sequence of cancer care. The paper concludes with a call for renewed attention to the ethical obligation to promote reasonable hope for patients with cancer.

**Mack JW, Wolfe J, Cook EF, Grier HA, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Onc* 2007;25:5636-5642**

This single-institution, U.S.-based paper refutes the conventional “wisdom” that withholding prognostic information, even when the child’s prognosis is terminal, provides hope. Among the study participants, hope was greatest when communication was frequent and honest and when it was inversely proportionate to prognosis.

**Recupero PR, Rainey SE. Informed consent to e-therapy. *Am J Psychother* 2005;59:319-331**

This article provides a basic background regarding the definition and development of e-therapy, addressing the ethical issues through the lens of informed consent. The article discusses some relevant risks and benefits of e-therapy and discusses the practicality of using computers for the informed consent process. In this time of expanding Internet access, this article provides a good introduction and a very thorough list of references.

**Salas H, Aziz Z, Villareale N, Diekema DS. The research and family liaison: enhancing informed consent. *IRB* 2008;30:1-8**

How best to present research information to families, ensure comprehension of that information, and facilitate the voluntary participation of families throughout a research study can be a significant challenge. The authors of this paper describe the creation of a new role designed to address these challenges—the Research and Family Liaison. The role focuses on assisting families in achieving genuine comprehension and improved decision-making about clinical trial enrollment. The authors argue that the presence of a Research and Family Liaison improves the consent process through direct engagement with families, interactive staff education, and the development of communication materials.

**Whitney SN, Ethier AM, Friget E, et al. Decision-making in Pediatric Oncology: Who should take the lead? Decisional priority in pediatric oncology model. *J Clin Oncol*, 2006;24:160-165**

The authors propose a new strategy for decision-making in pediatric oncology, coining the terms decisional priority and decisional authority to serve as guideposts in the strategy to determine the balancing act of who among the health care provider, parent and child-patient should make a decision in a given situation. By their definition, decisional authority is a legal and non-delegable task of the parent and mature minor. However, decisional priority rests on the likelihood of cure, which can only be determined by the clinician or the competing viability of alternative options when cure is less likely and values of the patient and family dictate the appropriate choice. Interestingly, the authors advocate for clinician decisional priority to cease disease-directed interventions when the child is irreversibly ill and suffering. Critical reading for oncology trainees and practitioners, though the strategy is applicable to all chronic and life-threatening conditions and is therefore appropriate for other pediatric trainees and practitioners.

## **BOOKS AND BOOK CHAPTERS**

**Diekema DS, Marcuse EK. Ethical issues in the vaccination of children. *Primum non nocere Today* (2nd ed). Edited by GR Burgio and JD Lantos. Amsterdam: Elsevier Science B.V., 1998:37-47**

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### **C. Minors as decision-makers**

## **JOURNALS**

**American Academy of Pediatrics Committee on Adolescence. Counseling the adolescent about pregnancy options. *Pediatrics* 1998;101:938-940**

Minors have legal rights protecting their privacy regarding the diagnosis and treatment of pregnancy. Pediatricians should be familiar with local laws that govern confidentiality and not convey the diagnosis of pregnancy to others, including parents, until an adolescent's consent is

obtained, except where there is a concern about suicide, homicide, or abuse. This policy statement argues that when consulted by a pregnant adolescent, pediatricians should be able to make a timely diagnosis, help the adolescent understand her options, and act on her decision to continue or terminate her pregnancy. Adolescents should be encouraged to include parents or other trusted adult(s) in a full discussion of their options. Pediatricians should not impose their values on the decision-making process and should be prepared to support the adolescent in her decision or refer her to a physician who can.

**American Academy of Pediatrics Committee on Adolescence. Contraception and adolescents. *Pediatrics* 2007;120:135-148**

This article recommends abstinence for adolescents but, recognizing that many will not adhere to these recommendations, provides guidance for the education and counseling of sexually active adolescents.

**American Academy of Pediatrics Committee on Adolescence. Emergency contraception. *Pediatrics* 2012;130:1174-1182.**

This clinical report reviews the available emergency contraceptive methods; summarizes the indications for the use of emergency contraception; provides current data on the safety, efficacy, and use of emergency contraception in adolescents; and encourages routine counseling and advance emergency contraception prescription as one part of a public health strategy to reduce adolescent pregnancy.

**Diekema DS. Adolescent refusal of lifesaving treatment: are we asking the right questions? *Adolesc Med State Art Rev* 2011;22:213-228**

This paper addresses the issue of whether adolescents, as a rule, possess capacity of sufficient quality that it should be respected even in the case of life-altering medical decisions. The author begins by reviewing the traditional approach to determining when adolescents should have their decisions respected, an approach that focuses on establishing capacity under a traditional informed consent model. The author then reviews the evolving understanding of adolescent brain development and explores the implications of that research for adolescent decision-making capacity. Finally, the author argues that a demonstration of understanding and mature reasoning abilities is not sufficient to establish decision-making capacity and that most minors do not possess fully mature decision-making capacity. The decision to withhold lifesaving interventions from adolescents should not be premised on the notion that the adolescent is capable of fully mature decision-making. The author concludes by suggesting an approach to adolescent decision-making that is more reflective of the developing state of the adolescent brain.

**Diekema DS. Parental refusals of medical treatment: The harm principle as threshold for state intervention. *Theor Med Bioeth.* 2004;25(4):243-264**

In this paper, the author argues that the best interest standard provides insufficient guidance for decision-making regarding children and does not reflect the actual standard used by medical

providers and courts. Rather, the Harm Principle provides a more appropriate threshold for state intervention than the Best Interest standard. He provides a series of criteria that can be used in deciding whether the state should intervene in a parent's decision to refuse medical care on behalf of a child.

**Freyer DR. Care of the dying adolescent: special considerations. *Pediatrics* 2004;113:381-388**

Providing appropriate end-of-life care for adolescents dying from a chronic illness poses unique developmental, ethical, and legal challenges. Such challenges include the adolescent as decision-maker, the parent who does not want the terminal illness disclosed to the adolescent, and psychosocial support for the patient and family. This article is a nice discussion of the challenges health care professionals face when caring for such patients and families, with practical suggestions for addressing these issues.

**King NM, Cross AW. Children as decision-makers: guidelines for pediatricians. *J Pediatr* 1989;115:10-16**

This is a classic article about informed consent in pediatrics. It is valuable for its clear description of informed consent, practical advice for assessing a child's capacity for informed consent, and discussion of a case. It is also noteworthy for its emphasis on the pediatrician's role in enhancing a child's decision-making role and its careful discussion of special issues like confidentiality and conflict.

**Center for Practical Bioethics. Minors' rights in health care decision-making. *Bioethics Forum* 1995 (winter); 11(4).**

This entire issue of *Bioethics Forum* is dedicated to an in-depth discussion of health care decision-making by minors, including a statement of guidelines developed by a multidisciplinary task force of the Midwest Bioethics Center. It is one-stop shopping for any ethics library for residents. It is particularly valuable for its breadth of discussion, including an article by Ross with a dissenting opinion and articles by young people. Two articles from this journal are reviewed below.

**Ross LF. Health care decision-making by children. Is it in their best interests? *Hastings Cent Rep* 1997;27(6):41-45**

In this updated version of the dissenting opinion published in the 1995 *Bioethics Forum*, Ross communicates her reasons for caution in articulating the decision-making rights of children. Since Ross critiques the 1995 AAP guidelines for the role of children in health care decision-making, this article would make an excellent companion piece to the AAP guidelines in a session about decision-making by children.

**Ross LF. Against the tide: arguments against respecting a minor's refusal of efficacious life-saving treatment. *Camb Q Healthc Ethics*. 2009;18:302-315 (discussion 315-322).**

The author reviews cases of adolescents who refused standard medical intervention for life-

threatening conditions, creates logic tables refuting their capacity to make such judgments independent of their families, and argues that the mature minor is also not actually upheld. This paper challenges the reader to think through the consequences and practicality of choosing who can decide but stops short of critiquing the role of the healthcare professional in decision-making. It is recommended especially for those working with adolescents as a primary population.

**Sigman GS, O'Connor C. Exploration for physicians of the mature minor doctrines. *J Pediatr* 1991;119:520-525**

This is a classic article about decision-making by minors that includes a thorough review of the mature minor doctrine complete with case vignettes. It is very concise and practical and includes guidelines for the daily practice of pediatricians.

**Strong C. Respecting the health care decision-making capacity of minors. *Bioethics Forum* 1995 (winter): 7-12**

From the *Bioethics Forum* issue on "Minor's rights in health care decision-making", Strong carefully reviews the Midwest Bioethics Center guidelines. He supports this distinction among minors: minors without decisional capacity, minors with developing capacity, and minors with decisional capacity. He also provides a useful critique of the guidelines, with a series of unanswered questions. This article is a good companion piece to the Midwest Bioethics Center guidelines.

**Waxse DJ. The role of minors in health care decision-making: current legal issues. *Bioethics Forum* 1995 (winter): 17-21**

Also from the special issue of the *Bioethics Forum* on "Minor's rights in health care decision-making", this article is a concise but thorough review of the legal issues involved in decision-making by minors.

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#### ***D. Advance care planning***

### **JOURNALS**

**Badzek L, Kanosky S. Mature minors and end-of-life decision-making: a new development in their legal right to participation. *J Nurs Law* 2002;8:23-29**

This article represents an important update on the legal right for adolescents to participate in end-of-life decision-making and the completion of advance directives. It describes the West Virginia Health Care Decisions Act, the first state law that allows minors to complete advance directives. The article also reviews other court cases and state statutes dealing with mature minors and medical decision-making. It concludes with a discussion of the implications of this new law for practice and future health policy. It is a very important article for discussion of advance directives and adolescents.

**Hammes BJ, Klevan J, Kempf M, Williams MS. Pediatric advance care planning. *J Palliat Med* 2005;8:766-773**

This is a small, single-institution study describing parental perceptions of the benefit of a formalized advance care planning process. Those interviewed identified the following ways advance care planning was helpful: ensuring the best care, providing time and information to make decisions, helping to communicate desired care, and offering peace of mind. This is important for pediatricians at all levels of training.

**McCabe MA, Rushton CH, Glover JJ, Murray MG, Leiken S. Implications of the Patient Self-Determination Act: guidelines for involving adolescents in medical decision-making. *J Adolesc Health* 1996;19:319-324**

This article is a very practical discussion of the role of adolescents in medical decision-making. It is very useful for resident education because of its clear and practical recommendations. Particularly valuable is the appendix that includes sample questions to be used in the self-assessment of the professional, the assessment of the adolescent, and the assessment of the family.

**Wharton RH, Levine KR, Buka S, Emanuel L. Advance care planning for children with special health care needs: a survey of parental attitudes. *Pediatrics* 1996;97:682-687**

This article, although old, is one of few exploring the ideas and preferences of parents of children who can benefit from long-term planning about their children's health care. Although respondents are not representative of the general population of parents facing such difficulties, the insights are prescient of subsequent research results regarding advance care planning for children and adults. These include a strong desire for comprehensive care planning in the face of a chronic and ultimately life-threatening condition; overwhelming parental perception of having insufficient information about their child's developmental potential and future medical needs; parents' correlation of the degree of the physicians' understanding of their needs with the likelihood of understanding the child's needs; the near-unanimous preference for clear information as soon as it is known (regardless of whether it is bad news); and a very high proportion of parents desiring written guidance about future medical care for their child, such as the execution of advance care planning documents (74% among those with strong rapport and 94% among those with less rapport with their physicians). This is important for pediatricians at all levels of training.

## **BOOKS AND BOOK CHAPTERS**

**Levetown M, Carter MA. Child-centered care in terminal illness: an ethical framework. In Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine* (2nd ed). Oxford, England: Oxford University Press, 1998:1107- 1117**

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## ***E. Gay, lesbian, bisexual, and transgender issues***

### **JOURNALS**

**Drescher J. Ethical issues in treating gay and lesbian patients. *Psychiatr Clin North Am* 2002;25:605-621**

This article discusses the ethical issues involved in regarding homosexuality as normal or as a disease and the ethical issues involved in sexual conversion therapies. The article traces the history of the debate in the psychiatric community. The article relies on the work of Paul Appelbaum in outlining five conditions that are necessary for any treatment modality to be ethical and applying these conditions to the case of sexual conversion therapies: 1) a reasonable basis to believe that the treatment may be effective; 2) appropriate disclosure of relevant information to a prospective patient; 3) the absence of illegitimate pressure on the patient; 4) the patient's ability to make a competent decision; 5) a fiduciary devotion by the therapist to the patient's best interests. The article is very thoughtful and well-written and could be a useful addition to the discussion of ethical issues with residents in psychiatry or adolescent medicine.

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# ETHICS AND THE USE OF TECHNOLOGY

## IV. New Technology

### A. *Genetics: Communicating difficult diagnoses*

#### JOURNALS

Conn J, Gillam L, Conway GS. Revealing the diagnosis of androgen insensitivity syndrome in adulthood. *British Medical Journal* 2005;331:628-30

A case history of a patient with complete androgen insensitivity syndrome is presented as a base for discussion of the ethical issues around informing patients of the basis of their condition. Emphasis is given to the principles of justice and respect for patient autonomy.

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### B. *Genetics: Genetic testing*

#### JOURNALS

American Society of Human Genetics, American College of Medical Genetics. Points to consider: ethical, legal, and psychosocial implications of genetic testing in children and adolescents. *Am J Hum Genet* 1995;57:1233-1241

This report, endorsed by the American Academy of Pediatrics, is an excellent discussion of important considerations in genetic testing of children and adolescents. It systematically addresses ethical, legal, and psychosocial issues, as well as providing a careful discussion of the medical issues, which typically are the main concern of the medical profession. There is a balanced analysis of the interests of children and their families and a thorough discussion of decision-making capacity of the child. The provider's responsibility to the child with respect to parental requests for testing or for nondisclosure of test results is also considered.

Caga-anan EC, Smith L, Sharp RR, Lantos J. Testing children for adult-onset genetic diseases. *Pediatrics* 2012;129:163-167.

This article begins with a couple of cases of parents seeking genetic testing for young children for what “could be” adult-onset genetic disorders. Ordinarily, testing for such disorders is strongly discouraged, in part because of privacy rights of the children. It is assumed that there is a sharp distinction between early-onset and adult-onset disorders, but these cases illustrate that the distinction will often not be as sharp or as clear as we might imagine. Further advances in genetics and medicine may blur the distinction even more.

**Clayton EW, McCullough LB, Biesecker LG, Joffe S, Ross LF, Wolf SM. Addressing the ethical challenges in genetic testing and sequencing of children. *Am J Bioeth* 2014;14(3):3-9.**

This article is a helpful summary of the differences in and tension between two sets of recent recommendations from the American Academy of Pediatrics (AAP) and the American College of Medical Genetics (ACMG) regarding predictive genetic testing in children. In one, there is affirmation of prior statements asserting that predictive genetic testing of children for adult-onset conditions should be deferred until the child is able to consent unless “ameliorative interventions” are available during childhood, with rare specific exceptions. In the other, if parents authorize exome or genome sequencing, laboratories are instructed to look for 56 specific mutations (not ordered) and report these to the ordering clinician. Parents should not be given a choice of opting out of this (unrequested) analysis. Issues of autonomy, best interest, locus of decision making, and risk/benefit are discussed.

**Cohen CB. Wrestling with the future: should we test children for adult-onset genetic conditions? *Kennedy Inst Ethics J* 1998;8:111-130**

Cohen presents a compelling argument for flexibility in determining whether to do predictive genetic testing in children. Benefits and burdens will vary greatly from case to case. Some ethicists argue that predictive testing will rob children of some measure of autonomy as adults. Cohen argues that it can enhance the future autonomy of the child and that the decision to test should belong to the parents and the mature child.

**Davis DS. Genetic dilemmas and the child's right to an open future. *Hastings Cent Rep* 1997;27:7-15**

This is an extremely important paper for pediatricians. The context of the discussion is genetic counseling and the desire expressed by many parents who are deaf to have a deaf child. With reference to Joel Feinberg's argument that children possess, among other things, "rights-in-trust" that must be presumed until the child reaches adulthood, Davis argues that children have a right not to have options closed off for them to benefit their parents or the parents' culture. Davis further argues that having many choices increases the likelihood that a child will find a happy and successful "fit" in society. A child should be treated as an end in himself (or herself) and not as a means to a parental goal. This paper should be part of a discussion of the "best interests" standard when making decisions about children.

**Elger BS, Harding TW. Testing adolescents for a hereditary breast cancer gene (BRCA-1): respecting their autonomy is in their best interest. *Arch Pediatr Adolesc Med* 2000;154:113-119**

Elger and Harding present a cogent argument for allowing decisional autonomy with regard to BRCA-1 gene testing for all psychologically "normal" adolescents ages 14 to 17 years. While the authors recognize the "unstable self-esteem of an adolescent," they seem to brush aside rather easily the psychological vulnerability of the adolescent. Nevertheless, the paper is well written and would be useful in teaching about ethical issues in adolescent medicine.

**Hanson JW, Thomson EJ. Genetic testing in children: ethical and social points to consider. *Pediatr Ann* 2000;29:285-291**

This article discusses the differences between genetic screening and diagnostic genetic testing, and why such testing is particularly sensitive. The article addresses the ethical and social concerns (risks) of performing genetic testing, with particular attention to these issues in children. It is a helpful introductory article prior to reading the AAP statement on genetic testing in pediatrics.

**Rosenthal SM, Diekema DS. Pediatric ethics guidelines for hereditary medullary thyroid cancer. *International Journal of Pediatric Endocrinology* 2011;2011(Article ID 847603):8 pages.**

Hereditary medullary thyroid cancer is an aggressive cancer for which there is no standard effective systemic therapy, but which can be prevented through genetic screening and prophylactic thyroidectomy. Although this cancer accounts for roughly 17% of all pediatric thyroid cancers, a significant percentage of affected families do not “accept” screening, while many gene carriers delay or refuse prophylactic thyroid surgery for their children. Current genetic screening practices in medullary thyroid cancer are inadequate: more than 50% of index patients with hereditary medullary thyroid cancer present with a thyroid mass, and up to 75% have distant metastasis. The authors propose screening and treatment guidelines that focus on two ethical issues that affect at-risk children: (1) how to identify at-risk children whose RET- positive relative refuses to disclose that they carry the mutation, and (2) how to protect RET-positive children whose parents refuse prophylactic thyroidectomy.

**Ross LF, Saal HM, Anderson R, David K, American Academy of Pediatrics Committee on Bioethics, American Academy of Pediatrics Committee on Genetics, and American College of Medical Genetics and Genomics Social, Ethical, and Legal Issues Committee. Ethical and policy issues in genetic testing and screening of children: policy statement. *Pediatrics* 2013;131:620–622.**

Genetic testing and screening of children have become more common over time. This policy statement represents a joint effort of the American Academy of Pediatrics Committee on Bioethics and the College of Medical Genetics and Genomics Social, Ethical, and Legal Issues Committee. The policy statement recommends that decisions about whether to offer genetic testing and screening be driven by the best interest of the child. Although testing for the purpose of diagnosis and treatment can be easily justified, routine carrier testing is more difficult to justify in children. Predictive testing may be authorized by parents or guardians for asymptomatic children at risk of childhood-onset conditions, but predictive genetic testing for adult- onset conditions generally should be deferred unless an intervention initiated in childhood may reduce morbidity or mortality or for families for whom diagnostic uncertainty poses a significant psychosocial burden. The statement also addresses newborn screening, histocompatibility testing of minors, genetic testing in the setting of adoption, and the use of direct-to-consumer and home kit genetic testing of children.

**Ross LF, Saal HM, Anderson R, David K, American Academy of Pediatrics Committee on Bioethics, American Academy of Pediatrics Committee on Genetics, and American College of Medical Genetics and Genomics Social, Ethical, and Legal Issues Committee. Ethical and policy issues in genetic testing and screening of children: technical report. *Genet Med* 2013;15(3):234-245.**

A technical report that accompanies the above policy statement provides the ethical justification and empirical data that supports the policy recommendations proposed.

**Ross LF. Ethical and policy issues in pediatric genetics. *Am J Med Genet C Semin Med Genet* 2008;15:1-7**

Although this article is an introduction to a special issue devoted to pediatric genetics, it very nicely summarizes the ethical issues inherent in pediatric genetic testing. The author then gives an overview of each article, so the reader can pursue a specific topic in greater depth if desired.

**Slijper FME, Frets PG, Boehmer ALM, Drop SLS, Niermeijer MF. Androgen insensitivity syndrome (AIS): emotional reactions of parents and adult patients to the clinical diagnosis of AIS and its confirmation by androgen receptor gene mutation analysis. *Horm Res* 2000;53:9-15**

A nationwide clinical study in The Netherlands presents the reactions of parents of patients with AIS as well as adult patients with AIS to the diagnosis. The results support fully informing adolescents with AIS about their condition.

**Wertz DC, Fanos JH, Reilly PR. Genetic testing for children and adolescents. Who decides? *JAMA* 1994;272:875-881**

This article is an excellent discussion of the ethical and psychosocial issues involved in presymptomatic genetic testing. There is a thorough analysis of informed consent and the justification and timing of assent from minors. Useful guidelines are proposed for presymptomatic genetic testing.

## **BOOKS AND BOOK CHAPTERS**

**Murray TH. *The Worth of a Child*. Berkeley: University of California Press, 1996**

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### **C. Cochlear implants**

## **JOURNALS**

**Crouch RA. Letting the deaf be deaf: reconsidering the use of cochlear implants in prelingually deaf children. *Hastings Cent Rep* 1997;27(4):14-21**

The author presents evidence that deaf persons are "members of a linguistic and cultural minority" and not disabled. The fact that cochlear implant technology has limitations may be less important than the choice about whether to let a child become an integrated member of the deaf community or have the opportunity for successful integration into the hearing world. This has particular

implications with regard to whether a child is allowed to immerse herself in American Sign Language (ASL) as her primary language.

**Tucker BP. Deaf culture, cochlear implants, and elective disability. *Hastings Cent Rep* 1998;28(4):6-14**

The author presents a strong argument for not considering the deaf as a true culture and for considering it unethical for the deaf not to take advantage of technology, including surgery, which "eliminates[s] or minimize[s] the effects of their disabilities" (p. 11). She quotes Dena S. Davis with regard to the right of a child "to an 'open future'" (p. 7) and supports the decision of parents for cochlear implants in their young deaf children.

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#### ***D. Sex/gender assignment and disorders of sexual development***

##### **JOURNALS**

**Chase C. Surgical progress is not the answer to intersexuality. *J Clin Ethics* 1998;9(4):385-392**

The executive director of the Intersex Society of North America provides a strong critique of the traditional model of medical treatment for intersexuality. She cites the lack of any legitimate efficacy data, complaints from patients, and the indefensibility of not allowing intersexual persons to make informed decisions when they reach the age of consent.

**Daaboul J, Frader J. Ethics and the management of the patient with intersex: a middle way. *J Pediatr Endocrinol Metab* 2001;149:1575-1583**

Daaboul and Frader provide an introduction to the intersex controversies and helpful historical background. Between the extremes of sex assignment of the neonate by a medical team and deferral of the assignment until the child with ambiguous genitalia can make an informed decision, the authors propose support for parental decision-making with adequate parental understanding of the facts and respect for sociocultural differences. This is felt to be particularly important when it is believed that a decision in infancy by the parents can prevent future emotional harm to the child. Unfortunately, there are limited data to help determine when this is the case.

**Diamond M, Sigmundson HK. Management of intersexuality: guidelines for dealing with persons with ambiguous genitalia. *Arch Pediatr Adolesc Med* 1997;151(10):1046-1050**

With an emphasis on respect for individual differences, sensitive guidelines are provided for the management of cases of traumatized or ambiguous genitalia. The importance of informed consent, whenever possible, is stressed.

**Dreger AD. "Ambiguous sex" Cor ambivalent medicine? Ethical issues in the treatment of intersexuality. *Hastings Cent Rep* 1998;28(3):24-35**

This is an excellent article by an historian and philosopher of science that examines historical background, treatment protocols, definition of normalcy, and issues related to deception and informed consent as these relate to intersexuality. The claim is made that the same principles of ethics and justice should apply to intersexuals as to others.

**Frader J, Alderson P, Asch A, et al. Health care professionals and intersex conditions. *Arch Pediatr Adolesc Med* 2004;158:426-428**

This article summarizes the recommendations of a project sponsored by the Hastings Center on the medical, psychosocial, and ethical issues associated with intersex children. Importantly, it states that in the absence of outcome data (and the dissatisfaction of many adults with intersex conditions), genital-altering surgery should be delayed until the child can assent. The authors recommend that these children and parents receive treatment by a team to address their multiple concerns.

**Kipnis K, Diamond M. Pediatric ethics and the surgical assignment of sex. *J Clin Ethics* 1998;9(4):398-410**

The authors question the hypothesis that sexual identity is the product of social learning, noting that most of the research to support this concept has been done by one individual (John Money) and his colleagues. They note that sex and gender occur along a spectrum rather than always being purely male or female. One case is cited in which surgical reassignment of sex was a complete failure, and other cases are cited where infants did not receive surgery and had satisfactory outcomes. The authors recommend a moratorium on surgical assignment of sex on the grounds of beneficence, nonmaleficence, and informed consent. They also request efforts to undo the effects of past deception.

**Kuhnle U, Krahl W. The impact of culture on sex assignment and gender development in intersex patients. *Perspect Biol Med* 2002;45(1):85-103**

This is an excellent and comprehensive review of the issues relevant to sex assignment and gender development. The authors explain the difference between gender identity, gender role, and sexual orientation, discuss the criteria for correct sex assignment, and then review outcome studies in patients with intersexuality, as well as reviewing cultural and historical observations. Finally, there is a nice discussion of the determinants of sex role behavior. This paper is strongly recommended for an understanding of intersex issues.

**Lee PA, Houk CP, Ahmed SF, Hughes IA; International Consensus Conference on Intersex organized by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology. Consensus statement on management of intersex disorders. *Pediatrics* 2006;118:e488-e500**

This is a comprehensive and up-to-date review of the clinical management of intersex conditions. Among other issues, the authors suggest open communication, joint decision-making, and respect for individuals while advocating for interdisciplinary management in addressing developmental concerns. The authors introduce a new nomenclature for this group of conditions and broach the topic homosexuality in the context of intersexuality.

**Stein E. Commentary on the treatment of gender variant and gender dysphoric children and adolescents: common themes and ethical reflections. *J Homosex* 2012;59:480-500.**

This commentary follows five clinical articles discussing treatments for gender variant and gender dysphoric children, adolescents, and young adults. Terminology is clarified, and there is a helpful discussion of the difference between sex and gender, as well as the meaning of gender identity and the significance of gender identity disorder. There is discussion of informed consent, full disclosure, minimizing/avoiding harm, and the maximization of life options as these relate to the author's concerns about certain treatment options advocated in the articles. There is an emphasis on the multiple pathways for expression of one's gender.

**Sutton EJ, Young J, McInerney-Leo A, Bondy CA, Gollust SE, Beisecker BB. Truth-telling and Turner Syndrome: the importance of diagnostic disclosure. *J Pediatr* 2006;148:102-107**

This article reports the results of qualitative interviews with women and girls (and some girls' parents) who have Turner Syndrome. This study is significant in that the women spontaneously reported that aspects of their diagnosis were kept secret from them and the impact it had on their self-image. Many felt betrayed by their parents and physicians, even when the information was withheld for only a few days. The discussion contains important suggestions applicable to any situation in which physicians have to break bad news to parents. The authors also suggest that a plan for revealing test results to pediatric patients be in place before testing is initiated.

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## **V. Imperiled Newborn Infants**

### **A. Delivery room resuscitation issues**

#### **JOURNALS**

**American Academy of Pediatrics Committee on Fetus and the Newborn (Bell EF). Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics* 2007;119:401-403**

The authors make four recommendations as to how physicians should proceed when deciding on non-initiation or withdrawal of intensive care for high-risk newborns. This is a great article for anyone who participates in delivery room resuscitations.



**Annas GJ. Extremely preterm birth and parental authority to refuse treatment-the case of Sidney Miller. *N Engl J Med* 2004;351:2118-2122**

The author reviews the case of Sidney Miller, an infant born at 23 weeks' gestation weighing 615 gm, and raises the question of the extent of parental authority to make treatment decisions for their premature infant prior to delivery. The Texas Supreme Court ruled that an informed decision about resuscitation in the delivery room could only be made after examining the infant, and that physicians in emergency situations, which include those attending a premature delivery, are permitted to err on the side of life even if the parents refuse treatment. This is a "must-read" article for any physician who attends deliveries of premature infants.

**Batton DG, and the American Academy of Pediatrics Committee on Fetus and Newborn. Antenatal counseling regarding resuscitation at an extremely low gestational age. *Pediatrics* 2009;124:422-427**

Sometimes it is possible to predict that an infant will be born extremely prematurely. The authors of this article suggest the following broad criteria for speaking to parents in these circumstances: (1) If the physician believes that there is virtually no chance of survival, resuscitation is not indicated and should not be initiated. (2) When a good outcome is considered very unlikely, parents should be given the choice of whether to initiate resuscitation, and their choice should be respected. (3) If a good outcome is considered likely, then resuscitation should be initiated and, with parental involvement, the response should be continuously evaluated to determine whether intensive care should be continued.

**Fleischman AR, Chervenak FA, McCullough LB. The physician's moral obligation to the pregnant woman, the fetus, and the child. *Semin Perinatol* 1998;22:184-188**

This article attempts to delineate (1) the specific obligations of physicians to the pregnant woman, (2) obligations of the physician *and* pregnant woman to the fetus, and (3) obligations of the physician and the new parents to the child. The discussion provides a helpful framework for addressing the conflicting duties of all involved. This article would be particularly helpful for residents on their first NICU rotation.

**Haward MF, Kirshenbaum NW, Campbell DE. Care at the edge of viability. *Clin Perinatol* 2011;38:471-492**

This is a comprehensive survey article addressing the ethics issues raised by infants born at 22 to 25 weeks gestation. The emphasis is on shared decision-making in light of the uncertainty regarding outcomes for these extremely premature infants. The basic considerations that must be taken into account in seeking to make ethically appropriate decisions include the likelihood of survival, the range of complications after birth, the impact of these complications on long-term health, and developmental care needs for the infant and the family.

**Krug EF. Law and ethics at the border of viability. *J Perinatol* 2006;26:321-324**

This is a helpful review of the issues in law and ethics related to decisions about resuscitation of extremely premature infants in the delivery room. The case of Miller versus HCA is discussed in detail. The argument is made that families should be allowed to make a decision regarding life-prolonging versus palliative medical care for infants at the border of viability (currently 23 weeks' gestation).

**Leuthner SR. Decisions regarding resuscitation of the extremely premature infant and models of best interest. *J Perinatology* 2001;21:193-198**

Dr. Leuthner compares two statements from the AAP Committee on Fetus and Newborn (COFN) and two from the AAP committee on Bioethics (COB) in the context of the care of the extremely premature infant. He demonstrates that the COFN statements argue for an "individualized prognostic strategy" to determine an infant's "best interest," which is dependent on a physician's clinical judgment. The COB argues for a "shared decision-making process," distinguishing between the medical and moral aspects of clinical decision-making. He finds the COFN statements to be based on an "expertise model" and the COB statements to be based on a "negotiated model" of best interest. He recommends the negotiated model of determining an infant's best interest to be the most appropriate and defensible.

**Mercurio MR. Physicians' refusal to resuscitate at borderline gestational age. *J Perinatol.* Nov 2005;25(11):685-689**

A companion to the Tripp article, the author here gives a cogent discussion of the problems inherent in choosing a particular gestational age cut-off for delivery room resuscitation.

**Robertson JA. Extreme prematurity and parental rights after Baby Doe. *Hastings Cent Rep* 2004;32-39**

What are the reaches of the Child Abuse Amendment (CAA) of 1984? Does the CAA apply to extreme premature neonates? The author begins with a nice review of the Baby Doe controversy and then examines the Miller vs HCA case in light of Baby Doe and the CAA. The Miller case raises the questions of whether parents have the right to deny life-saving treatment to their extremely premature infant based on the high probability of future disabilities and whether such a decision made prior to birth has the same weight as a decision made after birth. The author argues for modifying the standards outlined in the CAA to include a threshold level of cognitive ability based on relational capability. Treatment should not be required if, in the good-faith judgment of the parents, the infant would fall below this threshold. This assessment, however, can only be made once the infant is born. The author argues that "parents' directions not to resuscitate at birth should not be acted upon until a medical assessment of the child's condition and prognosis justifying non-treatment has been made." This is a "must-read" article for any clinician attending the deliveries of premature infants.

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## **B. In the neonatal intensive care unit**

### **JOURNALS**

**Carter BS, Sandling J. Decision making in the NICU: the question of medical futility. *J Clin Ethics* 1992;3:142-143**

This is an excellent case discussion that involves several issues: medical futility, cultural decision-making differences, and assessing the benefit/burden ratio for infants with significant incapacity due to chronic disease. The case can stand alone as a focus of discussion, or the commentaries can be used to illustrate the different issues involved.

**Harrison H. The offer they can't refuse: parents and perinatal treatment decisions. *Semin Fetal Neonatal Med* 2008;13:329-334**

This article, written by a seasoned, well-read, and well-informed parent activist, provides an important understanding of parental perspectives about decision-making in the NICU. This is critical reading for all pediatric residents and essential for neonatal fellows and attendings.

**Janvier A, Bauer KL, Lantos JD. Are newborns morally different from older children? *Theor Med Bioeth* 2007;28:413-425**

This provocative article raises the question of whether newborns are treated differently than older children in making decisions about treatment. The authors posit that outcome statistics for decisions regarding newborns would not justify such decisions in other populations. The authors offer several hypotheses pertaining to personhood, reproductive choices, "precious children," and probable evolutionary and anthropologic factors to explain this difference. This is an excellent article to challenge assumptions when discussing professional and parental decision-making in the NICU.

**Jones C, Freeman JM. Decision making in the nursery: an ethical dilemma. *J Clin Ethics* 1998;9:314-322**

Using a fictitious case based on several real cases, the authors have constructed a challenging look into the reality of neonatal decision-making. Written as more of a short story than a clinical case presentation, the authors draw the reader into the middle of the decision-making process. Though some readers might balk at some of the dialogue, the discussion is excellent in describing the possible options and outcomes of this all-too-familiar scenario. This is a great article for students and physicians at all levels.

**Kipnis K. Harm and uncertainty in newborn intensive care. *Theor Med Bioeth* 2007;28:393-412**

This article explores the role of various types of uncertainty in NICU decisions. The first type of uncertainty is in the understanding of what constitutes "intolerable deficits." The second type of uncertainty is whether a particular infant will be benefited or harmed by intensive care. The third

type of uncertainty is in judging the acceptability of a ratio between the likelihood of effecting good outcomes and the likelihood of effecting bad ones. The author uses this exploration of uncertainty to argue against the current standard of decision-making where professionals are obligated to override the decisions of parents to forgo treatment.

**Paris JJ, Schreiber MD, Moreland MP. Parental refusal of medical treatment for a newborn. *Theor Med Bioeth* 2007;28:427-441**

This article discusses the issues that arise when a parent refuses to give permission for medical treatment on behalf of a premature infant. It begins with a review of the history surrounding decision-making on behalf of imperiled newborns, starting with the 1963 Johns Hopkins case, and includes other classic cases, arguments, articles, and legal cases that have followed it. This review provides a nice summary of the evolution of thought regarding the refusal of medical care for imperiled newborns and provides a context for decision-making today. The authors then summarize a helpful and practical framework for decision-making in newborn cases that divides treatment decisions into one of four categories: mandatory, optional, investigational, and unreasonable. They conclude that parents should ultimately be allowed to make decisions about whether to use aggressive interventions for markedly premature newborns when the risks of treatment are very high and the benefits are at best uncertain or extremely low, or where the only intervention offering hope is new or not proven.

**Porta N, Frader J. Withholding hydration and nutrition in newborns. *Theor Med Bioeth* 2007;28:443-451**

This article discusses the unique aspects involved in withholding medically administered hydration and nutrition from newborn patients. Health care professionals and parents often have more difficulty withholding hydration and nutrition than they do with other medical interventions, and the authors articulate several reasons why this is so. Although the article includes a discussion of the unique features of hydration and nutrition in newborns, it also includes a justification for when it is appropriate to withhold such interventions. The article would be very useful in discussing cases that involve withholding hydration and nutrition in newborns.

**Saigal S, Tyson J. Measurement of quality of life of survivors of neonatal intensive care: critique and implications. *Semin Perinatol* 2008;32:59-66**

Quality of life (QoL) and quality of care are of increasing interest to payers and consumers. This paper addresses the fact that there is no universal consensus on even the very definition of what constitutes QoL, particularly for children; discusses the conceptual framework and operational definitions of QoL and health-related quality of life (HRQL); addresses some methodological issues; and reviews the literature on QoL studies among premature infants. It concludes with a description of areas of research that are likely to be fruitful in advancing the consideration of QoL in future studies and in clinical practice.

**Singh J, Fanaroff J, Andrews B, et al. Resuscitation in the "gray zone" of viability: determining physician preferences and predicting infant outcomes. *Pediatrics* 2007;120:519-526**

Rather than accede to a parental request for a delivery room DNR for a preterm infant born between 23 and 24 weeks' gestation, neonatologists often prefer to "wait and see how the infant does." This article demonstrates that neither a 1- or 5-minute Apgar score nor a heart rate of 1 to 5 beats per minute are predictive of an infant's survival or significant handicap.

**Truog RD, Campbell ML, Curtis JR, et al. Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American College of Critical Care Medicine. *Crit Care Med* 2008;36:953-963.**

This document should be read by anyone who works in the ICU. Because 22% of deaths in the U.S. occur in the ICU and a much higher proportion of pediatric deaths occur there, competence in end-of-life care is required for ICU practitioners. This article reviews the ethical principles that would enable such competence for critical care clinicians and provides tools to enhance communication and limit suffering, enabling compassionate, family-centered care when a patient will die.

**Walters JW. Approaches to ethical decision making in the neonatal intensive care unit. *Am J Dis Child* 1988;142:825-830**

This older article effectively analyzes four theoretical standpoints from which to begin the process of decision-making for severely handicapped newborns. It is more effective than some other articles because of its case-based approach. The strengths and weakness of the traditional four positions -- value of life, parental authority, best interests, and personhood -- are presented well. The author also introduces a fifth approach -- proximate personhood -- which is believed to address some of the limitations of the other four positions. This is a brief, effective article that is useful for the analysis of decisions affecting not just newborns, but for any patient who has never been competent.

## **BOOKS AND BOOK CHAPTERS**

**Lantos JD, Meadow WL. *Neonatal Bioethics: The Moral Challenges of Medical Innovation*. Baltimore: Johns Hopkins University Press, 2006**

**Walco GA, Cassidy RC. The ethics of pain control in neonates and infant. In Anand KJ, Stevens BJ, McGrath PJ, eds. *Pain in Neonates (2nd ed)*. The Netherlands: Elsevier, 2000:229-235**

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## **VI. Organ Transplantation and Donation**

### **JOURNALS**

**American Academy of Pediatrics Committee on Bioethics. Ethical controversies in organ donation after circulatory death. *Pediatrics* 2013;131:1021-1026.**

The practice of controlled organ donation after circulatory death (DCD) is becoming more prevalent in an effort to increase the supply of scarce organs for transplantation. Controlled DCD involves organ recovery after the planned withdrawal of life-sustaining treatment and the declaration of death using cardiorespiratory criteria. This policy statement discusses two central ethical issues related to DCD: when organ recovery can begin and how to manage conflicts of interests. The authors argue for the maintenance of the “dead donor rule”, which allows the declaration of death only after the permanent cessation of circulatory function, which is generally established by a 2- to 5-minute waiting period. Because of the ongoing controversy over whether the cessation of circulatory function must also be irreversible, physicians should not be required to participate in DCD. Because the donor’s and recipient’s interests may potentially diverge, organ procurement organization personnel and members of the transplant team should not be involved in the discontinuation of life-sustaining treatment or the declaration of death.

**American Academy of Pediatrics Committee on Bioethics. Children as hematopoietic stem cell donors. *Pediatrics* 2010;125:392-404**

Hematopoietic stem cell transplantation has become standard treatment for a variety of diseases in children and adults. There are three sources of allogeneic hematopoietic stem cells: bone marrow, peripheral blood, and umbilical cord blood. Using a burden-benefit calculation from the perspective of both donor and recipient, this statement reviews the issues that arise when minors serve as hematopoietic stem cell donors, most commonly for siblings. The statement suggests a number of conditions that must be met in order for a minor to serve as a donor. It also examines what the informed consent process should entail, including the role for a donor advocate.

**American Academy of Pediatrics Committee on Hospital Care, Section on Surgery, and Section on Critical Care. Pediatric organ donation and transplantation. *Pediatrics* 2010;125:822-828**

Emphasizing the broad role that organ procurement organizations play in all aspects of organ donation, this policy statement concisely summarizes important practical considerations that the knowledge of which will enhance pediatricians’ contributions to organ donation and transplantation in children and adolescents.

**American Medical Association Council on Ethical and Judicial Affairs. Ethical considerations in the allocation of organs and other scarce medical resources among patients. *Arch Intern Med* 1995;155:29-40**

This position paper discusses ethically appropriate and inappropriate criteria for allocation of scarce medical resources. Ethically appropriate criteria include likelihood of benefit, urgency of need, change in quality of life, duration of benefit, and, in some cases, the amount of resources required. Ethically inappropriate criteria include ability to pay, social worth, perceived obstacles to treatment, patient contribution to illness, and past use of resources. The application of these criteria and appropriate decision-makers are also discussed. The appendix includes discussions on ethical issues in the allocation of intensive care and ethical issues in organ allocation. This is an excellent overview of potential allocation criteria and should be read by anyone who is involved in allocation decisions.

**Anderson-Shaw L, Orfali K. Child-to-parent bone marrow donation for treatment of sickle cell disease. *J Clin Ethics*. 2006;17:53-61**

Bone marrow transplantation (BMT) for sickle cell disease (SCD) in children has been done for the past 20 years with a greater than 80% cure rate and a 10% morbidity/mortality rate. BMT for adult SCD patients, however, has rarely ever been done. This article explores some of the ethical issues related to a minor child donating bone marrow for her mother with SCD and briefly explores the area of family decision-making.

**Bernat JL. Are organ donors after cardiac death really dead? *J Clin Ethics* 2006;17:122-132**

The Uniform Determination of Death Act defines death as the irreversible cessation of heartbeat and respiration or the irreversible cessation of the function of the entire brain including the brain stem. It is only when an individual is declared dead that a vital organ can be harvested for transplantation. There are some individuals, however, who are being kept alive by technology but for whom it is determined that the technology should be removed, knowing that the individual will die. Is there a possibility for such an individual to donate organs? Donation after cardiac death may provide such a possibility. The author reviews this concept in relation to how death is determined in clinical practice and discusses the distinction between permanence and irreversibility.

**Crouch RA, Elliott C. Moral agency and the family: the case of living related organ transplantation. *Camb Q Healthc Ethics* 1999;8:275-287**

This article notes that renal transplantation between minor siblings has been justified in terms of the psychological "best interests of the donor," and suggests that sharing B a critical operation in families Bis more important.

**Diekema DS, Joffe S, Vandeven AM, Lantos JD. Bone marrow donation between siblings living in different families. *Pediatrics* 2011;127:158-162.**

Minor siblings are often considered as potential bone marrow donors when a child needs a bone marrow transplant. The practice of using minors as bone marrow donors is ethically controversial, because there is some risk to the donor – and some pain and suffering – but no medical benefit. Nevertheless, most courts and most ethics committees have sanctioned bone marrow donation procedures as long as the donor and the recipient are in the same family and have an emotional tie. This paper presents a case involving a child in need of a bone marrow transplant for infantile osteopetrosis whose biological sibling is being raised in a different family. The authors discuss the ethical issues that arise when a biologically related sibling should be considered a bone marrow donor when the siblings may have no future relationship.

**Dwyer J, Vig E. Rethinking transplantation between siblings. *Hastings Cent Rep* 1995;25:7-19**

The authors present the standard approach taken B through informed consent, substituted judgment, or best interests Bwhen persons are placed at risk. Then they review two cases of renal

transplantation between siblings in which the standard approach was not satisfactory, and discuss how parents may reconcile their concerns for two of their children through a realization that family relationships justify imposing some risks, providing the expected benefits are substantial.

**Glannon W, Ross LF. Do genetic relationships create moral obligations in organ transplantation? *Camb Q Healthc Ethics* 2002;11:153-159**

The authors contrast organ donations occurring in intimate relationships with those made altruistically.

**Price DP. Minors as living donors: ethics and law. *Transplant Proc* 1996;28:3607- 3608**

The author acknowledges the rarity of nonregenerative organ donation by minors, identifies legislation developed in many countries that specifically prohibits or permits such practice, presents a concise discussion that supports donation by competent minors, and examines critically the concept of "benefit" from donation by incompetent minors.

**Robertson JA, Kahn JP, Wagner JE. Conception to obtain hematopoietic stem cells. *Hastings Cent Rep* 2002;32:34-40**

Parents who have a child with a disease that can be effectively treated with stem cell transplantation may choose to conceive a child who can serve as the donor. This article discusses the use of prenatal diagnosis or preimplantation genetic diagnosis to assure HLA compatibility and freedom from autosomal recessive disease. It also explores parental discretion and obligation to reproduce for this purpose and considers a variety of possible outcomes for the fetus or infant.

**Ross LF, Thistlethwaite JR Jr, and the American Academy of Pediatrics Committee on Bioethics. Minors as living solid-organ donors. *Pediatrics* 2008;122:454-461**

This clinical report includes a discussion of the ethical considerations regarding minors serving as living donors, using the traditional benefit/burden calculus from the perspectives of both the donor and the recipient. The report also includes an examination of the circumstances under which a minor may morally participate as a living donor, how to minimize risks, and what the informed-consent process should entail. The American Academy of Pediatrics holds that minors can morally serve as living organ donors but only in exceptional circumstances when specific criteria are fulfilled.

**Ross LF. Moral grounding for the participation of children as organ donors. *J Law Med Ethics* 1993;21:251-257**

The author reviews distinctions between the best-interest standards to which intimate and formal guardians should be held in the process of considering whether certain minors may become organ donors. She argues that respect for persons can be accomplished in the setting of intrafamilial organ donation: as the donor advances the family's interests, the donor's own interests are promoted as well. Further discussion suggests that, for donations of minimal or slightly greater than minimal risk, parental permission alone is necessary and sufficient. Organ donations involving



significant risk would be limited to adolescents who have become capable of giving informed consent and would require permission from an intimate guardian as well.

**Siminoff LA, Chillag K. The fallacy of the "gift of life." *Hastings Cent Rep* 1999;29:34-41**

The authors review the organ donation experience of families and the transplant experience of recipients and illuminate the sense of obligation that adult organ recipients are noted to develop to donors and donors' families, as well as the recipients' dependency on the transplantation team. As this article appears to be based entirely on observations of adult recipients, caution is needed in applying the discussion to children who receive transplants.

**Spital A. Should children ever donate kidneys? Views of US transplant centers. *Transplantation* 1997;64(2):232-236**

This survey of 117 U.S. pediatric renal transplant centers found that, for patients younger than 18 years, 33% would allow monozygotic twin-to-twin donation and 21% would allow non-twin-to-sibling donation. Sixty-eight percent of centers require all donors to be 18 or older. The author provides a useful discussion of the major ethical issues, focusing on a minor's competency, the voluntary nature of the decision, and the health risks of uninephrectomy.

**Truog RD, Cochrane TI. The truth about "donation after cardiac death." *J Clin Ethics* 2006;17:133-136**

In this article the authors argue that the dead donor rule is a poor basis by which to obtain organs, that patient prognosis and wishes should be the focus, and that donation after cardiac death does not serve the interests of those who wish to donate. This is a nice companion article to Bernat's article entitled "Are organ donors after cardiac death really dead?"

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## **VII. Enhancement Therapies**

### **A. General considerations**

#### **JOURNALS**

**Parens E. Is better always good? The Enhancement Project. *Hastings Cent Rep* 1998;28(1):S1-S17**

This is an excellent introduction and overview of the philosophical and ethical issues important for an understanding of treatment versus enhancement in medical practice. The author discusses questions like: "What is normal?" "What does it mean to be authentic?" "How does enhancement exacerbate unfairness, complicity, and inauthenticity?" This article is a valuable foundation for anyone interested in further conversation about what limits to place on new biotechnologies and for greater understanding of the potential dangers ahead as such technologies reach the marketplace.

## **B. Growth hormone**

### **JOURNALS**

**Allen DB, Fost NC. Growth hormone therapy for short stature: panacea or Pandora's box? *J Pediatr* 1990;117:16-21**

This is a useful companion to the article by Lantos et al (cited below). The authors argue that growth hormone responsiveness, not deficiency, is the proper criterion for growth hormone treatment provided a handicap is present. They define a height handicap as height below the 1st percentile and believe that children meeting that requirement are entitled to treatment, if they prove to be growth hormone responsive. They also argue that a child's diagnosis should be irrelevant in determining eligibility for treatment.

**Lantos J, Siegler M, Cuttler L. Ethical issues in growth hormone therapy. *JAMA* 1989;261:1020-1024**

Though published in 1989, this article is a very well-reasoned analysis of issues that should be considered when evaluating a new therapy that addresses enhancement rather than disease. The situation here is the use of growth hormone therapy in non- growth hormone-deficient short children. The ethical implications of decisions regarding growth hormone treatment are reviewed and should be part of any discussion of enhancement therapies.

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## **C. Performance enhancement**

### **JOURNALS**

**Diller LH. The run on Ritalin: attention deficit disorder and stimulant treatment in the 1990s. *Hastings Cent Rep* 1996;26(2):12-18.**

The author examines the medical and social context for the striking increase in prescriptions for Ritalin in the 1990s. Pressures on physicians and educators in a time of increasing pupil/teacher ratios, the tendency to "medicalize" output problems in children and adults, the increasing acceptance of medication to treat problems in behavior and performance, the supporting role of mass media, and the tendency to ignore social and environmental factors contributing to attention deficits are elaborated upon. The final section of the paper raises some specific ethical concerns. This article would be very useful in a discussion of the ethics of prescribing performance-enhancing medications.

**Whitehouse PJ, Jeungst E, Mehlman M, Murray TH. Enhancing cognition in the intellectually intact. *Hastings Cent Rep* 1997;27(3):14-22.**

The authors first review the biological basis of cognition and current uses of cognitive enhancers. They then discuss philosophical issues, for example, whether there is an "optimum norm for cognition in human beings" and how society's obligation to provide for cognitive enhancement should be defined, if such an obligation exists. Potential moral pitfalls, as well as legal implications, are also addressed. The authors conclude that public analysis and discussion are needed before society seeks to develop and regulate cognitive enhancers, with attention to their impact on "social institutions," rather than simply the "tension between individual liberty and paternalism." This article would be a useful way to introduce the philosophical issues surrounding the use of cognitive enhancers.

# ALLOCATION OF HEALTH CARE RESOURCES

## VIII. Just Allocation of Health Care

### JOURNALS

**American Medical Association Council on Ethical and Judicial Affairs. Ethical considerations in the allocation of organs and other scarce medical resources among patients. *Arch Intern Med* 1995;155:29-40**

This position paper discusses ethically appropriate and inappropriate criteria for allocation of scarce medical resources. Ethically appropriate criteria include likelihood of benefit, urgency of need, change in quality of life, duration of benefit, and, in some cases, the amount of resources required. Ethically inappropriate criteria include ability to pay, social worth, perceived obstacles to treatment, patient contribution to illness, and past use of resources. The application of these criteria and appropriate decision-makers are also discussed. Two sections of the article are devoted to ethical issues in the allocation of intensive care and ethical issues in organ allocation. This is an excellent overview of potential allocation criteria and should be read by anyone who is involved in allocation decisions.

**Cassel CK, Brennan TE. Managing medical resources: return to the commons? *JAMA* 2007;297:2518-2521**

This article is very useful for a discussion of the role of physicians in the just allocation of health care. It is an excellent update of Hiatt's classic discussion of protecting the medical commons published in the mid-70s in the *New England Journal of Medicine*. The authors review the ethical issues involved and argue for a professional responsibility to think beyond the bedside to establish and protect the medical commons.

**Daniels N. Justice, fair procedures, and the goals of medicine. *Hastings Cent Rep* 1996;26(6):10-12**

This short commentary responds to calls for social conversations about medicine's goals as a way to reconfigure health care delivery by calling for insurers and managed care organizations to adopt publicly accountable procedures for treatment coverage decisions. It discusses the limits of the conceptual frameworks of distributive justice and the goals of medicine. As a practical alternative, the author suggests that insurers make public their decisions, and the reasons behind them, for limiting coverage. The author suggests that over time these public decisions and reasons would establish a form of "case law" that will facilitate social conversation on the goals of medicine.

**Diekema DS. Children first: the need to reform financing of health care services for children. *J Health Care Poor Underserved* 1996;7:3-14**

Many children in the United States live in poverty, lack health insurance, and receive inadequate health care. Current methods of financing health care fail to provide adequately for the needs of children. This paper argues that on the basis of the moral principles of beneficence and justice, adult members of society have a duty to assure that all children receive at least a basic level of health care. He further argues that this is a societal duty, not one to be left to parents, and that any health care reform should assure health care coverage of all children, that health insurance plans must guarantee access and adequate coverage for important medical needs of children, and that out-of-pocket expenditures must not discourage the use of effective health care for children.

**Eddy DM. Clinical decision making: from theory to practice. Principles for making difficult decisions in difficult times. *JAMA* 1994;271:1792-1798**

This article offers eleven principles to guide the debates on treatment evidence and cost containment. Beginning with the principle that financial resources for health care are limited, the article offers ten more principles on how to set priorities for equal distribution of services that maximize the health of the population served. The article argues that treatment priorities must be based on empirical evidence of the costs and benefits and patient preference rather than on individual patients. Further, the burden of proof of a particular treatment rests with those who are promoting it.

**Levine MA, Wynia MK, Schyve PM, et al and the Ethical Force Program. Improving access to health care: A consensus ethical framework to guide proposals for reform. *Hastings Cent Rep* 2007;37:14-19**

This consensus ethical framework for health care reform was developed by the multi-stakeholder Ethical Force Program of the Institute for Ethics at the American Medical Association. It is very useful to help discuss ethical issues in access to health care for two major reasons. First, it is very practical and avoids overly theoretical discussions of justice. Secondly, it is based on a broad consensus of stakeholders and thereby helps to avoid the polarizing political debates that often surround discussions of justice and access to health care. In addition to identifying the participants, the article also includes four key ethical obligations and recommendations that follow from them to guide health care reform. These obligations and recommendations are based on three core American values that are at stake: equality of opportunity, justice, and compassion.

## **BOOKS AND BOOK CHAPTERS**

**Fleck LM. *Just Caring: Health Care Rationing and Democratic Deliberation*. New York: Oxford University Press, 2009**

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## IX. Managed Care Issues

### JOURNALS

**American Academy of Pediatrics Committee on Child Health Financing. Guiding principles for managed care arrangements for the health care of newborns, infants, children, adolescents, and young adults. *Pediatrics* 2006;118:828-833**

Managed care has the potential to increase access to health care professionals and services by including the precepts of primary care and the medical home in the delivery of health care. However, patient and physician disincentives could result in underutilization of such services. This policy statement discusses the principles of managed care for children, including principles related to access to primary care pediatricians, access to pediatric specialty services, treatment authorization, quality of care, and financing and payment. Any physician enrolled in a managed care plan should be familiar with these principles.

**Andereck WS. Commodified care. *Camb Q Healthc Ethics* 2007;16:398-406**

This is a very readable and provocative essay about being a physician in a world where care is a commodity. The author discusses the essential components of a commodity as quantifiability and fungibility – neither of which is totally applicable to healing. This article can be very useful to encourage discussion about the current health care market among residents.

**Emanuel EJ. Justice and managed care: four principles for the just allocation of health care resources. *Hastings Cent Rep* 2000;30(3):8-16**

This article offers four principles for the just allocation of resources that the author attempts to ground in the practical context of the American health care system. The four principles are the following: 1) improving health should be the primary goal; 2) patients and members of managed care organizations should be informed about the allocation of health care resources and underlying justifications; 3) patients and members should have the opportunity to consent to the allocation of resources that will affect them; and 4) conflicts of interest should be minimized. From this premise, the author goes on to discuss the implications of these principles for managed care in relation to consent regarding allocation decisions, the market, and the appeals process. The discussion concludes with commentary on management of conflict of interests.

**Emanuel EJ, Dubler NN. Preserving the physician-patient relationship in the era of managed care. *JAMA* 1995;273:323-329**

This article maintains that the patient-physician relationship is the cornerstone of health care. It outlines the ideal conception of patient-physician relationship from which to gauge the impact of the expansion of managed care: “choice, competence, communication, compassion, continuity, and (no) conflict of interest.” The article discusses the potential costs and benefits of managed care to these aspects of the patient-physician relationship. It recognizes the potential of managed care to

secure choice and expand continuity for patients but cautions that managed care's emphasis on price competition could ultimately erode the ideal patient–physician relationship. It offers seven recommendations to protect against this.

**Hall MA, Berenson RA. Ethical practice in managed care: a dose of realism. *Ann Intern Med* 1998;128:395-402**

How can society, and physicians specifically, deal with the ethical dilemmas posed by managed care? While resource allocation is a real problem faced by health care as an institution, the article questions the ethical problems faced by physicians when responsible for "bedside rationing." The authors provide a broad discussion of the dilemma presented by financial incentives, as well as practical ways of managing it.

**Lazarus JA, Sharfstein SS. Ethics in managed care. *Psychiatr Clin North Am* 2002;25:561-574**

This article is a very practical review of the ethical issues that arise for psychiatrists in managed care. It is well written and includes case examples involving confidentiality, conflicts of interest, informed consent, double agency, honesty, interference in the doctor-patient relationship, and relationships with other mental health professionals. It would be very useful in a discussion of managed care issues with residents in psychiatry.

**Rodwin MA. Medical commerce, physician entrepreneurialism, and conflicts of interest. *Camb Q Healthc Ethics* 2007;16:387-397**

This article provides a very helpful historical perspective on medicine and commercialism. The author divides medical commerce and entrepreneurialism in America into three phases: Phase I – From the Colonial Period through the 19th century; Phase II – Medicine in the first half of the 20th century; Phase III – Medicine in the second half of the 20th century. Medicine is much more commercial today than in the past. This author argues that the central problem of commercialism is physician entrepreneurship and the conflicts of interest that it promotes. This historical perspective is very useful for residents to understand how American medicine developed in order to reflect on possible guidelines to address conflicts of interest.

## **BOOKS AND BOOK CHAPTERS**

**Morreim EH. *Balancing Act: The New Medical Ethics of Medicine's New Economics*. Dordrecht, The Netherlands: Kluwer Academic Publishers, 1991**

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# PROFESSIONALISM AND INSTITUTIONAL ETHICS

## X. Cultural, Religious, and Spiritual Issues

### JOURNALS

**American Academy of Pediatrics Committee on Bioethics. Ritual genital cutting of female minors. *Pediatrics* 2010;125:1088-1093**

In this revised policy statement, the forms of traditional female genital surgery are described, and the relevant cultural and ethical issues are briefly discussed. The commentary focuses attention on using culturally sensitive educational programs as a means of reducing demand for surgery that is illegal in the United States. This revision made brief reference to the suggestion of some authors that offering a “ritual nick” of the clitoral hood might offer a non-mutilating alternative that would satisfy the cultural needs of some families and prevent a more dangerous and genital-altering procedure. The statement concludes that the American Academy of Pediatrics (AAP) opposes all types of female genital cutting (FGC) that pose risks of physical or psychological harm, counsels its members not to perform such procedures, recommends that its members actively seek to dissuade families from carrying out harmful forms of FGC, and urges its members to provide patients and their parents with compassionate education about the harms of FGC while remaining sensitive to the cultural and religious reasons that motivate parents to seek this procedure for their daughters.

Note: The discussion of a “ritual nick” resulted in significant controversy that led the AAP Board to retract the statement several weeks following its publication and to replace it with the following statement: “The AAP reaffirms its strong opposition to FGC and counsels its members not to perform such procedures. As typically practiced, FGC can be life-threatening. Little girls who escape death are still vulnerable to sterility, infection, and psychological trauma. The AAP does not endorse the practice of offering a ‘clitoral nick.’ This minimal pinprick is forbidden under federal law and the AAP does not recommend it to its members. The AAP is steadfast in its goal of protecting all young girls from the harms of FGC.”

**American Academy of Pediatrics Committee on Bioethics. Conflicts between religious or spiritual beliefs and pediatric care: informed refusal, exemptions, and public funding. *Pediatrics* 2013;132:962-965.**

Religion plays an important role in the lives of many individuals and families, and some parents’ reasons for refusing medical treatment are based on their religious or spiritual beliefs. Although respect for parents’ decision-making authority is an important principle, pediatricians should report suspected cases of medical neglect and the state should at times intervene to require medical treatment of children, particularly in cases in which treatment is likely to prevent death or serious disability or relieve severe pain. This policy statement argues that because religious exemptions to child abuse and neglect laws do not equally protect all children and may harm some children by causing confusion about the duty to provide medical treatment, these exemptions should be



repealed. It also argues that public health care funds should not cover alternative unproven religious or spiritual healing practices because such payments may inappropriately legitimize these practices as appropriate medical treatment. All pediatricians should be familiar with this very important policy statement.

**Barnes LL, Plotnikoff GA, Fox K, Pendleton S. Spirituality, religion, and pediatrics: intersecting worlds of healing. *Pediatrics* 2000;106(suppl):899-908**

This is an excellent article introducing residents (and practitioners) to some ways that spirituality can be incorporated into medical practice. This article is unique in that it encourages physicians to think of patient and family spirituality outside the traditional "death and dying" context.

**Beach MC, Price EG, Gary TL, et al. Cultural competence: A systematic review of health care provider educational interventions. *Medical Care* 2005;43:356-373**

This review of 34 studies of cultural competence training published between 1980 and 2005 examines critically their impact on several important outcome measures and will be of value to those planning and evaluating similar programs.

**Flores G. Culture and the patient-physician relationship: achieving cultural competency in health care. *J Pediatr* 2000;136:14-23**

Among the topics considered in this discussion about achieving cultural competency in health care, two are of particular usefulness. Clear descriptions of Latino normative cultural values – *simpatia*, *personalismo*, *respeto*, *familismo*, and *fatalismo* – and their clinical consequences offer background that may enhance the quality of cross-cultural practice. In addition, several childhood folk illnesses are presented with recommendations for culturally sensitive approaches to their clinical management.

**Hatano Y, Yamada M, Fukui K. Shades of truth: cultural and psychological factors affecting communication in pediatric palliative care. *J Pain Symptom Manage* 2011;41:491-495**

Although only a case study, this paper presents an interesting discussion of the ways in which the individual needs of the child, cultural norms, associated parental preferences, and Western bioethical mores can be honored in an attempt to produce the least bad outcome. This is a good paper for teaching about cultural differences and honoring the individual.

**Hedayat KM, Pirzadeh R. Issues in Islamic biomedical ethics: a primer for the pediatrician. *Pediatrics* 2001;108:965-971**

The authors concisely review aspects of the Islamic faith, present a developmentally oriented approach to medical issues that are affected by Islamic ethical principles, and discuss an array of specific topics, knowledge of which should benefit cross-cultural care of Muslims.

**Lane SD, Rubenstein RA. Judging the other: responding to traditional female genital surgeries. *Hastings Cent Rep* 1996;26(3):31-40**

The authors present a detailed commentary on the history and practice of traditional female genital surgery and examine the impasse that results from framing debate about it in terms of ethical universalism or cultural relativism. An interesting and practical framework is provided for attending to this and other intercultural issues that arise in clinical medicine.

**Macklin R. Ethical relativism in a multicultural society. *Kennedy Inst of Ethics J* 1998;8:1-22**

Acknowledging that cultural change usually comes from within, the author examines autonomous versus family-centered models in determining how patients and families communicate with physicians. In addition, drawing examples from diverse cultural and religious groups – Voodoo, Native American, Santería, and Lu Mien – she focuses on cross-cultural tolerance of the beliefs and practices of others that can harm patients. In arguing against allowing cultural relativism to overwhelm common sense, she distinguishes between equality in the treatment of different groups and equality in the acceptance of their practices.

**MacLean CD, Susi B, Phifer N, Schultz L, Bynum D, Franco M, Klioze A, Monroe M, Garrett J, Cykert S. Patient preference for physician discussion and practice of spirituality. *J Gen Intern Med*. 2003;18:38-43**

For many, religion and spirituality are an important part of their lives. These authors explore patient preferences for addressing religion and spirituality in the medical encounter. They surveyed patients at 6 academic primary care clinics. Sixty-six percent of patients surveyed felt that their physician should be aware of their religious/spiritual beliefs with 10% willing to give up time spent discussing medical issues in order to discuss religious/spiritual issues. African-American patients were more likely to accept this time trade-off than non-African-American patients. Patients' interest in spiritual dialogue increased as the severity of the illness increased. This study is a good reminder of the importance of religion/spirituality for many of our patients and their families.

**Orr RD, Marshall PA, Osborn J. Cross-cultural considerations in clinical ethics consultations. *Arch Fam Med* 1995;4:159-164**

Using four adult clinical case vignettes, the authors illustrate the importance of effective communication, sensitivity to cultural background, identification of cultural value conflicts and course of action, and a willingness to compromise in cross-cultural encounters between patients and physicians.

**Paasche-Orlow M. The ethics of cultural competence. *Acad Med* 2004;79:347-350**

The author argues that there are ethical reasons to be culturally competent: patient-centeredness; enhanced ability to support choices that would not be the recommendation of the medical culture; and understanding of potential resistances to “optimal care” – to enable the patient to have the best outcome possible within his or her values. The author distinguishes between cultural competence and moral relativism. This article will provoke those who teach about cultural competency to think more broadly and more convincingly about the importance of their mission.

**Post SG, Puchalski CM, Larson DB. Physicians and patient spirituality: professional boundaries, competency, and ethics. *Ann Intern Med* 2000;132:578-583**

This brief article addresses the importance of acknowledging patient spirituality while avoiding coercion or boundary violations. It is most useful for its guidance in responding to patient/family requests for physician prayer.

**Robinson MR, Thiel MM, Backus MM, Meyer EC. Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics* 2006;118:e719-e729**

The purpose of this study was to examine the nature and the role of spirituality and religion at the end of life from the parents' perspective. The authors administered parent self-report questionnaires to 56 parents of children who had died in an ICU after forgoing life-sustaining treatment. The questionnaire was administered 12 to 45 months after the child's death. For many parents, spiritual/religious themes played a role in making end-of-life decisions, in finding meaning in loss, and in sustaining them emotionally. Four explicit spiritual/religious themes were present: 1) the importance of prayer, 2) the parents' faith in God, 3) the need to have access to clergy (family clergy and hospital chaplains), and 4) the transcendent nature of the parent- child relationship. Additional themes included personal values, hope and trust, and compassion. This study highlights the importance of developing a hospitable culture in the ICU for parents to be able to express spiritual/religious concerns and to be respected in their struggle.

**Ross LF, Aspinwall TJ. Religious exemptions to the immunization statutes: balancing public health and religious freedom. *J Law Med Ethics* 1997;25:202-209**

Does a parent's failure to obtain immunizations for his/her children because of religious convictions constitute medical neglect? Should religious exemptions to childhood immunizations be repealed to protect the public health? How should the values of family autonomy and religious freedom be balanced with the public good? The authors of this article offer five possible approaches to immunizations and religious exemptions and conclude that maintaining the status quo with an emphasis on immunizing nonexempt children is the most morally acceptable approach. This article should be read in conjunction with the AAP statement on religious objections to medical care.

**Sheldon M. Ethical issues in the forced transfusion of Jehovah's Witness children. *J Emerg Med* 1996;14:251-257**

Physicians generally turn to the parents of a minor child to help define what is in the child's best interest. But how should best interest (harms, benefits, well-being) be defined when the parents are coming from an eternal perspective and the physician is coming from a temporal perspective? This article is a succinct review of Jehovah's Witnesses' beliefs, applicable legal concepts, and arguments in favor of forced blood transfusions for minor children of Jehovah's Witness parents. Since no one truly knows what is in a child's best interest, the state's responsibility should be to preserve the future autonomy of the child. This article should be read by all who care for the children of Jehovah's Witness parents.

Sloan RP, Bagiella E, Powell T. Religion, spirituality, and medicine. *Lancet* 1999;353:664-667

Sloan et al review the empirical evidence of religion's effect on health outcomes. Although it is not a systematic review, the authors present a good overview of the literature on the connections between spirituality and health and its limitations. In light of their findings, the authors argue caution for physicians in promoting spirituality to patients or families solely to improve health.

## BOOKS AND BOOK CHAPTERS

American Medical Association. *Cultural Competence Compendium*. Chicago: American Medical Association, 1999 [Note: This is primarily a listing of other resources.]

Diekema DS, Marcuse EK. Ethical issues in the vaccination of children. *Primum non nocere Today* (2nd ed). Edited by GR Burgio and JD Lantos. Amsterdam: Elsevier Science B.V., 1998:37-47

Fadiman A. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*. New York: Farrar, Straus & Giroux, 1997

Galanti G. *Caring for Patients from Different Cultures* (3rd ed). Philadelphia: University of Pennsylvania Press, 2003

Hayes-Bautista D, Chiprut R. *Healing Latinos: Realidad y Fantasia: The Art of Cultural Competence in Medicine*. Los Angeles: Cedars-Sinai Health System, 1998

Infield DL, Gordon AK, Harper CB, eds. Identifying and meeting needs of ethnic minority patients. In *Hospice Care and Cultural Diversity*. New York: Haworth Press, 1995

The Cross Cultural Health Care Program. *Death and Dying in Ethnic America: A Research Study*. Seattle: The Cross Cultural Health Care Program, 2000

Wolf SM, ed. *Feminism and Bioethics*. New York: Oxford University Press, 1996

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## XI. Family-Centered Care

### JOURNALS

American Academy of Pediatrics Committee on Hospital Care and Institute for Patient- and Family-Centered Care. Patient- and family-centered care and the pediatrician's role. *Pediatrics* 2012;129:394-404

This policy statement outlines the core principles of patient- and family-centered care, summarizes

some of the recent literature related to patient- and family-centered care, and lists various other benefits to be expected when engaging in patient- and family- centered care practice. The statement concludes with specific recommendations for how pediatricians can integrate patient- and family-centered care in hospitals, clinics, and community settings, and broader systems of care as well.

**American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health. The pediatrician and childhood bereavement. *Pediatrics* 2000;105:445-447**

In a society in which death is rarely discussed, how to respond to a death remains unclear. It is clear that children have long-term and potentially adverse outcomes associated with bereavement. This paper provides advice to the pediatrician regarding how to respond to the questions parents and school personnel have about the child's reactions to the death of a loved adult. Key childhood issues such as the need for honesty, reassurance of security, the need for the child to be told that he or she was not at fault, and the developmental spectrum of the concept of death and the need to respond accordingly are addressed in this key reference. Excellent resources are also listed for parental intervention with children.

**Beach MC, Inui T, and the Relationship-Centered Care Research Network. Relationship-centered care. A constructive reframing. *J Gen Intern Med* 2006;21:S3–S8**

All illness, care, and healing processes occur in relationships of an individual with self and with others. Relationship-centered care (RCC) is a clinical philosophy that stresses partnership, careful attention to relational process, shared decision-making, and self-awareness. Relationship is a missing element in medicine as practiced today. This paper returns us to the roots from which we grew and provides a framework to better meet the needs and expectation of our patients and their families. This paper is recommended for all health care providers.

**Levetown M, and the American Academy of Pediatrics Committee on Bioethics. Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Pediatrics* 2008;121:e1441-e1460**

This article provides a review of the evidence regarding clinical communication in the pediatric setting, covering the spectrum from outpatient primary care consultation to death notification, and provides practical suggestions to improve communication with patients and families, enabling more effective, efficient, and empathetic pediatric health care.

## **BOOKS AND BOOK CHAPTERS**

**Levetown M, Carter MA. Child-centered care in terminal illness: an ethical framework. In Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine (2nd ed)*. Oxford, England: Oxford University Press, 1998:1107- 1117**

**Nelson HL, Nelson JL. *The Patient in the Family: An Ethics of Medicine and Families*. New York: Routledge, 1995**

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## **XII. Institutional Ethics Committees and Ethics Consultation**

### **JOURNALS**

**American Academy of Pediatrics Committee on Bioethics. Institutional ethics committees. *Pediatrics* 2001;107:205-209**

This statement discusses the roles of an institutional ethics committee, its membership and structure, and expectations for those serving on such a committee. Specific recommendations are made at the end. This statement will be useful for those planning to form or to serve on an institutional ethics committee.

**Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med* 2007;35:605-622**

This article recognizes the stress and emotional turmoil associated with ICU admission for both patients and families and presents evidence-based recommendations to improve care, relationships, and outcomes for patients, families, and staff. Topics addressed include decision-making, family coping, staff stress related to family interactions, cultural support, spiritual/religious support, family visitation, family presence on rounds, family presence at resuscitation, family environment of care, and palliative care. This should be required reading for anyone rendering care in an ICU setting.

**Fleetwood JE, Arnold RM, Baron RJ. Giving answers or raising questions? The problematic role of institutional ethics committees. *J Med Ethics* 1989;15:137-142**

The authors provide a succinct discussion of the origin, roles, and composition of institutional ethics committees with attention to the potential pitfalls confronting them, particularly the variety of institutional pressures to provide answers rather than to raise ethical questions that make decision-making more complex. The value of process and pluralism is emphasized.

**Fox E, Berkowitz KA, Chanko BL, Powell T. *Ethics Consultation: Responding to Ethics Questions in Health Care*, a primer for ethics consultants featuring the CASES approach. National Center for Ethics in Health Care, Veterans Health Administration.**

This primer for ethics consultants presents an approach to ethics consultation that is well-organized and user-friendly. These materials introduce the CASES approach to ethics consultation that includes clarifying the consultation request, assembling the relevant information, synthesizing the information, explaining the synthesis, and supporting the consultation process. The materials, available for downloading from the Web site, provide detailed instructions for each step and useful tools for the ethics consultant.

**La Puma J, Schiedermayer DL. Ethics consultation: Skills, roles, and training. *Ann Intern Med* 1991;114:155-160**

This classic paper reviews the role of the ethics consultant and the skills and training necessary to effectively carry out that role. The authors argue that an ethics consultant must have the ability to identify and analyze ethical problems, use reasonable clinical judgment, communicate effectively, negotiate and facilitate negotiations, and teach others about how to apply ethical frameworks to clinical decision-making. Training must include instruction in patient care, health care law, moral reasoning, and medical humanities.

**Lyren A, Ford PJ. Special considerations for clinical ethics consultation in pediatrics: pediatric care providers as advocate. *Clin Pediatr (Phila.)* 2007;46:771- 776**

This article reviews the differences between medical decision-making for adults and medical decision-making for children, the basic ingredients of a pediatrics ethics consultation, the various models of ethics consultation (individual consultant, full ethics committee, and a small group), the criterion to be considered in selecting ethics consultants, and the importance of ongoing evaluation and improvement of pediatric ethics consultation services.

**Schenkenberg T, Kochenour NK, Botkin JR. Ethical considerations in clinical care of the “VIP.” *J Clin Ethics* 2007;18:56-63.**

This article is a thoughtful discussion of the ethical issues that arise in the treatment of VIP patients – including a broad definition of VIP and the effects on the VIPs, other patients, the clinicians and the institution. Special mention is made of the issues in the emergency department and in psychiatric settings. Although it does not mention the issue of treating the children of VIPs, the issues raised could easily be applied in pediatrics. This is a very thorough article that could be used for discussion if the issue arises in your facility.

## **BOOKS AND BOOK CHAPTERS**

**American Society for Bioethics and Humanities Core Contemporary Task Force. *Core Competencies for Healthcare Ethics Consultation (2nd ed)*. Glenview, IL: American Society for Bioethics and Humanities, 2011**

**Aulisio MP, Arnold RM, Youngner SJ. *Ethics Consultation: From Theory to Practice*. Baltimore: Johns Hopkins University Press, 2003**

**Gawande A. *Better: A Surgeon’s Notes on Performance*. New York: Metropolitan Books: Henry Holt and Company, LLC, 2007**

**Groopman J. *How Doctors Think*. New York: Houghton Mifflin Company, 2007**

**Hester D, ed. *Ethics by Committee: A Textbook on Consultation, Organization, and Education for Hospital Ethics Committees*. Lanham, MD: Rowman and Littlefield Publishers, 2007**

Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* (7th ed). New York: McGraw-Hill, 2010

Jonsen AR, Veatch RM, Walters L, eds. *Source Book in Bioethics: A Documentary History*. Washington, DC: Georgetown University Press, 1998

Jonsen AR. *A Short History of Medical Ethics*. New York: Oxford University Press, 2000

Lo, B. *Resolving Ethical Dilemmas: A Guide for Clinicians* (5th ed). Philadelphia: Lippincott Williams and Wilkins, 2013

Ross JW, Glaser JW, Rasinski-Gregory D, Gibson JM, Bayley C. *Health Care Ethics Committees: The Next Generation*. American Hospital Publishing, 1993

Schechter NL, Berde CB, Yaster M, eds. Pain in infants, children, and adolescents: an overview. In *Pain in Infants, Children, and Adolescents*. Baltimore: Williams and Wilkins, 1993:3-9

Tivnan E. *The Moral Imagination: Confronting the Ethical Issues of Our Day*. New York: Simon & Schuster, 1995

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## **XIII. Professionalism**

### **A. General issues**

#### **JOURNALS**

**American Academy of Pediatrics Committee on Bioethics. Pediatrician-family- patient relationships: managing the boundaries. *Pediatrics* 2009;124:1685-1688**

Trust and objectivity are key elements in the therapeutic relationship. These elements may be compromised by personal relationships with patients and their family members; by confusing or offensive words, body language, or touching; and by non- monetary payments and gifts. Romantic and/or sexual relationships with patients are always inappropriate. This AAP statement is an excellent overview of the potential conflicts when appropriate boundaries in the pediatrician-family- patient relationship are not in place.

**American Academy of Pediatrics Committee on Bioethics. Physician refusal to provide information or treatment on the basis of claims of conscience. *Pediatrics* 2009;124:1689-1693**

Health care professionals with moral objections to particular medical interventions may refuse to provide or cooperate in the provision of these interventions. Conflicts arise when claims of



conscience impede a patient's access to medical information or care. This committee policy statement recognizes the importance of an individual physician's integrity but argues that conscientious objection may need to be limited under certain circumstances. Physicians have a duty to disclose to prospective patients the treatments they refuse to perform. As part of informed consent, physicians also have a duty to inform their patients of all relevant and legally available treatment options, including options to which they object. They have a moral obligation to refer patients to other health care professionals who are willing to provide those services when failing to do so would cause harm to the patient, and they have a duty to treat patients in emergencies when referral would significantly increase the probability of mortality or serious morbidity. Finally, the committee argues that the health care system should make reasonable accommodations for physicians with conscientious objections.

**American Academy of Pediatrics Committee on Bioethics, Fallat ME, Glover J. Professionalism in pediatrics: statement of principles. *Pediatrics* 2007;120:895-897**

This brief paper expounds on the principles of professionalism put forth by the American Board of Pediatrics, with further elaboration in an accompanying paper. Emphasizing the developmental and interpersonal dynamic differences between pediatric and adult practices, this is a succinct reminder of our most basic obligations as physicians.

**American Academy of Pediatrics Committee on Bioethics, Fallat ME, Glover J. Professionalism in pediatrics. *Pediatrics* 2007;120:e1123-e1133**

This paper expands on the article above ("Professionalism in pediatrics: statement of principles") by the same authors, using concrete topics and examples under the broad headings; obligations to patient's families and communities (broken further into subheadings, including resolving conflicting goals of care, boundaries in patient care, advocacy); medical school teaching faculty responsibilities to residents and students (including modeling appropriate behavior, caring, and compassion); responsibilities to the other members of the health care team; responsibilities to the profession (including peer review and medical testimony); and industry and potential conflict of interest.

**American College of Physicians Ethics and Human Rights Committee, Snyder L, Leffler C. Ethics manual: fifth edition. *Ann Intern Med* 2005;142:560-582**

This manual is a comprehensive but succinct review of most key issues in clinical bioethics, including professionalism, the physician-patient relationship, confidentiality, informed consent, genetic testing, medical risk to physician and patient, complementary and alternative care, boundary issues, care of patients near the end of life, organ donation, euthanasia, financial conflicts of interest, obligations of the physician to society, resource allocation, relation of the physician to government, expert witness testimony, relationship to other clinicians, the impaired physician, and human subjects research. In addition, there is a helpful appendix on "A Case Method to Assist with Clinical Ethics Decision Making." This excellent manual should be read by all physicians.

**Answering parents' questions. *J Clin Ethics* (special section) 2003;14:59-87**

Have you ever been asked: “Doctor, if this were your child, what would you do?” How did you respond? Should such a question be ignored, or should you freely reveal what you would do for your child based not only on the medical facts but also on your personal and family values? What is the true meaning behind such a question, and how would you go about exploring that meaning? This special section of *The Journal of Clinical Ethics* contains commentaries by leading ethicists that explore the many facets of this question. This is a must read for all clinicians, generalists as well as subspecialists.

**Berg SL. Ethical challenges in cancer research in children. *Oncologist* 2007;12:1336- 1343**

Clinical research has led to great advances in cancer therapy for children, and a greater proportion of children than adults with cancer participate in clinical trials. Despite this success, there remain important ethical challenges in conducting this research. There are challenges in obtaining informed consent and assent when children are research subjects; challenges arising from study design issues in phase III, II, or I clinical trials; and challenges related to the development of new classes of drugs, especially molecularly targeted therapies. This article provides a very practical and accessible introduction to the ethical issues in research in children. It is designed for online CME credit and includes objectives and important information in clear tables. It would be a very useful article for resident education.

**Blumenthal D. Doctors and drug companies. *N Engl J Med*. 2004;351:1885-1890**

This article is a nice review of the nature and extent of the relationship between the pharmaceutical industry and physicians, the influences of such a relationship, and the existing efforts to manage this relationship.

**Brody H. The company we keep: why physicians should refuse to see pharmaceutical representatives. *Ann of Fam Med*. 2005;3:82-85**

The author takes a fresh look at the physician-pharmaceutical representative relationship and argues from professional integrity and time-management perspectives why physicians should refuse to see pharmaceutical representatives. This is an important issue for anyone in clinical practice.

**Cassell EJ. The sorcerer's broom: medicine's rampant technology. *Hastings Cent Rep* 1993;23(6):32-39**

Technologies tend to take on a life of their own. This article discusses the reasons behind this tendency, including technology's ability to induce wonder, root us in the immediate, remove ambiguity, increase certainty, and enhance power. The author offers a solution to medicine's rampant technology that involves teaching physicians who are the primary instruments of diagnosis and treatment to be tolerant of uncertainty and ambiguity. This article is an excellent reflection of why technology captivates health care professionals.

**Churchill LR. The hegemony of money: commercialism and professionalism in American medicine. *Camb Q Healthc Ethics* 2007;16:407-414**

This article is a very accessible discussion of the dominance of money and markets in American medicine and the impact on the profession of medicine. The most provocative discussion is about money and moral worth in a meritocracy and the author's argument that physicians, like other professions and occupations, are tempted to define themselves inordinately through money. The author concludes with a call to reorient the profession – and thereby regain public trust – by redefining its identity around a public mission.

**Diekema DS. Provider dismissal of vaccine-hesitant families: misguided policy that fails to benefit children. *Hum Vaccin Immunother* 2013;9(12):2661-2662.**

Some health care providers have adopted the policy of refusing to accept families who refuse to vaccinate their children according to the standard vaccine schedule into their practices. The author argues that these policies are misguided because such a strategy does not benefit the child or the health of the community and may have a negative impact on both. Physicians represent the best opportunity to influence the vaccine-hesitant parent. Maintaining open communication and trust remains the best strategy for addressing the problem of parental vaccine hesitancy.

**Feudtner C. The breadth of hopes. *N Engl J Med* 2009;361:2306-2307**

In this two-page essay, the challenging notion of hope is analyzed and repackaged to enable clinicians to see hope as neither a concept to fear nor one to misuse or manipulate, but rather to harness to assist families facing a desperate challenge. This should be required reading for all pediatricians.

**Peabody FW. The care of the patient. *JAMA* 1984;252:813-818 [originally published *JAMA* 1927;88:877-882]**

This landmark article, written by a generalist in the early 1900s, highlights the importance of knowing the whole patient and not just the disease and of caring for the patient and not just the symptom. This is a "must read."

**Pellegrino ED. Toward a reconstruction of medical morality. *Am J Bioeth* 2006;6:65-71**

In this essay, Pellegrino argues that medical ethics should have a strong philosophical basis, one based on the unique obligations associated with the patient-physician healing relationship. He further suggests that the patient's values must be solicited and have substantial influence on the outcome of the ultimate care decisions. This is a thoughtful discussion of the need to fend off modern assaults to the basis of the therapeutic endeavor.

**Reder EAK, Serwint JR. Until the last breath: exploring the concept of hope for parents and health care professionals during a child's serious illness. *Arch Pediatr Adolesc Med* 2009;163:653-657**

This article explores parental, nurse, and physician understanding and associated implications of hope in the face of a child's terminal condition. A clearer understanding of parents' perspectives will

lead to fewer feelings of conflict and increased ability to support parental concerns. This is an essential read for all pediatricians.

**Rhodes R. Ethical considerations for residents. *Acad Med* 1998;73:854-864**

This article provides an overview of the ethical landscape of clinical practice and is a good foundation for further reflection. The author argues that "the doctors' primary obligation is to use the knowledge of science in working together with others for the good of their patients. This involves (1) relying on the scientific method ... and supporting or conducting scientific research; (2) embracing the cooperative model (i.e., ...working cooperatively with other physicians and other health care providers); and (3) working for the good of the patient to preserve life, cure disease, restore or preserve function, educate, and alleviate suffering. In order to fulfill this complex obligation physicians must be professionally competent, they must respect their colleagues and patients, and they must genuinely care about their patients' well-being."

**Sigman GS, Kraut J, La Puma J. Disclosure of a diagnosis to children and adolescents when parents object: a clinical ethics analysis. *Am J Dis Child* 1993;147:764-768**

Telling someone the truth is one way of respecting that person. However, there may be times when willfully hiding the truth from someone is morally justified. This article reviews the factors (physician, disease-specific, patient, family) that should be considered when deciding to disclose information to a pediatric patient. It provides a reasonable, systematic approach to responding to a parent's request not to tell his/her child the truth about the child's diagnosis.

**Ulrich CM, Hamric AB, Grady C. Moral distress: a growing problem in the health professions? *Hastings Cent Rep* 2010;40:20-22**

This essay both describes the problem of moral distress and provides ways to minimize it in individual cases as well as in policy. Although the case described involves an adult patient, the inherent problems and proposed solutions affect pediatricians equally.

**Vaught W. Parents, lies and videotape: covert video surveillance in pediatric care. *J Clin Ethics* 2004;15:161-175**

The use of covert video surveillance to diagnose Munchausen syndrome by proxy (MSBP) is controversial. One must balance the issues of invasion of privacy and breach of trust in the doctor-patient/family relationship with the protection of the innocent child. The author examines the fiduciary relationship between physician and parents as well as physician and pediatric patient and makes a cogent argument for the use of covert video surveillance as a diagnostic tool in the treatment of MSBP.

## **BOOKS AND BOOK CHAPTERS**

**Ahronheim JC, Moreno JD, Zuckerman C. *Ethics in Clinical Practice* (2nd ed). Gaithersburg, MD: Aspen Publishers, 2000**

American Medical Association Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations*. Chicago: American Medical Association, 2000

Beauchamp TL, Childress JF. *Principles of Biomedical Ethics (7th ed)*. New York: Oxford University Press, 2012

Cassidy RC, Fleischman AR, eds. *Pediatric Ethics — From Principles to Practice*. Amsterdam, Netherlands: Harwood Academic Publishers, 1996

Engelhardt HT. *The Foundations of Bioethics (2nd ed)*. New York: Oxford University Press, 1996

Frankel LR, Goldworth A, Rorty, MV, Silverman, WA, ed. *Ethical Dilemmas in Pediatrics: Cases and Commentaries*. Cambridge: Cambridge University Press, 2005

Gawande A. *Better: A Surgeon's Notes on Performance*. New York: Metropolitan Books: Henry Holt and Company, LLC, 2007

Groopman J. *How Doctors Think*. New York: Houghton Mifflin Company, 2007

Lipkin M, Putnam SM, Lazare A. *The Medical Interview: Clinical Care, Education, and Research*. New York: Springer-Verlag, 1995

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## **B. Gifts**

### **JOURNALS**

American Medical Association Council on Ethical and Judicial Affairs. *AMA Code of Medical Ethics*. Gifts to physicians from industry (Opinion E-8.061)

The practice of giving gifts has a significant social and psychological influence on a relationship. The receiver of a gift often feels obligated to the giver in some way. This might result, for example, in a more positive attitude toward the giver or offering a gift in return. The influence of gift-giving within the physician–industry relationship has the potential of having a profound influence on the practice of medicine. This annotation provides guidelines about the practice of gift-giving within the physician-industry relationship, including the influence on physician practices, the appearance of impropriety, the cost of the gifts, and practical guidelines for physicians and sponsors of continuing medical education conferences. Question-and-answer clarification is also provided for each of seven guidelines.

Chren MM, Landefeld S, Murray TH. Doctors, drug companies, and gifts. *JAMA* 1989;262:3448-3451

Whenever a physician accepts a gift from an industry representative, a relationship is established with its inherent obligation to respond to the gift. This article discusses the ethical implications of this practice from the standpoint of justice, the physician- patient relationship, and the physician's character. The authors conclude that, in general, physicians should avoid accepting gifts directly from drug companies. This is a good overview of gift-giving and its potential effect on the physician-patient relationship.

**Coyle SL. Physician-industry relations. Part 1: individual physicians. *Ann Intern Med* 2002;136:396-402**

It is well known that commercial rewards can influence medical judgment. In 1999, the pharmaceutical industry spent \$8.0 billion marketing to physicians' offices and at medical conferences. This position paper by the American College of Physicians takes the fundamental principles of beneficence, nonmaleficence, respect, and autonomy and applies them to specific physician-industry relationships. It offers three helpful questions: 1) What would my patients think about my relationship with industry? 2) What is the purpose of the industry offer? 3) What would my colleagues think about my arrangement with industry? The bottom line is that "...the primary purpose of entering relationships with industry should be the enhancement of patient care and medical knowledge." This is a "must read" for all physicians.

**Gibbons RV, Landry FJ, Blouch DL, Jones DL, Williams FK, Lucey CR, Kroenke K. A comparison of physicians' and patients' attitudes toward pharmaceutical industry gifts. *J Gen Intern Med* 1998;13:151-154**

In 1990, the American Medical Association adopted guidelines on gifts to physicians from industry and in 1992 published an update that provided details and clarification on the original guidelines. Since the early 1990s there has been a great deal of interest in the influence of gifts from industry on the practice of medicine. This study explores how patients versus physicians view the practice of gift giving by industry. Approximately 50% of the patients surveyed were unaware of this practice and 24% of those who were unaware stated that this knowledge altered their perception of medicine. The data suggest that their perception of medicine most likely became more negative. The findings of this study indicate that, in general, patients view the acceptance of gifts as less appropriate and more influential than physicians and are concerned that gifts might influence prescribing practices.

**Lyckholm LJ. Should physicians accept gifts from patients? *JAMA* 1998;280:1944- 1946**

Patients may give their physicians gifts for many reasons, but most commonly it is done out of gratitude. There are times, however, when the motive may be to "buy" extra time from the physician or to "bribe" the physician not to address particularly sensitive issues. How does a physician determine whether a particular gift is appropriate to accept? This is a very thoughtful article that addresses an issue faced by all physicians but not addressed widely in the literature. The author suggests that physicians should keep the best interest of their patients in mind and treat gift-giving patients in the same manner as other patients. This is a "must read" for all physicians.

**Margolis LH. The ethics of accepting gifts from pharmaceutical companies. *Pediatrics* 1991;88:1233-123**

The author takes a hard line on accepting gifts from pharmaceutical companies. Pens, note pads, and even refreshments are unacceptable. "Educational activities, to the extent that they improve the quality of care provided to patients, are the only activities for which support can be justified." This article should be read in conjunction with both the AMA statement and the article by Chren above.

**Wazana A. Physicians and the pharmaceutical industry: is a gift ever just a gift? *JAMA* 2000;283:373-380**

It has been estimated that pharmaceutical companies spend \$8,000 to \$13,000 per physician per year on direct marketing. Obviously, companies would not spend such a large sum if there were not a benefit in terms of increasing sales. Most physicians believe that interactions with pharmaceutical representatives will not influence their prescribing practices. This article examines 29 other articles in the literature that address the extent to which relationships between physicians and pharmaceutical representatives influence physician knowledge, attitudes, and behaviors and serves to raise awareness about the subtle implications of such relationships.

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### **C. Mistakes and malpractice**

## **JOURNALS**

**Baylis F. Errors in medicine: nurturing truthfulness. *J Clin Ethics* 1997;8:336-340**

Why don't physicians discuss medical errors with their patients? The author suggests three possible reasons: uncertainty about whether a particular adverse event was caused by a medical error; patients' anxiety and loss of confidence in the physician and the profession; and fear of litigation. He then argues that the medical culture must be changed to create a supportive environment in which errors may be discussed openly with colleagues and truthfulness is encouraged. This is a good discussion of why disclosure of error is difficult for physicians.

**Gallagher TH, Studdert D, Levinson W. Disclosing harmful medical errors to patients. *N Engl J Med* 2007;356:2713-2719**

This paper reviews some of the history of concerns regarding medical error disclosure and the new regulatory push for more transparent communication when error occurs, as well as a system to prevent recurrence and legal implications. However, its greatest value in a learning environment is the detailed recommendations about how to disclose a medical error, both in terms of the delivery, the preparation, and support for the disclosing clinician and the institutional policies that should facilitate disclosure and protect the individuals involved.

**Hevia A, Hobgood C. Medical error during residency: to tell or not to tell. *Ann Emerg Med* 2003;42:565-570**

This article addresses the practical, psychological, and ethical aspects of medical errors in the context of training, honestly addressing the pros and cons of disclosure based on reports in the literature. It concludes that, on balance, error disclosure is beneficial for all parties.

**Hilfiker D. Facing our mistakes. *N Engl J Med* 1984;310:118-122**

Errors are a part of everyday life. How we respond when a mistake is made, in particular a medical mistake that led to complications or death, is of vital importance. This article is a very personal account of the emotional toll on one family practitioner following an error in medical judgment and his need to be forgiven by the patient. It is a "must read" for anyone in the health care field.

**Hobgood C, Tamayo-Sarver JH, Elms A, Weiner B. Parental preferences for error disclosure, reporting, and legal action after medical error in the care of their children. *Pediatrics* 2005;116:1276-1286**

Although disclosure of error is a moral and ethical obligation, physician disclosure of medical error is uncommon, in part because physicians are uncertain of patient responses to error disclosure and may fear disciplinary or legal action. This single-institution study with a large sample size and high response rate indicates a uniform parental preference for disclosure of medical errors, regardless of race (only black and white were included in the analysis), sex, age, or insurance status of the parent. Desire for disclosure increased with the severity of the consequences of the error. Moreover, based on theoretic scenarios, the parents surveyed asserted a dramatic decrease in the likelihood of bringing a lawsuit if errors are revealed in a timely manner. (This is substantiated in fact by studies of a large insurer, a children's hospital, and a university medical center, each of which adopted education around and policy to uniformly disclose medical errors).

**Levinson W. Doctor-patient communication and medical malpractice: implications for pediatricians. *Pediatr Ann* 1997;26:186-193**

Quality of care is not the major determinant of decisions to initiate malpractice litigation; in 70% of cases it is issues of communication and caring. Usual communication problems leading to litigation are deserting the patient, devaluing patient's views, delivering information poorly, and failing to understand patients' or families' perspectives. Adequate, unrushed explanations about diagnosis and treatment and close, trusting, respectful relationships are protective. Emotions must be dealt with directly; the process is therapeutic, does not lengthen the interview time, and enhances health outcomes as it invites the expression of concerns. Patient/family beliefs, experiences, and expectations must be elicited in order to tailor therapy to meet the needs of children and parents. Nonjudgmental inquiries of the child and parents about expected difficulties following the proposed treatment plan enhances the development of appropriate options and compliance. Explanations must be developmentally appropriate and may include written, play, and drawing communication, but this does not replace physician-patient discussion. In situations of bad news, one should



prepare families in advance when possible, keep medical information to a minimum immediately after revealing the diagnosis (since it is difficult for such information to be processed at that time), and discuss treatment options at a subsequent interview. Indicate and demonstrate compassion and nonabandonment. Communication with adolescents must emphasize respect for confidentiality of the information and encourage the sharing of appropriate information with parents. This paper concludes with resources to develop improved communication skills.

**Madsen LE. Diesel gas, rice, and medical errors. *Pharos* 2002;65:4-10**

This article is a medical student's personal reflection on being human and working in a profession that expects perfection. This is a good article for students as they encounter the medical culture, with suggestions for self-reflection and self-care.

**Wu AW, Cavanaugh TA, McPhee SJ, Lo B, Micco GP. To tell the truth: ethical and practical issues in disclosing medical mistakes to patients. *J Gen Intern Med* 1997;12:770-775**

The authors look at medical mistakes derived from individual error and analyze the issue of disclosure to the patient (or the patient's surrogate decision-maker) from a consequentialist and deontological position. They go on to address some practical issues in disclosing mistakes such as timing, who should disclose, and what to say. The authors conclude that, although there may be rare instances where disclosure would be more harmful than beneficial to the patient, physicians have an ethical obligation to disclose significant errors to the patient. This is an excellent, succinct discussion of a very important topic.

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#### **D. Conflicts of Interest**

### **JOURNALS**

**Bodenheimer T. Uneasy alliance: clinical investigators and the pharmaceutical industry. *N Engl J Med* 2000;342:1539-1544**

Approximately 70% of the money for clinical drug trials comes from industry. This money goes to academic medical centers and to the commercial sector. There is an inherent conflict of interest in such funding when one partner in the relationship is bottom-line oriented and the other is patient-protection oriented, with such conflict being greater in the academic setting. This article nicely outlines the shift to commercial drug networks and the inherent problems with industry-investigator relationships. It is a "must read" for all who do clinical research, as well as for the practitioners who ultimately use the products studied.

**Moffatt B, Elliot C. Ghost marketing: pharmaceutical companies and ghostwritten journal articles. *Perspect Biol Med* 2007;50:18-31**

The use of ghostwriters by industry is subject to increasing public attention and scrutiny. This article addresses the practice and ethics of scientific ghostwriting, focusing on the type of ghostwriting that involves a pharmaceutical company hiring a medical education and communications company to write a paper favorable to their product; the company then hires a well-known academic to publish the paper under his or her name without disclosing the paper's true origins. The authors argue that this practice is harmful both to the public and to the institutions of science and that it is not justified by an analogy to accepted scientific authorship practices. Finally, the authors consider ways to discourage the practice. This article is useful for resident discussions of conflicts of interest.

## **BOOKS AND BOOK CHAPTERS**

**Angell M. *The Truth About Drug Companies: How They Deceive Us and What to Do About It*. New York: Random House, 2005**

**Kassirer JP. *On the Take: How Medicine's Complicity with Big Business Can Endanger Your Health*. New York: Oxford University Press, 2006**

**Weber LJ. *Profits Before People? Ethical Standards and the Marketing of Prescription Drugs*. Bloomington, IN: Indiana University Press, 2006**

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## ***E. Medical testimony and expert witness***

## **JOURNALS**

**American Academy of Pediatrics Committee on Medical Liability. Expert witness participation in civil and criminal proceedings. *Pediatrics* 2009;124:428-438**

The expert witness is a powerful voice in the court of law. This AAP policy statement outlines qualifications for an expert witness, defines expert testimony, reviews the elements of medical negligence, discusses ethical standards for expert witness testimony and reimbursement, and explores various proposals for improving the quality of expert testimony. This is an important policy for anyone who may be in the position of testifying in court as an expert witness.

**Chadwick DL, Krous HF. Irresponsible testimony by medical experts in cases involving the physical abuse and neglect of children. *Child Maltreatment* 1997;2:313- 321**

Irresponsible medical testimony appears to be a growing problem. This article highlights various types of irresponsible testimony, including the use of unique theories of causation, alleging nonexistent medical findings, and misquoting of medical journals and texts and offers criteria to qualify as a medical expert in the area of child abuse and neglect. This is an important article for anyone who might give expert testimony in court.

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## ***F. Physicians who may present a risk to patients***

### **JOURNALS**

**Morreim EH. Am I my brother's warden? Responding to the unethical or incompetent colleague. *Hastings Cent Rep* 1993;23(3):19-27**

Self-policing is a characteristic of all professions. In medicine, we do a fairly good job helping impaired physicians, i.e., those physicians who are unable to practice reasonable and safe medicine because of physical or mental illness. But incompetent or unethical physicians pose unique challenges. How is incompetence defined? How is unethical behavior defined? In some circumstances the answer to these questions is quite clear; however, it can often be very murky. The author identifies five levels of adverse outcomes to consider when there is a question about a colleague's competence and offers several questions to consider when a colleague's behavior is thought to be unethical. Problems with competence and ethics cannot be ignored. Physicians have a fiduciary responsibility toward their patients that supports the reforming and/or removing of incompetent or unethical colleagues from the practice of medicine. This is a very important article for anyone in the medical field.

### **BOOKS AND BOOK CHAPTERS**

**Schechter NL, Berde CB, Yaster M, eds. Pain in infants, children, and adolescents: an overview. In *Pain in Infants, Children, and Adolescents*. Baltimore: Lippencott Williams and Wilkins, 2002:3-9**

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## **XIV. Research and Children**

### ***A. General research issues***

### **JOURNALS**

**American Academy of Pediatrics Committee on Native American Child Health and Committee on Community Health Services. Ethical considerations in research with socially identifiable populations. *Pediatrics* 2004;113:148-151**

Community-based research brings up ethical issues not normally encountered in research conducted in academic settings. In particular, conventional risk-benefits assessments frequently fail to recognize harms that can occur in socially identifiable populations as a result of research participation. This policy statement identifies special risks and special potential benefits to socially identifiable populations and makes specific recommendations for reducing risks. This is an excellent addition to a discussion of culturally sensitive research.

**Diekema DS. Conducting ethical research in pediatrics: a brief historical overview and review of pediatric regulations. *J Pediatr* 2006;149:S3-S11**

This paper provides a brief overview of the history of research involving children and includes a basis for understanding the context within which the current federal regulations were written. The author provides overviews of the regulatory, ethical, and legal requirements that relate to research involving children. This paper is a nice introduction for fellows, residents, or junior faculty.

**Emanuel EJ, Wendler D, Grady C. What makes clinical research ethical? *JAMA* 2000;283:2701-2711**

This article is an excellent resource for resident education. It contains a very concise discussion of seven ethical requirements for clinical research, which are also summarized in a useful table. Another table describes the historical development of various guidelines. The article also includes an excellent list of references.

**Etzel RA, APA Research Committee. Ensuring integrity for research with children. *Amb Ped.* 2005;5:3-5**

This short policy statement by the Ambulatory Pediatric Association outlines the values that should guide research in general pediatrics and provides concrete examples of how these principles should be applied. This statement is meant as a guide for new and seasoned investigators.

**Glannon W. Phase I oncology trials: why the therapeutic misconception will not go away. *J Med Ethics* 2006;32(5):252-255**

In this paper, Glannon argues that the therapeutic misconception may be an unavoidable part of recruitment and consent in medical research. He further discusses some strategies for addressing this problem.

**Glantz LH. Research with children. *Am J Law Med* 1998;24:213-244**

For readers interested in tracing legal cases regarding consent by parents on behalf of children and consent by mature or emancipated minors, and the relationship of such consent to research, this article provides an excellent review. It also provides a discussion of the federal regulations regarding children, in addition to very detailed footnotes. Its major drawback for use in residency education is its length. The discussion of "How Policy Should Evolve" provides an excellent background for the Institute of Medicine (IOM) work on interpreting federal guidelines regarding minimal risk.

***Journal of Adolescent Health* 1995;17:259-330 (Entire issue devoted to various aspects of health research in adolescents)**

In an effort to balance the need to protect individual adolescent research subjects and the need to facilitate important youth research, the Society for Adolescent Medicine has published an excellent

position paper that provides guidelines for researchers. It is published in one convenient issue along with extensive discussion of the following related topics: legal perspectives; ethical consideration for the involvement of adolescent research subjects without permission of their parents or guardians; developmental issues; choice of research setting; issues of race and class; and results of a national survey of Institutional Review Boards (IRB) concerning current practices with consent for adolescent minors. This entire article is a must-read for researchers and IRB members who are involved with adolescent populations. The position paper is an excellent overview for residency education along with the Code of Research Ethics reviewed below.

**Rogers AS, Kinsman SB, Santelli JS, Silber TJ. The society for adolescent medicine's code of research ethics. *J Adolesc Health* 1999;24:283**

The Society for Adolescent Medicine (SAM) was among the first professional societies to adopt a code of research ethics. It did so to identify the norms and values by which its members should act and to initiate new members into the research life of its society. In so doing, the Society was striving to reaffirm its contract with the general population to seek knowledge through research in an irreproachably ethical manner. An excellent preamble discussing why a professional society needs a code of research ethics, and a summary of the major points of ethical research, make this article an excellent resource for residency education.

**Shaddy RE, Denne SC, and The American Academy of Pediatrics Committee on Drugs and Committee on Pediatric Research. Guidelines for the ethical conduct of studies to evaluate drugs in pediatric populations. *Pediatrics* 2010;125:850-860**

This policy statement is the update of a 1995 policy statement and provides a comprehensive overview of the ethical requirements for drug research in pediatrics. It begins with an ethical justification for the requirement to study drugs in pediatric populations and reviews specific guidelines for study design, investigator concerns, Institutional Review Boards (IRBs), risk/benefit assessments, and vulnerable populations. The section on informed consent/permission/assent is particularly valuable. This is an excellent resource for new researchers.

## **BOOKS AND BOOK CHAPTERS**

**Grodin MA, Glantz LH. *Children as Research Subjects: Science, Ethics, and Law*. New York: Oxford University Press, 1994**

**Kodish E, ed. *Ethics and Research with Children: A Case-based Approach*. New York: Oxford University Press 2005**

**Menikoff J. *What the Doctor Didn't Say: The Hidden Truth About Medical Research*. New York: Oxford University Press 2006**

**National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *The Belmont Report: Ethical Principles for the Protection of Human Subjects of Research*. OPRR Reports. Washington, DC: US Government Printing Office, 1979**

Ross LF. *Children in Medical Research: Access Versus Protection*. New York: Oxford University Press, 2006

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## **B. Child and adolescent assent**

### **JOURNALS**

**Susman EJ, Dorn LD, Fletcher JC. Participation in biomedical research: the consent process as viewed by children, adolescents, young adults, and physicians. *J Pediatr* 1992;121:547-552**

This article summarizes the results of a research project that examined the capacity of children, adolescents, and young adults to assent and consent to participation in research. The research involved 44 male and female subjects ranging in age from 7 to 20 years. The subjects were receiving experimental treatment for pediatric cancers or receiving treatment for obesity. The researchers found that study subjects were most knowledgeable about those elements of consent that assessed concrete information such as the freedom to ask questions, time elements, and the benefits of participation. The study subjects were less knowledgeable about those elements that assessed abstract information such as scientific versus therapeutic purpose, and alternative treatments. Chronological age was not related to knowledge of the elements of informed consent. The authors conclude that their findings should not be used to discourage the inclusion of children, adolescents and young adults in the consent/assent process, but rather to encourage attention to developmental processes and individual differences when requesting assent to participate in research. This article adds concrete empirical data to any discussion of the assent/consent requirements for minors.

**Truog RD, Robinson W, Randolph A, Morris A. Is informed consent always necessary for randomized, controlled trials? *N Engl J Med* 1999;340:804-807**

This provocative and practical “sounding board” article continues dialogue about how to ethically use innovative therapies. It is an excellent resource for residency education because it includes a number of practical examples and four very concrete guidelines for the waiver of informed consent. Together with the Lantos/Frader article about ECMO, it provides valuable resources for an excellent discussion of the tension between therapy and research in the use of innovative therapies.

**Wendler D, Shah S. Should children decide whether they are enrolled in nonbeneficial research? *Am J Bioeth* 2003;3:1-7**

The federal regulations stipulate two broad categories of risks versus benefits for clinical research involving minors: prospect of direct benefit and no prospect of direct benefit. These categories are further divided into minimal risk, minor increase over minimal risk, and more than a minor increase over minimal risk. In addition, the regulations require assent from children capable of providing it.

This article and the commentaries that follow it examine the issue of assent in general and specifically when enrolling minors in nonbeneficial research. This is a must read for all clinical researchers.

**Wilfond BS, Diekema DS. Engaging children in genomics research: decoding the meaning of assent in research. *Genet Med* 2012;14:437-443**

This article considers how to approach assent from children for genomics research. The authors examine several historical rationales for assent, including those who argue that assent serves a protective function and those who argue that it serves to recognize developing autonomy. The authors suggest that “engagement” is a more useful construct for understanding the role of assent. This construct emphasizes that children have development capacities that should be respected and includes a limited role for assent to allow children to protect themselves, but it focuses on the primary role of assent: to engage the child in the decision-making process surrounding research. Engaging children does not require disclosure of all of the benefits and risks of genomics research that might be conveyed to an adult and may permit a degree of parental control over the final decision regarding research participation.

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### ***C. Scientific integrity and misconduct***

#### **JOURNALS**

**Weed DL. Preventing scientific misconduct. *Am J Public Health* 1998;88:125-129**

The National Science Foundation defines scientific misconduct as fabrication, falsification, plagiarism, or any other serious deviation from accepted practices. Misconduct involves intentional actions and not unintentional errors. Although there are proposed causes of misconduct, little empirical data exist to support these causes. The author suggests a framework for primary and secondary prevention, modeled after a public health approach, and suggests that scientists should develop the virtues of honesty, excellence, and self-effacement. This is a good basic article for those in the research field.

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### ***D. Uncontrolled innovation versus experimentation***

#### **JOURNALS**

**Fost N. Ethical dilemmas in medical innovation and research: distinguishing experimentation from practice. *Semin Perinatol* 1998;22:223-232**

This article reviews the difficulties encountered in trying to differentiate research, experimentation,

and standard practice. The author raises concerns about the protection of children in research, but more so in the distinction between research and "medical innovation." This is an excellent article for interns and students that should raise awareness about how certain practices fall "between the lines" and how oversight of research may actually provide more protection for pediatric patients than is found in clinical practice.

**Lantos JD, Frader J. Extracorporeal membrane oxygenation and the ethics of clinical research in pediatrics. *N Engl J Med* 1990;323:409-413**

This important article uses the development of Extracorporeal Membrane Oxygenation (ECMO) to explore the tension between the need to utilize innovative treatments and the need to utilize randomized, controlled trials as the gold standard and the ultimate basis for the resolution of medical disagreements. The article traces the development of ECMO and the challenges posed to a sustained research initiative, not the least of which includes how to ethically randomize when "standard" therapy is not clear and an innovative technology looks promising. Because this article has implications for other future developments besides ECMO, it is a must-read for critical care researchers and it would also be very useful for residency education about the use and evaluation of innovative therapies.



## SPECIAL MEDICAL CIRCUMSTANCES

### XV. Care of Patients with Disabilities

#### JOURNALS

**American Academy of Pediatrics Committee on Bioethics. Sterilization of minors with developmental disabilities. *Pediatrics* 1999;104:337-340**

This policy statement addresses the interests of minors with developmental disabilities for whom sterilization might be contemplated by parents or guardians. The issue of competency is discussed, as well as the importance of assessing completely the benefits and burdens of parenthood. The interests of potential children are also noted. The committee emphasizes that sterilization should only be considered when there is a need for permanent prevention of reproduction, in contrast to lesser concerns such as menstrual hygiene. Moreover, the minor for whom this is contemplated should be involved in the decision-making to the extent possible and the minor's views on the matter respected when the minor demonstrates adequate decision-making capacity. Pediatricians are also reminded to be familiar with applicable state law regarding sterilization of persons with developmental disabilities.

**Diekema DS. Involuntary sterilization of persons with mental retardation: an ethical analysis. *Ment Retard Dev Disabil Res Rev* 2003;9:21-26**

Parents of a mentally retarded adolescent/young adult may have legitimate concerns regarding their child's sexuality and may approach a physician about the possibility of sterilization. The right to procreate is fundamental, but is there an ethically justified argument in some circumstances for sterilization? This article reviews the history of involuntary sterilization in the United States and discusses competency in relation to reproductive decision-making. The author concludes that mentally retarded persons who lack (1) the capacity for reproductive decision-making, (2) the ability to raise a child, and (3) the capacity to consent to marriage should be considered for sterilization only if it serves their best interest and a less intrusive method of birth control is not acceptable. A fair decision-making process must be assured. This is a very important article for anyone working with mentally retarded adolescents or young adults.

**Diekema DS, Fost N. Ashley revisited: a response to the critics. *Am J Bioeth* 2010; 10:30-44**

The case of Ashley X involved a young girl with profound and permanent developmental disability who underwent growth attenuation using high-dose estrogen, a hysterectomy, and surgical removal of her breast buds. This paper includes a point-by-point response to the many individuals and groups who were critical of the decisions made by Ashley's parents, physicians, and the hospital ethics committee that supported the decision. The authors provide a brief review of the case and the issues it raised, then address 25 distinct substantive arguments that had been proposed as reasons that Ashley's treatment might be unethical. They conclude that while some important

concerns have been raised, the weight of these concerns is not sufficient to consider the interventions used in Ashley's case to be contrary to her best interests, nor are they sufficient to preclude similar use of these interventions in the future for carefully selected patients who might also benefit from them.

**Fost NC. Counseling families who have a child with a severe congenital anomaly. *Pediatrics* 1981;67:321-324**

This article, though more than two decades old, remains a well-articulated and relevant discussion of parent and child interests, as well as physician interests/responsibilities, when an infant is born with a severe congenital anomaly. Parental needs, potential conflicts of interest, the proper moral weight of parental preferences, the need at times for outside consultation for decision-making, and legal issues are presented clearly and succinctly. This article will inform any discussion of the care of infants with severe disabilities.

**Gunther DF, Diekema DS. Attenuating growth in children with profound developmental disability: a new approach to an old problem. *Arch Pediatr Adolesc Med* 2006;160:1013-1017**

This case report discusses the medical and ethical implications of growth attenuation with high-dose estrogen of a profoundly developmentally disabled child. The authors review the history of growth-attenuation therapy, discuss the risks of such therapy, and analyze the benefits to the child. They conclude that with proper review and informed consent, this therapeutic option should be available to such children at the request of the parents. This is a "must read" for anyone working with profoundly developmentally disabled children.

**Wilfond BS, Miller PS, Korfiatis C, et al; and the Seattle Growth Attenuation and Ethics Working Group. Navigating growth attenuation in children with profound disabilities: children's interests, family decision-making, and community concerns. *Hastings Cent Rep* 2010;40:27-40**

This paper is the result of a twenty-person working group convened to discuss the ethical and policy considerations of the controversial intervention called growth attenuation. A consensus proved elusive, but most of the members did reach a compromise. This paper considers the impact of growth attenuation on children, the importance of shared decision-making between parents and doctors, strategies for safeguards and oversight, and community concerns about social implications.

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## **XVI. Children With AIDS/HIV Infection**

### **JOURNALS**

**American Academy of Pediatrics Committee on Pediatric AIDS. Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics* 1999;103:164-166**

This commentary focuses on the risks and benefits to children, their parents, and their medical professionals of informing children at various developmental stages about their HIV infections.

**American Academy of Pediatrics Committee on Pediatric AIDS. Adolescents and HIV infection: the pediatrician's role in promoting routine testing. *Pediatrics* 2011;128:1023-1029.**

Pediatricians play a key role in preventing and controlling HIV infection by promoting risk-reduction counseling and offering routine HIV testing to adolescent and young adult patients. Most sexually active youth do not feel that they are at risk of contracting HIV and have never been tested. Obtaining a sexual history and creating an atmosphere that promotes nonjudgmental risk counseling is a key component of the adolescent visit. This policy statement reviews the epidemiologic data and recommends that routine screening be offered to all adolescents at least once by 16 to 18 years of age in health-care settings when the prevalence of HIV in the patient population is > 0.1%. In areas of lower community HIV prevalence, routine HIV testing is encouraged for all sexually active adolescents and those with other risk factors for HIV. This statement addresses many of the real and perceived barriers that pediatricians face in promoting routine HIV testing for their patients.

**Flanagan-Klygis E, Ross LF, Lantos J, Frader J, Yogev R. Disclosing the diagnosis of HIV in pediatrics. *J Clin Ethics* 2000;12:150-157**

This article reports parents' reasons for nondisclosure of a diagnosis of HIV infection to children at various developmental stages, as well as physicians' experience with, and attitudes toward, nondisclosure. The discussion compares truth-telling in the care of pediatric cancer patients and in those with HIV infection.

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## **XVII. Violence and Child Abuse**

### **A. Domestic violence**

#### **JOURNALS**

**American Medical Association Council on Ethical and Judicial Affairs. Physicians and domestic violence: ethical considerations. *JAMA* 1992;267:3190-3193**

The authors stress that is important for doctors to address not only the physical effects of family violence, but also the actual diagnosis of abuse. The negative effects of ignoring the underlying abuse are addressed, and statistics implying a high rate of disregard by health care professionals are provided. This disregard is attributed to a lack of knowledge, lack of resources, and larger societal misconceptions. In actually addressing domestic violence, physicians must carefully consider the issues of confidentiality and informed consent, always respecting the wishes of the

patient. The authors further conclude that comprehensive domestic violence training should routinely be provided during the schooling of physicians who will likely encounter domestic violence.

**Thackeray JD, Hibbard R, Dowd MD, and The American Academy of Pediatrics Committee on Child Abuse and Neglect, and the Committee on Injury, Violence, and Poison Prevention. Intimate partner violence: the role of the pediatrician. *Pediatrics* 2010;125:1094-1100**

This statement emphasizes the importance of improving the physician's ability to recognize intimate partner violence (IPV) and understand its effects on child health and development and its role in the continuum of family violence. Pediatricians occupy a position that enables them to identify abused caregivers and to evaluate and treat children raised in homes in which IPV may occur. Children exposed to IPV are at increased risk of being abused and neglected and are more likely to develop adverse health, behavioral, psychological, and social disorders later in life. Identifying IPV may be one of the most effective means of preventing child abuse and identifying caregivers and children who may be in need of treatment and/or therapy. Pediatricians should remain alert to the signs and symptoms of exposure to IPV in caregivers and children and should consider attempts to identify evidence of IPV either by targeted screening of high-risk families or universal screening.

## **BOOKS AND BOOK CHAPTERS**

**American Medical Association. *What You Can Do About Family Violence: A Federation Guide to the Physician's Campaign Against Family Violence*. Chicago: American Medical Association, 1992**

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### **B. Violence in society**

## **JOURNALS**

**Rivara FP, Farrington DP. Prevention of violence. Role of the pediatrician. *Arch Pediatr Adolesc Med* 1995;149:421-429**

This article addresses the important role physicians and, more specifically, pediatricians play in the prevention and control of societal violence. The issue of violence concerns pediatricians because of its innate public health nature, the high number of youth involved both directly and indirectly, and the dire need for primary prevention. Early violent behavior is linked to adult violence, which leads the authors to conclude that early intervention results in a reduction of adult offending. Factors related to adulthood violence include parenting, familial stress/support, peer support, and academic failure. The authors suggest that pediatricians can play a role in counteracting the negative effects of these factors. They emphasize that pediatricians should be trained to aid in developing positive parenting skills, identify behavior problems for various types of early intervention, and suggest appropriate educational opportunities.

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## **C. Child abuse**

### **JOURNALS**

**American Academy of Pediatrics Committee on Bioethics and Committee on Child Abuse and Neglect. Forgoing life-sustaining medical treatment in abused children. *Pediatrics* 2000;106:1151-1153**

This policy statement gives guidance about the criteria for decision-makers' roles and the unchanged role of the benefit-burden calculus for all children who have been seriously injured by abuse. The role of a guardian ad litem, the medical examiner, and the possibility of organ donation, as well as the need to provide family support, are described. This statement provides excellent guidance for PICU personnel, consultants, ethics committees, guardians ad litem, and judges.

**Brown AN, Gonzalez GR, Wiester RT, Kelley MC, Feldman KW. Caretaker blogs in caregiver fabricated illness in a child: a window on the caretaker's thinking? *Child Abuse Negl* 2014;38(3):488–497.**

The authors discuss three cases of caregiver-fabricated illness that shed light on a new manifestation of caretakers' attention seeking behavior. The patients' mothers were actively blogging about their children's reputed illnesses. The blogs portrayed their child's illness as more severe than what treating physicians had conveyed, reported contacts with palliative care teams and "Wish" organizations, and sought online donations for their children's health needs. Such blogs may provide additional direct evidence of the suspected caregivers' fabrications. This paper discusses the ethical implications of using parent blogs in investigations of possible caregiver-fabricated illness and suggests that child protective services and/or police investigators could consider querying the Internet for blogs related to children at risk for caregiver-fabricated illness.

**Gladsjo JA, Breeding J, Sine D et al. Termination of life support after severe child abuse: the role of a guardian ad litem. *Pediatrics* 2004;113:e141-e145**

Termination of life support for a child can pose ethical and occasionally legal concerns. These concerns are magnified when the child is a victim of abuse by a parent or guardian. This article, a case discussion of an 8-month-old infant who was severely abused by her father, describes the involvement of the medical team, the ethics consultation service, and ultimately the appointment of a guardian ad litem to ensure that the best interests of the infant were honored. This is a must read for any physician who deals with such tragic cases.

**Kaufman M and the American Academy of Pediatrics Committee on Adolescence. Care of the adolescent sexual assault victim. *Pediatrics* 2008;122:462-470**

This article provides an overview of adolescent sexual assault for health care providers. It is asserted that understanding the definitions of terms related to sexual assault, such as sexual

assault, rape, acquaintance rape, date rape, molestation, and statutory rape, is key to understanding and treating the adolescent sexual assault victim. These definitions are provided. The epidemiology of the sexual assault of adolescents is discussed (specifically addressing gender differences, identity of the perpetrator, and relation of alcohol/drug use), as well as adolescent understanding of and reactions to sexual assault. Suggestions and recommendations are provided for treating adolescent victims and prevention counseling.

**Kellogg ND and The American Academy of Pediatrics Committee on Child Abuse and Neglect. The evaluation of sexual abuse in children. *Pediatrics* 2005;116:506-512**

The purpose of this article is to update the 1991 guidelines for evaluating child sexual abuse that were revised in 1999. Approximately 1% of all children are sexually abused each year. Because pediatricians have close relationships with children and their families, the authors of this article stress the importance of preparing pediatricians to properly handle these situations. This paper outlines the medical assessment of suspected sexual abuse with respect to obtaining a history, physical examination, and appropriate laboratory data. The role of the physician may include determining the need to report sexual abuse; assessment of the physical, emotional, and behavioral consequences of sexual abuse; and coordination with other professionals to provide comprehensive treatment and follow-up of victims.

**Vaught W. Parents, lies and videotape: covert video surveillance in pediatric care. *J Clin Ethics* 2004;15:161-175**

The use of covert video surveillance to diagnose Munchausen syndrome by proxy (MSBP) is controversial. One must balance the issues of invasion of privacy and breach of trust in the doctor-patient-family relationship while protecting the innocent child. The author examines the fiduciary relationship between physician and parents as well as physician and patient and makes a cogent argument for the use of covert video surveillance as a diagnostic tool in the treatment of MSBP.

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## **XVIII. Complementary and Alternative Medicine**

### **JOURNALS**

**American Academy of Pediatrics Committee on Children with Disabilities. Counseling families who choose complementary and alternative medicine for their child with chronic illness or disability. *Pediatrics* 2001;107:598-601**

Because the use of complementary and alternative medicine modalities is likely to increase in the future, this statement from the AAP gives residents and practitioners practical guidance in responding to parents' requests and information about the prevalence of various practices. The advice contained here should not be limited only to parents with children who are disabled or who have chronic diseases but can be useful in interacting with all parents.

**Vohra S, Cohen MH. Ethics of complementary and alternative medicine use in children. *Pediatr Clin North Am* 2007;54:875-884**

This article is an excellent tool to discuss the ethical issues of complementary and alternative medicine (CAM) in children. It is thorough and well written, using the ethical commitments articulated in the 2005 Institute of Medicine (IOM) report on CAM as an ethical framework. The article also includes a very thoughtful discussion of the impact on clinical care and research.

## **BOOKS AND BOOK CHAPTERS**

**Diekema DS, Marcuse EK. Ethical issues in the vaccination of children. *Primum non nocere Today* (2nd ed). Edited by GR Burgio and JD Lantos. Amsterdam: Elsevier Science B.V., 1998:37-47**

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## **XIX. Care of Patients with Psychiatric Disorders**

### **JOURNALS**

**Campbell AT. Consent, competence, and confidentiality related to psychiatric conditions in adolescent medicine practice. *Adolesc Med Clin* 2006;17-25-47**

Respect for the adolescent, parental responsibility toward their child's best interests, and the family unit generally are paramount. Respect – coupled with caution, greater disclosure and cultural sensitivity, and a participatory approach to decision-making that seeks the least restrictive and least coercive options – can help avoid potential legal traps. How best to proceed? Law and ethics should be the start (not end) of discussion and analysis.

**Tan JOA, Fegert JM. Capacity and competence in child and adolescent psychiatry. *Health Care Analysis* 2004;12(4):285-294**

This article focuses on child and adolescent decisional capacity and competence relevant to child mental health. The authors summarize helpful information about the context of psychiatric decision-making, describing some of the unique issues that arise in this field. They discuss ethical duties of child psychiatrists; these are also relevant to pediatricians providing behavioral health care. The complexity of capacity and competence is illustrated with a discussion of treatment of anorexia nervosa. The authors contend that common standards for conceptualizing capacity rely on intellectual criteria, and do not adequately incorporate social and emotional maturity factors.

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## XX. Emergency and Disaster Preparedness

### JOURNALS

**Morin K, Higginson D, Goldrich M, for the Council on Ethical and Judicial Affairs of the American Medical Association. Physician obligation in disaster preparedness and response. *Camb Q Healthc Ethics* 2006;15:417-421**

This paper reviews the history of physician ethical obligations in the face of personal risk, the ethics of the medical profession and professional obligations in the face of personal risk, and the limits on a physician's duty to treat. The authors conclude that the ethical foundation of medical practice creates an obligation for physicians to respond in times of disaster and emergency, but that obligation need not be absolute and may be limited in some situations.

**The University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group. Stand on guard for thee: ethical considerations in preparedness planning for pandemic influenza. November 2005.**

This report is a classic in the ongoing discussion of ethical issues in pandemic planning. It is very thorough and clearly written. Although rather long, it is well- organized and very accessible with tables, summary points, and clear recommendations. It includes a table describing ten substantive values to guide ethical decision-making and a table describing five procedural values. A discussion of four key ethical issues is also included: 1) the obligations of health care workers to provide care; 2) restricting liberty by quarantine; 3) allocation of scarce resources such as vaccines and antiviral medicines; 4) travel advisories. This initial work should be the starting point for any education about the ethical issues in pandemic planning for residents.

**Tuohey JF. A matrix for ethical decision making in a pandemic. The Oregon tool for emergency preparedness. *Health Prog* 2007; 88:20-25**

This article is an excellent addition to the groundbreaking ethical framework outlined above in "Stand on Guard for Thee" from the University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group. The Oregon matrix acknowledges the Toronto framework but goes beyond it to suggest ways in which the different ethical values should be prioritized and balanced. It is a very practical review of other efforts to examine the ethical framework for decision-making. This article is very thorough and practical and is an excellent resource for discussions about the ethical issues in pandemic planning.



## BIOETHICS EDUCATION AND RESOURCES

### XXI. Education, Training, and Evaluation

#### A. Curriculum resources

##### JOURNALS

**Diekema DS, Shugerman RP. An ethics curriculum for the pediatric residency program: confronting barriers to implementation. *Arch Pediatr Adolesc Med* 1997;151:609-614**

The Residency Review Committee for Pediatrics of the Accreditation Council for Graduate Medical Education requires ethics instruction during residency training. This article highlights some of the barriers to implementing an ethics curriculum, such as time constraints and the attitude of residents toward the material, and offers suggestions for overcoming these obstacles. A 36-month curriculum outline is provided. For those who are involved in resident education, this article can serve as a foundation on which to build an ethics curriculum.

**Fiester A. Viewpoint: why the clinical ethics we teach fails patients. *Acad Med* 2007;82:684-689**

This paper argues that the clinical ethics framework typically used to train residents – the principlist model – is necessary but not sufficient for analyzing ethical conflicts. The danger of an exclusively principlist approach to ethical conflicts is that it blinds clinicians to the full set of their moral obligations to patients. An approach based exclusively on principles fails to discern these additional obligations and limits the range of options a physician sees as available while he or she attempts to navigate through ethical conflicts. The author includes a case to illustrate how using a principlist approach failed to recognize three obligations that a clinician owed the patient: the obligation to express regret, the obligation to apologize, and the obligation to make amends. The author makes the point that this model is insufficient as the sole paradigm used to train residents to successfully navigate the complex ethical dilemmas they will face in practice. He urges educators to reexamine the approach they use in teaching clinical ethics.

**Gawande A. The learning curve. *The New Yorker*. January 28, 2002**

For all of us who have been learners and will continue to be, this is a must-read article. It is a first-person account of "the learning curve" of a young surgeon-in-training and of the adage "see one, do one, teach one." It raises the question as to whether the system of medical training can be sustained by depending on patients agreeing to allow those in training to practice on them.

**Kaczmarczyk JM, Chuang A, Dugoff L, et al. e-Professionalism: a new frontier in medical education. *Teach Learn Med* 2013;25(2):165-170.**

This article, prepared by the Association of Professors of Gynecology and Obstetrics Undergraduate

Medical Education Committee, discusses the evolving challenges facing medical educators posed by social media and a new form of professionalism that has been termed e-professionalism. E-professionalism is an essential and increasingly important element of professional identity formation, and the consequences of violations of e-professionalism have escalated from academic sanctions to revocation of licensure. The authors argue that e-professionalism should be included in the definition, teaching, and evaluation of medical professionalism.

**Sahler OJ, Frager G, Levetown M, Cohn FG, Lipson MA. Medical education about end-of-life care in the pediatric setting: principles, challenges, and opportunities. *Pediatrics* 2000;105:575-584**

This article, written by ethicists and pediatric clinicians, suggests curricular content for pediatric residents pertaining to palliative care issues. It concludes that no separate curriculum is needed, but that better advantage be taken of naturally occurring opportunities during residency training. Educational strategies are suggested, such as inviting trainees to be present during family meetings and to debrief them after the meeting about what they saw and how they felt about it. This article is useful for residency and fellowship directors who recognize the need to incorporate palliative care education into their curricula but are struggling to do so within an already overburdened time frame and despite ever-decreasing resident work hours.

## **BOOKS AND BOOK CHAPTERS**

**Adam MB, Diekema DS, Mercurio MR, eds. *American Academy of Pediatrics Bioethics Resident Curriculum: Case-Based Teaching Guides*.**

This gift to pediatrics ethics educators comes from members of the AAP Section on Bioethics. It is a case-based, modular curriculum designed to function as a how-to resource for residency and fellowship training programs, with the goal of assisting pediatric faculty to help trainees to develop basic competencies in bioethics. The modules review relevant resources and identify current debates. Each module contains references and links to AAP policies. References are separated into: “Suggested Reading for Instructor” and “Further Reading,” allowing instructors to efficiently identify pertinent resources on the topic.

**Ahronheim JC, Moreno JD, Zuckerman C. *Ethics in Clinical Practice (2nd ed)*. Gaithersburg, MD: Aspen Publishers, 2000**

**American Medical Association Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations*. Chicago: American Medical Association, 2009**

**Beauchamp TL, Childress JF. *Principles of Biomedical Ethics (6th ed)*. New York: Oxford University Press, 2008**

**Cassidy RC, Fleischman AR, eds. *Pediatric Ethics — From Principles to Practice*. Amsterdam, Netherlands: Harwood Academic Publishers, 1996**

Diekema DS, Mercurio MR, Adam MB (eds). *Clinical Ethics in Pediatrics: A Case- Based Textbook*. New York: Cambridge University Press, 2011

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## **B. Evaluation**

Teaching and Assessing Professionalism: A Program Director's Guide. Available under "Program Directors" at the American Board of Pediatrics website ([www.abp.org](http://www.abp.org))

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