Better than Best (Interest Standard) in Pediatric Decision Making

Lainie Friedman Ross, The Journal of Clinical Ethics 30, no. 3 (Fall 2019): 183-95.

Healthcare decision making for children has adopted the best interest of the child standard, a principle originally employed by judges to adjudicate child placement in the case of parental death, divorce, or incompetence. Philosophers and medical ethicists have argued whether the best interest principle is a guidance principle (informing parents on how they should make healthcare decisions for their child), an intervention principle (deciding the limits of parental autonomy in healthcare decision making), or both. Those who defend it as only a guidance principle often cite the harm principle as the appropriate intervention principle. In this article, I challenge current use of the best interest principle in pediatric decision making as a guidance principle and as an intervention principle. I propose a model that I call constrained parental autonomy, which focuses on promoting and protecting the child’s primary goods or basic needs. I show that constrained parental autonomy can serve as both a guidance principle and an intervention principle in making decisions. I conclude by examining a case study involving bone marrow donation by a young child to her sister.

Offering the “Reasonable Interests Standard” in Response to Ross’s Analysis of the Best Interests Standard


Ross’s argument against the best interest standard (BIS) makes a clear case for the problems of the BIS, and she also notes challenges with such notions as the harm principle. In light of these critiques, Ross champions her longstanding pediatric moral norm for decision making, constrained parental autonomy (CPA). This article argues that while Ross’s critique of the traditional accounts of the BIS is correct, her solution still raises some concerns. As such, I offer the “reasonable interests standard” as a way of addressing what I see as weaknesses in both the BIS and CPA.

Guidance and Intervention Principles in Pediatrics: The Need for Pluralism

Mark Christopher Navin and Jason Adam Wasserman, The Journal of Clinical Ethics 30, no. 3 (Fall 2019): 201-6.

Two core questions in pediatric ethics concern when and how physicians are ethically permitted to intervene in parental treatment decisions (intervention principles), and the goals or values that should direct physicians’ and parents’ decisions about the care of children (guidance principles). Lainie Friedman Ross argues in this issue of The Journal of Clinical Ethics that constrained parental autonomy (CPA) simultaneously answers both questions: physicians should intervene when parental treatment preferences fail to protect a child’s basic needs or primary goods, and both physicians and parents should be guided by a commitment to protect a child’s basic needs and primary goods. In contrast, we argue that no principle—neither Ross’s CPA, nor the best interest standard or the harm threshold—can serve as both an intervention principle and a guidance principle. First, there are as many correct intervention principles as there are different kinds of interventions, since different kinds of interventions can be justified under different conditions. Second, physicians and parents have different guidance principles, because the decisions physicians and parents make for a child should be informed by different values and balanced by different (potentially) conflicting commitments.

Decision Making on Behalf of Children: Understanding the Role of the Harm Principle


Thirty years ago, Buchanan and Brock distinguished between guidance principles and interference principles in the setting of surrogate decision making on behalf of children and incompetent adult patients. They suggested that the best interest standard could serve as a guidance principle, but was insufficient as an interference principle. In this issue of The Journal of Clinical Ethics, Ross argues that the best interest standard can serve as neither a guidance or interference principle for decision making on behalf of children, but that her model of constrained parental autonomy can serve as both. I will argue that Buchanan and Brock were correct that a single model or standard cannot serve as both a guidance and interference principle in pediatrics and that the best interest standard is a sufficient guidance
In this commentary, the author discusses two strengths and two weaknesses of "Better than Best (Interest Standard) in Pediatric Decision-Making," in which Lainie Friedman Ross critiques the best interest standard and proposes her own model of constrained parental autonomy (CPA) as a preferable replacement for both an intervention principle and a guidance principle in pediatric decision making. The CPA's strengths are that it detaches from the language and concept of "best" and that it better respects the family as a distinct and intimate decision-making unit. The first weakness of the framework, as an intervention principle, is that because it imports a Rawlsian understanding of basic interests, it neglects certain populations of children (for example, children with intellectual disabilities). The second weakness is that, as a guidance principle, it is unclear what actual guidance the CPA is positioned to offer and how that guidance would be justified. To conclude, this commentary offers suggestions for what should be required of both an intervention principle and a guidance principle in pediatric decision making.

**Constrained Parental Autonomy and the Interests of Children in Non-Intimate Families**

**Erin Paquette, The Journal of Clinical Ethics 30, no. 3 (Fall 2019): 218-22.**

Children's age and developmental capacity leave them incapable of making medical decisions for themselves. Decisions for children are traditionally made under the best interest standard. Ross calls into question whether the best interest standard can function as both a guidance and intervention principle, able to be applied across the spectrum of pediatric decision making. Ross describes constrained parental autonomy as an alternative model, arguing that it affords parents the ability to make decisions within the context of their family while upholding a child's current and future interests. Although the model provides a robust framework for intrafamilial decision making, I question whether it can be broadly applied to children living in non-intimate families.

**The Best Interest Standard Is the Best We Have: Why the Harm Principle and Constrained Parental Autonomy Cannot Replace the Best Interest Standard in Pediatric Ethics**

**Johan C. Bester, The Journal of Clinical Ethics 30, no. 3 (Fall 2019): 223-31.**

While the best interest standard (BIS) enjoys wide endorsement as ethical and decision-making standard in pediatrics, it has been criticized as vague and indeterminate. Alternate decision-making standards have been proposed to replace or augment the BIS, notably the harm principle (HP) and constrained parental autonomy (CPA) model. In this edition of *The Journal of Clinical Ethics*, Lainie Friedman Ross argues that CPA is a better standard than the BIS or the HP as both guide and limiter in pediatrics. In response, I review the important work done by the BIS in pediatrics, and argue that neither the HP nor the CPA can take over these functions or replace the BIS. Among other things I argue: (1) The BIS provides more robust protections for the moral claims of children. (2) The CPA model and the HP do not resolve the indeterminacy and vagueness present in complex medical situations, and the BIS is better suited to deal with this vagueness and indeterminacy. (3) The BIS is a general principle of medical ethics with special application in pediatrics; it fits seamlessly into the system of medical ethics and fulfills many functions within pediatrics. The HP and the CPA model do not fit in so readily within medical ethics, and are not equipped to take over the functions of the BIS.

**In Further Defense of “Better than Best (Interest)”**

**Lainie Friedman Ross, The Journal of Clinical Ethics 30, no. 3 (Fall 2019): 232-9.**

In their thoughtful critiques of my article "Better than Best (Interest Standard) in Pediatric Decision Making," my colleagues make clear that there is little consensus on what is (are) the appropriate guidance and intervention principles in pediatric decision making, and disagree about whether one principle can serve both functions. Hester proposes his own unitary principle, the reasonable interest standard, which, like the best interest standard from which it is derived, encourages parents to aim for the great, although Hester tempers it with a pragmatic principle that allows consideration of cultural/family values and practical/financial/social/psychological circumstances. I reject the aspirational guidance principle because it is too demanding, and I also reject the notion that this pragmatic condition "gives permission for others to extol parents to give reasons" for their decisions, because it allows too much interference into the family and its decision making. Whereas the other respondents and I focus on whether and when third parties should intervene in the doctor-patient (surrogate) relationship, Navin and Wasserman mistakenly redefine intervention to include physicians' behaviors that attempt to influence parents, ignoring the integral role of shared decision making—a bidirectional discussion in which physicians help patients (surrogates) select among reasonable medical options through education, and, when necessary, motivation or persuasion. Diekema and Salter focus on the harm principle for intervention, ignoring other conditions in which intervention may be appropriate and institutions other than the state that may intervene. Paquette's overly narrow interpretation of who has positive obligations to children fails to ensure that a child's basic interests and needs are met. Finally, Bester claims that the "need to choose the available option that best promotes or protects the child's basic interests" is akin to a focus on best interests. But constrained parental autonomy does not require parents to choose the option that best promotes a
child’s basic interests. Rather, it requires respect for broad parental discretion about how they raise their child unless their decisions fail to promote the child’s basic needs and interests.

**Pediatric Decision Making: Ross, Rawls, and Getting Children and Families Right**


What process ought to guide decision making for pediatric patients? The prevailing view is that decision making should be informed and guided by the best interest of the child. A widely discussed structural model proposed by Buchanan and Brock focuses on parents as surrogate decision makers and examines best interests as guiding and/or intervention principles. Working from two recent articles by Ross on “constrained parental autonomy” in pediatric decision making (which is grounded in the Buchanan and Brock model), I discuss (supportively) features of Ross’s effort *vis-a-vis* the best interest standard. I argue that any pediatric decision-making model that brackets or formally limits an engagement with the child patient assumes too much. Further, any model that under appreciates the place of parents and their autonomy, and the dynamic parent-child relationship, misses an opportunity to broaden the clinical encounter by considering questions of justice for the child (Rawls) and within a family (Ross). In this context, I focus on the child’s emerging and ongoing emotional and intellectual development and autonomy—their capabilities and identifying primary goods.

**A Working Un-Conference**

**A Working Un-Conference to Advance Innovations Among Clinical Ethics Programs**


In an effort to create new synergies to fill gaps in evaluation of value, assessment of quality, and definition of roles in clinical ethics programs, we convened a meeting entitled Innovations in Clinical Ethics: A Working Un-Conference (the Un-Conference) in August 2018. The Un-Conference was conceived to be a working event aimed at promoting cross-pollination and idea generation for innovative practices in clinical ethics. The event was attended by 95 individuals from 62 institutions, representing a wide diversity of healthcare systems, who believed in the concept and brought their enthusiasm and expertise to share with others. As a product of the Un-Conference, whitepaper groups developed summaries and broad overviews of areas that need to be further addressed within our field. The whitepapers are being published in this issue of *The Journal of Clinical Ethics*. The first three whitepapers highlight the broad themes of demonstrating value to the institution, quality assessment, and emerging roles for clinical ethics programs and ethicists. The final whitepaper offers guidance to clinical ethicists engaged in pediatric ethics work and, in conversation with the emerging roles article, thoughtfully reflects on the role of pediatric ethicists.

**Clarifying a Clinical Ethics Service’s Value, the Visible and the Hidden**


Our aim in this article is to define the difficulties that clinical ethics services encounter when they are asked to demonstrate the value a clinical ethics service (CES) could and should have for an institution and those it serves. The topic emerged out of numerous presentations at the Un-Conference hosted by the Cleveland Clinic in August 2018 that identified challenges of articulating the value of clinical ethics work for hospital administrators. After a review these talks, it was apparent that the field of clinical ethics may be at a crisis of sorts due to increased pressure to provide explicit measures to healthcare institutions to concretely demonstrate that CESs make a valuable difference in healthcare delivery. In this article we grapple with how to satisfy the need for demonstrable value in a field in which metrics alone may not capture the scope of clinical ethics practice. We suggest that capturing the value of a CES has been difficult because the benefits of ethics consultation may be overt or attributable to the CES, but are often hidden due to the systems-level and process-oriented nature of clinical ethics work. Part of the difficulty in demonstrating the value of CESs is capturing and conveying all of the ways the integration of a CES throughout an institution positively affects patients, families, visitors, healthcare professionals, administrators, and the institution itself. Our aim is to (1) elucidate the multifaceted value added by a CES, including value that tends to be hidden and (2) suggest how to demonstrate value to others in a way that is not simplistic or reductionistic.

**Emerging Roles of Clinical Ethicists**


Debates regarding clinical ethicists’ scope of practice are not novel and will continue to evolve. Rapid changes in healthcare delivery, outcomes, and expectations have necessitated flexibility in clinical ethicists’ roles whereby hospital-based clinical ethicists are expected to be woven into the institutional fabric in a way that did not exist in more traditional relationships. In this article we discuss three emerging roles: the ethicist embedded in the interdisciplinary team, the ethicist with an expanded educational mandate, and the ethicist as a therapeutic presence in the patient care space. Such expanded capacities offer more robust, positive contributions to institutional culture, stakeholders’ relationships, and patient-centered care.

**Pediatric Ethics Consultation: Practical Considerations for the Clinical Ethics Consultant**

Caroline A. Buchanan, Johan C. Bester, Bethany Bruno, Clare Delany, Kerri O. Kennedy, Tracy Kooogler,

Clinical ethics consultants face a wide range of ethical dilemmas that require broad knowledge and skills. Although there is considerable overlap with the approach to adult consultation, ethics consultants must be aware of differences when they work with infant, pediatric, and adolescent cases. This article addresses unique considerations in the pediatric setting, reviews foundational theories on parental authority, suggests practical approaches to pediatric consultation, and outlines current available resources for clinical ethics consultants who wish to deepen their skills in this area.

Comprehensive Quality Assessment in Clinical Ethics

Scholars and professional organizations in bioethics describe various approaches to “quality assessment” in clinical ethics. Although much of this work represents significant contributions to the literature, it is not clear that there is a robust and shared understanding of what constitutes “quality” in clinical ethics, what activities should be measured when tracking clinical ethics work, and what metrics should be used when measuring those activities. Further, even the most robust quality assessment efforts to date are idiosyncratic, in that they represent evaluation of single activities or domains of clinical ethics activities, or a range of activities at a single hospital or healthcare system. Countering this trend, in this article we propose a framework for moving beyond our current ways of understanding clinical ethics quality, toward comprehensive quality assessment. We first describe a way to conceptualize quality assessment as a process of measuring disparate, isolated work activities; then, we describe quality assessment in terms of tracking interconnected work activities holistically, across different levels of assessment. We conclude by inviting future efforts in quality improvement to adopt a comprehensive approach to quality assessment into their improvement practices, and offer recommendations for how the field might move in this direction.

Letters
Letter: Words Matter in the Lives of Transgender Youth: Response to “Family Discordance Regarding Fertility Preservation for a Transgender Teen: An Ethical Case Study”

Letter: In Response to “Words Matter in the Lives of Transgender Youth”

The Journal of Clinical Ethics, Volume 30, Number 2, Summer 2019

At the Bedside
When Adolescents May Die

In this article I will discuss how clinicians might best treat adolescents who may die. I initially discuss these patients’ cognition, emotional tendencies, and sensitivity to interpersonal cues. I next discuss their parents’ feelings of loss and guilt and their clinicians’ risk of imposing their own moral views without knowing this. I then address the practical concerns of helping these patients gain or regain resilience and to identify strengths they have had in the past. I finally explore who, among staff, might be best able to do this. I highlight as the main goal that patients, their parents, and ideally also their clinicians are able to come to agree on the best course the patients should take.

Features
The States as Laboratories: Regulation of Decisions for Incapacitated Patients

In the United States, patients who lose the ability to make their own medical decisions are subject to the laws of their respective states. Laws governing advance directives and physician orders for life-sustaining therapies (POLST), and establishing a surrogate in the absence of an advance directive, vary substantially by jurisdiction. This article traces those laws from their origins, describes current practices and challenges with their application to patient care, and considers future avenues for ethics research and legislative reform.

The Clinician as Clinical Ethics Consultant: An Empirical Method of Study

Some 30 years ago the role of the clinical ethics consultant (CEC) was formalized. At the time, the perception of the role differed between two groups serving in that capacity, clinicians and nonclinicians. Differences in their roles reflected their training and experience.
These divergent views were resolved semantically by designating the role of the CEC as “ethics facilitation.” In practice, the different perspectives have remained. However, the subsequent published literature on clinical ethics consultation has not adequately reflected the activity of the clinician as a CEC.

There have been recurring unanswered calls for the acquisition of empirical data on the nature of the problems that prompt ethics consultation requests and the functions required to address them. The authors introduce a template that provides a means to acquire such data for clinician ethicists. A similar instrument could be constructed to reflect the role of the nonclinician ethicist serving in that capacity.

The ASBH Approach to Certify Clinical Ethics Consultants Is Both Premature and Inadequate
In November 2018 the American Society for Bioethics and Humanities (ASBH) administered the first Healthcare Ethics Consultant Certification examination to 138 candidates, 136 of whom (98.5 percent) passed and were “certified” as “healthcare ethics consultants.” I believe this certification process is both premature and inadequate.

Certification for ethics consultants is premature because, as Kornfeld and Prager state repeatedly in their article in this issue of The Journal of Clinical Ethics, “The Clinician as Clinical Ethics Consultant: An Empirical Method of Study,” there is a lack of “empirical data on the nature of the problems that prompt ethics consultation requests and on the functions required to address them.” These authors proceed to provide a model for the kind of empirical data collection that is needed.

Even more relevant, the ASBH model that certifies clinical ethics consultants is inadequate. First, it is inappropriate for a nonclinical organization such as the ASBH to claim the right to certify a clinical process, ethics consultation, involving patients and health professionals. Second, the current certification process requires only a written examination in contrast to the two-step quality attestation process proposed in 2013 by Eric Kodish, MD, and 11 other senior members of the ASBH, including its then president.

Third and most importantly, the eligibility criteria for being certified to work on hospital units and to make clinical recommendations for patients and families are minimal and insufficient. The only stated requirements are a bachelor’s degree and 400 hours of healthcare ethics consulting experience. By contrast, practicing physicians and nurses train for many years to gain clinical experience that enables them to apply clinical ethical standards in the care and management of all inpatients and outpatients, not just the small percent for whom an ethics consultation is requested.

Roles of the Clinical Ethics Consultant: A Response to Kornfeld and Prager,
We believe that clinical ethics consultants (CECs) should offer advice, options, and recommendations to attending physicians and their teams. In their article in this issue of The Journal of Clinical Ethics, however, Kornfeld and Prager give CECs a somewhat different role. The CEC they describe may at times be more aptly understood as a medical interventionist who appropriates the roles of the attending physician and the medical team than as a traditional CEC. In these remarks, we distinguish the role of the CEC from that of the physician, in contrast to some of these authors’ recommendations, which confuse the two roles.

Moving Towards a New Hospital Model of Clinical Ethics
The role of clinical ethics consultant in hospitals was created about 30 years ago. Since that time, two very different models for clinical ethics consultation, and who should perform it, have arisen: clinician ethicists or nonclinician ethicists, or bioethicists. Neither model provides everything that hospitals might need, and both include perspectives that are not ideal for hospital practice. It’s time for a new model, one designed specifically to meet the needs of hospital patients, one we might call the hospital model of clinical ethics (HMCE).

Elements of an Ethics Consultation
In the context of all of the discussion about “Fletcherian” ethics consultation, we’re including this description of ethics consultation for clarity and in deference to the work of John C. Fletcher. It’s reprinted from the third edition of Fletcher’s Introduction to Clinical Ethics.—The Editors

Physicians’ Perspectives on Adolescent and Young Adult Advance Care Planning: The Fallacy of Informed Decision Making
Advance care planning (ACP) is a process that seeks to elicit patients’ goals, values, and preferences for future medical care. While most commonly employed in adult patients, pediatric ACP is becoming a standard of practice for adolescent and young adult patients with potentially life-limiting illnesses. The majority of research has focused on patients and their families; little attention has been paid to the perspectives of healthcare providers (HCPs) regarding their perspectives on the process and its potential benefits and limitations. Focus groups were conducted
with 15 physicians as part of a larger study of adolescent and young adult ACP in hematopoietic stem cell transplant (HSCT) patients. This study identified two categories important to the utility of ACP in pediatric HSCT patients; (1) the temporal context of ACP and decision making and (2) the limitations of pediatric ACP, with subcategories identified as (a) embodied and witnessed knowing, (b) the impact of clinical cascades—when the treatment of one organ system creates complications in another system that needs to be treated—and a creation of a “new normal” following complications of illness and its treatment in the pediatric intensive care unit (PICU), (c) the balancing of adolescents’ autonomy with their capacity to make informed medical decisions, and (d) the epistemological frames that differ between HCP and patients and their families. These findings support ACP in adolescent and young adult HSCT patients, with a number of implications for practice as this process becomes more common.

**Fertility Preservation for a Teenager with Differences (Disorders) of Sex Development: An Ethics Case Study**

Fertility preservation has become more common for various populations, including oncology patients, transgender individuals, and women who are concerned about age-related infertility. Little attention has been paid to fertility preservation for patients with differences/disorders of sex development (DSD). Our goal in this article is to address specific ethical considerations that are unique to this patient population. To this end, we present a hypothetical DSD case. We then explore ethical considerations related to patient’s age, risk of cancer, concern about genetic transmission of a DSD condition to children, co-occurring gender dysphoria, and access to experimental fertility preservation procedures. Given the limitations of current technologies, we recommend offering fertility preservation to individuals living with DSD using an informed decision-making approach that instills realistic expectations and minimizes the potential for false hope. Finally, we conclude with practical recommendations for this case based on the ethical considerations.

**Medical Education and Practice**

**Perils of the Hidden Curriculum: Emotional Labor and “Bad” Pediatric Proxies**

Today’s medical training environment exposes medical trainees to many aspects of what has been called “the hidden curriculum.” In this article, we examine the relationship between two aspects of the hidden curriculum, the performance of emotional labor and the characterization of patients and proxies as “bad,” by analyzing clinical ethics discussions with resident trainees at an academic medical center. We argue that clinicians’ characterization of certain patients and proxies as “bad,” when they are not, can take an unnecessary toll on trainees’ emotions. We conclude with a discussion of how training in ethics may help uncover and examine these aspects of the hidden curriculum.

**Consent Obtained by Residents: Informed by the Uninformed?**

Informed consent is central to the bioethical principle of respect for persons, a process that involves a discussion between the physician and patient with disclosure of information sufficient to allow the patient to make an informed decision about her or his care. However, despite the importance of informed consent in clinical practice, the process is often ritualized, perfunctory, and performed by individuals with little or no training in the consent process. This article discusses the lack of medical students’ and residents’ training in informed consent and questions the practice of allowing untrained residents and surrogates to obtain consent from patients.

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**At the Bedside**

**The Edge-of-the-Field of Clinical Ethics Now, After 30 Years: Does Research Ethics Show Us the Way?**

There have been many advances in clinical ethics over the last three decades, since The Journal of Clinical Ethics first came about. This issue of JCE notes some of them. Fortuitously for this goal, new requirements for doing research just have been published, and the leading United States research ethics meeting has just concluded. The conference offered edge-of-the-field presentations in research ethics, and indicates where we should go beyond this edge: what we still have to do. In this article I build upon foundations to explore what they imply for what we should do now in our clinics.

**Special Section: 30 Years of The Journal of Clinical Ethics**

**Clinical Medical Ethics: Its History and Contributions to American Medicine**

In 1972, I created the new field of clinical medical ethics (CME) in the Department of Medicine at the University of Chicago. In my view, CME is an intrinsic part of medicine and is not a branch of bioethics or philosophical ethics or legal ethics. CME must be practiced and applied by licensed clinicians in their routine, daily encounters with inpatients and outpatients. CME addresses many clinical issues such as truth-telling, informed consent, confidentiality,
surrogate decision making, and end-of-life care, while also encouraging personal, humane, and compassionate interactions between doctors and patients.

The goals of CME are to improve patient care and outcomes by helping physicians and other health professionals identify and respond to clinical-ethical challenges that arise in the ordinary care of patients. As Edmund Pellegrino, Peter A. Singer, and I wrote in the first issue of The Journal of Clinical Ethics, 30 years ago: “The central goal of CME is to improve the quality of patient care by identifying, analyzing, and contributing to the resolution of ethical problems that arise in the routine practice of clinical medicine.”

In this article, I intend to discuss the origins of the field of CME, its goals and methods, the relationship between the broad field of CME and the much narrower practice of ethics consultation, the contributions of the MacLean Center at the University of Chicago in developing the field of CME, and, finally, how CME has improved the practice of medicine in the United States.

Once and Future Clinical Neuroethics: A History of What Was and What Might Be

While neuroethics is generally thought to be a modern addition to the broader field of bioethics, this subdiscipline has existed in clinical practice throughout the course of the 20th century. In this essay, Fins describes an older tradition of clinical neuroethics that featured such physician-humanists as Sir William Osler, Wilder Penfield, and Fred Plum, whose work and legacy exploring disorders of consciousness is highlighted. Their normative work was clinically grounded and focused on the needs of patients, in contrast to modern neuroethics, which is more speculative and distant from the lived reality of the clinic. Using recent developments in the diagnosis and treatment of disorders of consciousness, and the history of the vegetative and minimally conscious states, Fins asks why modern neuroethics has taken this turn and what can be done to restore clinical neuroethics to a more proportionate place in the field.

Clinical Ethics in Pediatrics: An International Perspective

In this article, we first review the development of clinical ethics in pediatrics in the United States. We report that, over the last 40 years, most children’s hospitals have ethics committees but that those committees are rarely consulted. We speculate that the reasons for the paucity of ethics consults might be because ethical dilemmas are aired in other venues. The role of the ethics consultant, then, might be to shape the institutional climate and create safe spaces for the discussion of difficult and sometimes contentious issues. Finally, we report how pediatric clinical ethics has evolved differently in a number of other countries around the world.

Reflection of a Physician-Writer: On Why I Write

In the course of their increasingly busy lives, physicians encounter many emotions that move and challenge them. Writing is a valuable tool for self-expression and making sense of the world. Physicians are often concerned about patients’ confidentiality and not upsetting their colleagues, but writing can be one of the best ways of sustaining a healthy and meaningful career and effecting change.

“Clinical” Surgical Ethics

The practice of surgery requires consideration of a number of specific aspects of clinical medical ethics that are different from those most influential in other areas of medical care. The nature of surgical care alters the sense of responsibility that surgeons feel for their actions and also alters the relationship between surgeons and patients. Because surgical care requires patients to place such great trust in their surgeons, surgical informed consent must emphasize the importance of that trust. Surgeons must use innovative means to solve individual patient problems even if the result is a novel operation. Surgical procedures may be altered due to the unexpected findings in the operating room and therefore surgeons must have considered how to respond in such situations. The future of surgical practice will inevitably lead to increasing ethical concerns in maintaining the ethical dimension of surgery, in allowing autonomy for trainees while maintaining patients’ safety, and in balancing surgical risks of prophylactic surgery with the genetic predisposition to develop cancer.

Ethics and Evidence

Towards the end of the last century, bioethics underwent an “empirical turn,” characterized by an increasing number of empirical studies about issues of bioethical concern. Taking a cue from the evidence-based medicine movement, some heralded this as a turn toward evidence-based ethics. However, it has never been clear what this means, and the strategies and goals of evidence-based ethics remain ambiguous. In this article, the author explores what the potential aims of this movement might be, ultimately arguing that, while the development of good empirical research can and should aid in ethical deliberation, one ought to avoid assuming or suggesting that empirical studies themselves determine normative prescriptions and proscriptions. The limits of the use of empirical studies in bioethics are
explored in detail, and 10 potential ways that such studies can soundly contribute to bioethics are described. Good ethics depends upon sound facts, but ethics cannot be based on evidence alone.


Questions related to end-of-life decision making are common in clinical ethics and may be exceedingly difficult. Chief among these are the provision of cardiopulmonary resuscitation (CPR) and do-not-resuscitate orders (DNRs). To better address such questions, clarity is needed on the values of medical ethics that underlie CPR and the relevant moral framework for making treatment decisions. An informed consent model is insufficient to provide justification for CPR. Instead, ethical justification for CPR rests on the rule of rescue and on substituted interest judgments. Patients’ known wishes and values are relevant, particularly in protecting them from unwanted CPR. Clinicians should rescue patients with the means at their disposal, as a prima facie moral imperative, unless there are compelling reasons to refrain. We present a moral framework for making decisions regarding CPR and DNR.

2018

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At the Bedside

Helping Patients to Achieve What They Find Most Meaningful in Life


Patients’ and families’ greatest need is often to do what for them is most meaningful. This may be, for example, their religion, their family, or their doing good for others. This piece will explore ways in which care providers may help maximize these ends. Paradigms offered will include Jehovah’s Witness patients needing kidney transplants, a transgender adolescent wanting his sperm preserved, care providers’ deciding whether to disclose that a deceased organ donor had HIV, and care providers seeking to do good for children profoundly impaired and adults who feel shame for just existing.

Features

Familial Discordance Regarding Fertility Preservation for a Transgender Teen: An Ethical Case Study


A 16-year-old adolescent who identifies as transgender wishes to consider fertility preservation prior to the use of gender-affirming hormones. The adolescent’s parents are divorced, and one parent supports fertility preservation while the other does not. This case explores the minor’s future reproductive autonomy and parental decision making in a field where there is limited evidence of known harms and benefits to the use of fertility preservation in the transgender population and about future potential regret from lack of consideration of fertility preservation during the prime window of opportunity. This case is created from a composite of cases seen at multiple institutions.

Proxy Consent by a Physician When a Patient’s Capacity Is Equivocal: Respecting a Patient’s Autonomy by Overriding the Patient’s Ostensible Treatment Preferences


Respect for patients’ autonomy has taken a central place in the practice of medicine. Received wisdom holds that respect for autonomy allows overriding a patient’s treatment preferences only if the patient has been found to lack capacity. This understanding of respect for autonomy requires a dichotomous approach to assessing capacity, whereby a patient must be found either to have full capacity to make some particular treatment decision or must be found to lack capacity to make that decision. However, clinical reality is more complicated, and, in borderline cases, different physicians may arrive at disparate judgments of capacity. In such cases, when capacity-determination protocols fail to achieve consensus, physicians would benefit from guidance regarding the clinical decision-making process necessary to elucidate the most ethically sound course of action. This article considers one such case and argues that, in a limited number of cases, respect for autonomy may require overriding a patient’s stated treatment preference when a capacity determination is equivocal, even though the patient has not clearly demonstrated a lack of capacity.

Training to Increase Rater Reliability When Assessing the Quality of Ethics Consultation Records with the Ethics Consultation Quality Assessment Tool (ECQAT)


The Ethics Consultation Quality Assessment Tool (ECQAT) establishes standards by which the quality of ethics consultation records (ECRs) can be assessed. These standards relate to the ethics question, consultation-specific information, ethical analysis, and recommendations and/or conclusions, and result in a score associated with one of
four levels of ethics consultation quality. For the ECQAT to be useful in assessing and improving the quality of healthcare ethics consultations, individuals who rate the quality of ECRs need to be able to reliably use the tool.

We developed a short course to train ethics consultants in using the ECQAT, and evaluated whether the participants (1) achieved an acceptable level of calibration in matching expert-established quality scores for a set of ethics consultations, and (2) were satisfied with the course. We recruited 28 ethics consultants to participate in a virtual, six-session course. At each session participants and faculty reviewed, rated, and discussed one to two ECRs. The participants’ calibration in matching expert-established quality scores improved with repeated exposure at all levels of ethics consultation quality. Participants were generally more accurate when assessing consultation quality at the dichotomous level of “acceptable” (scores of three or four) versus “unacceptable” (scores of one or two) than they were with more a specific score. Participants had higher rates of accuracy with the extreme ratings of “strong” (level four) or “poor” (level one). Although participants were highly satisfied with the course, only a minority of participants achieved the prespecified acceptable level of calibration (that is, 80 percent or greater accuracy between their score and expert-established scores). These results suggest that ECQAT training may require more sessions or need modification in the protocol to achieve higher reliability in scoring. Such trainings are an important next step in ensuring that the ECQAT is a tool that can be used to promote improvement in ethics consultation quality.

**Technical Considerations for Implementation of Tele-Ethics Consultation in the Intensive Care Unit**


**Background:** Robust ethics consultation services cannot be sustained by all hospitals; consultative service from a high-volume center via teleconferencing is an attractive alternative. This pilot study was conceived to explore the feasibility and understand the practical implications of offering such a service.

**Methods:** High-definition videoconferencing was used to provide real-time interaction between the rounding clinicians and a remote clinical ethicist. Data collection included: (1) evaluation of the hardware and software required for teleconferencing, and (2) comparison of ethics trigger counts between the remote and on-site ethicist during rounds.

**Results:** Issues with audio represented the majority of technical problems. Once technical difficulties were addressed, the on-site ethicist’s count of “triggers” was not statistically different from the count of the remote ethicist.

**Conclusion:** Remote clinical ethics rounding is feasible when the equipment is optimized. Remote ethicists can identify similar numbers of “triggers” for possible ethical issues when compared to on-site ethicist numbers.

**Systematic Review of Typologies Used to Characterize Clinical Ethics Consultations**


**Introduction:** Classifying the ethical issues in clinical ethics consultations is important to clinical practice and scholarship. We conducted a systematic review to characterize the typologies used to analyze clinical ethics consultations.

**Methods:** We identified empirical studies of clinical ethics consultation that report types of ethical issues using PubMed. We screened these articles based on their titles and abstracts, and then by a review of their full text. We extracted study characteristics and typologies and coded the typologies.

**Results:** We reviewed 428 articles; 30 of the articles fulfilled our inclusion criteria. We identified 27 unique typologies. Each typology contained five to 47 categories (mean = 18). The most common categories were DNAR (do-not-attempt-resuscitation) orders (19 of the 27 typologies, or 70 percent), capacity (18 of the typologies, or 67 percent), withholding (18 of the typologies, or 67 percent), withdrawing (17 of the typologies, or 63 percent), and surrogate or proxy (16 of the typologies, or 59 percent). Only seven (26 percent) of the typologies contained all five of the most common categories.

The typologies we used to characterize clinical ethics consultation exhibit significant heterogeneity and several conceptual limitations. A common typology is needed whose development may require multi-institutional collaboration and could be facilitated by professional organizations.
patients who need an organ and will accept blood transfusion to include the Jehovah’s Witness patient on a waiting list for a donated organ. If the Jehovah’s Witness patient is listed and receives an organ, then a patient who also needs an organ, and who is willing to accept all care to optimize the success of the transplant, may be denied an organ.

To frame the ethical dilemma outlined above we present an anonymized case of a Jehovah’s Witness woman in urgent need of a kidney, who was referred to one of the authors’ institution’s transplant center. We review the evolution of the Jehovah’s Witness position on blood transfusion and the medical community’s efforts to provide care that accommodates this religious commitment. If Witnesses are to be denied transplant in the name of justice, there must be an ethically sound reason. We identify two rationales in the literature: (1) this allocation is unacceptable because it will cost lives; (2) resources should be allocated to patients who comply with the standard of care. We argue that neither apply to this dilemma. We also emphasize the importance of examining the data on outcomes of transplant with and without transfusion. Our interpretation of the published data on transplant without transfusion is that the outcomes are similar. We conclude that, in the absence of data that resources are risked, it is not ethical to refuse to include a Jehovah’s Witness patient on a waiting list for an organ. Finally, we reflect on the heterogeneity in transplant institutes’ polices for accepting Jehovah’s Witness patients.

Cases from the Cleveland Clinic

Discomfort as a Catalyst: An Ethical Analysis of Donation after Cardiac Death in a Patient with Locked-In Syndrome


Donation after cardiac death (DCD) traditionally occurs in two patient populations: (1) those who do not meet neurological death criteria but who have suffered severe neurological damage, and (2) those who are fully alert and awake but are dependent on machines. This case highlights the unique dilemma when a patient falls between these two populations—conscious and cognitively intact, but completely paralyzed except for limited eye movement, afflicted by what the medical community refers to as locked-in syndrome. Prompted by the treatment team’s discomfort, an ethics consultant examined whether the team was obligated to discuss a decision to donate with the patient, who was a registered organ donor. This article shows how, in determining whether or not to talk to the patient or family during end-of-life decision making, the weight assigned to the various ethical concerns in the case—the patient’s condition, the decision to be made, and the family’s agreement or disagreement regarding the patient’s wishes—can “swing the pendulum” of ethical analysis in different ways. The comfort of the patient must be accorded the highest priority, as well as the needs of the patient’s family. This case study highlights the nuanced contextual factors necessary to guide a treatment team’s approach to DCD for a patient with uncertain decision-making capacity.

Perspective

To Give or Not to Give: The Challenge of Pharmaceutical Coupons


Diabetes is epidemic and many people cannot afford insulin, a lifesaving medication, as its price has increased by almost 160 percent in the past five years. To help subsidize the cost of insulin, one of the staff members at my hospital would like to give patients copayment coupons provided to her by pharmaceutical companies. I advised my colleague to stop distributing these branded coupons, as they promote particular pharmaceutical companies. This practice is not consistent with the policy on interaction with industry established by the Johns Hopkins Health System. Yet at the same time, I want my patients to be able to afford their insulin so they can treat their diabetes. I truly believe in utilitarianism. Would temporarily subsidizing patients’ insulin make me and my staff better healthcare providers? Would this minimize my patients’ financial burden? Would giving away medications coupons help pharmaceutical companies influence me as a prescriber? This challenge created a personal internal debate and profound moral distress.

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At the Bedside

How We May Become Detached from Our Patients and What We Can Do If This Happens


When clinicians provide clinical care or participate in ethics consultations, they may feel exceptionally painful emotions. When they do, they may distance themselves emotionally from patients and families. This distancing may harm these parties profoundly. It is therefore critical that clinicians avoid this distancing. In this piece, I present an approach that lies outside traditional practice that clinicians may use to try to avoid and even reverse this distancing, if and when they sense that this may be occurring. This approach may also benefit patients and families. It may increase their sense that their clinicians are working with them as allies to achieve their shared medical goals.

Features
Deathbed Confession: When a Dying Patient Confesses to Murder: Clinical, Ethical, and Legal Implications
Laura Tincknell, Anne O’Callaghan, Joanna Manning, and Phillipa Malpas, *The Journal of Clinical Ethics* 29, no. 3 (Fall 2018): 179-84.
During an initial palliative care assessment, a dying man discloses that he had killed several people whilst a young man. The junior doctor, to whom he revealed his story, consulted with senior palliative care colleagues. It was agreed that legal advice would be sought on the issue of breaching the man’s confidentiality. Two legal opinions conflicted with each other. A decision was made by the clinical team not to inform the police.

In this article the junior doctor, the palliative medicine specialist, a medical ethicist, and a lawyer consider the case from their various perspectives.

Ethical Challenges in Acute Evaluation of Suspected Psychogenic Stroke Mimics
Tissue plasminogen activator (tPA) is administered to patients with suspected ischemic stroke to improve blood flow to the brain. In rare cases, patients present with complaints of stroke symptoms that appear to be non-organic due to malingering, factitious disorder, or conversion disorder (psychogenic stroke mimics). Deciding whether or not to administer tPA to these patients can be challenging. The risk of hemorrhage after administration of tPA is low, but not zero. The ethical principles of beneficence and nonmaleficence need to be weighed carefully in these situations. We present two cases of patients with suspected psychogenic stroke mimics to illustrate the ethical challenges faced in identifying and managing psychogenic stroke mimics. Further research is needed to demonstrate effective treatment strategies for patients with acute stroke symptoms of psychogenic etiology.

Positive HIV Test Results from Deceased Organ Donors: Should We Disclose to Next of Kin?
In the context of deceased organ donation, donors are routinely tested for HIV, to check for suitability for organ donation. This article examines whether a donor’s HIV status should be disclosed to the donor’s next of kin.

On the one hand, confidentiality requires that sensitive information not be disclosed, and a duty to respect confidentiality may persist after death. On the other hand, breaching confidentiality may benefit third parties at risk of having been infected by the organ donor, as it may permit them to be tested for HIV and seek treatment in case of positive results.

We conclude that the duty to warn third parties surpasses the duty to respect confidentiality. However, in order to minimize risks linked to the breach of confidentiality, information should be restrained to only concerned third parties, that is, those susceptible to having been infected by the donor.

Posthumous HIV Disclosure and Relational Rupture
In response to Anne L. Dalle Ave and David M. Shaw, we agree with their general argument but emphasize a moral risk of HIV disclosure in deceased donation cases: the risk of relational rupture. Because of the importance that close relationships have to our sense of self and our life plans, this kind of rupture can have long-ranging implications for surviving loved ones. Moreover, the now-deceased individual cannot participate in any relational mending. Our analysis reveals the hefty moral costs that disclosure can bring, which should influence what information is given to would-be donors and how organ procurement coordinators approach these conversations.

Plain Anabaptists and Healthcare Ethics
Plain Anabaptists are a small but rapidly growing ethnonreligious society with significant concentrations of population in a number of regions in North America. Among the most widely known of the various groups of Plain Anabaptists are the Amish and the Old Order Mennonites. It is the purpose of this article to provide insight into the culture and values of the Plain Anabaptists so that those who may be called upon to address ethical conflict involving Plain Anabaptists can do so with appropriate knowledge and sensitivity. The discussion of the culture and values of the Plain Anabaptists will be organized as follows: first we will explore the implications of Plain Anabaptist culture and values for applying the ethical principles of respect for autonomy and beneficence/nonmaleficence. Second, a brief description of several elements of Plain Anabaptist culture will be discussed with attention to the potential they create for ethical conflict in the healthcare setting.

Refusal of Vaccination: A Test to Balance Societal and Individual Interests
While all states in the United States require certain vaccinations for school attendance, all but three allow for religious exemptions to receiving such vaccinations, and 18 allow for exemptions on the basis of other deeply held personal beliefs. The rights of parents to raise children as they see fit may conflict with the duty of the government and society to protect the welfare of children. In the U.S., these conflicts have not been settled in a uniform and consistent
manner. We apply a test that provides a concrete and formal rubric to evaluate such conflicts. For some vaccinations, based on the individual medical characteristics of the disease and the risks of being unvaccinated, the test would suggest that permitting conscientious exemptions is ethical. However, for vaccinations protecting against other diseases that are more severe or easily transmitted, the test would suggest that the federal government may ethically impose laws that deny such exemptions.

**Nursing Ethics Huddles to Decrease Moral Distress among Nurses in the Intensive Care Unit**


Background: Moral distress (MD) is an emotional and psychological response to morally challenging dilemmas. Moral distress is experienced frequently by nurses in the intensive care unit (ICU) and can result in emotional anguish, work dissatisfaction, poor patient outcomes, and high levels of nurse turnover. Opportunities to discuss ethically challenging situations may lessen MD and its associated sequela.

Objective: The purpose of this project was to develop, implement, and evaluate the impact of nursing ethics huddles on participants’ MD, clinical ethics knowledge, work satisfaction, and patient care among ICU nurses.

Sample and Setting: The sample, 32 nurses from three ICU settings in an 800-bed tertiary academic medical center, participated in six nursing ethics huddles over a two-month period.

Methods: Alvita K. Nathaniel’s Theory of Moral Reckoning guided development of the nursing ethics huddle process. The Moral Distress Thermometer was administered at three data points: baseline level of MD, and pre- and post-huddle to determine changes in the subjects’ level of MD. Focused content analysis was used to analyze qualitative responses from questionnaires about the subjects’ perception of the effect of the huddles on work satisfaction and patient care. Knowledge attainment was evaluated via open-ended short-answer questions.

Results: Overall, use of nurse-ethicist-led nursing ethics huddles was associated with improved quality of work life, patient care, and clinical ethics knowledge. The change in pre- and post-nursing ethics huddles MD scores was statistically significant (p < 0.0001).

"I Would Do It All Over Again": Cherishing Time and the Absence of Regret in Continuing a Pregnancy after a Life-Limiting Diagnosis


Parents, after learning of a life-limiting fetal condition (LLFC), experience emotional distress and must consider options that impact the remainder of the pregnancy, their future lives, and family members. For those who continue, little is known about their long-term presence or absence of regret about their choice, the reasons for this feeling, or its impact on their life. The aim of this research was to examine the concept of decision regret in parents who opted to continue a pregnancy affected by an LLFC. The contextual factors, conditions, and consequences surrounding the presence or absence of regret were analyzed.

Data were retrieved from a cross-sectional study using the Quality of Perinatal Palliative Care and Parental Satisfaction Instrument. Participants were parents (N = 405) who experienced a life-limiting prenatal diagnosis and opted to continue their pregnancy. Secondary data analysis examined qualitative responses (121/402) to an item addressing regret. Dimensional analysis was used to examine data, identifying context, conditions, and consequences associated with the presence or absence of regret.

Absence of regret was articulated in 97.5 percent of participants. Parents valued the baby as a part of their family and had opportunities to love, hold, meet, and cherish their child. Participants treasured the time together before and after the birth. Although emotionally difficult, parents articulated an empowering, transformative experience that lingers over time.

**Perspectives**

**The Mission of Safety Net Hospitals: Charity or Equity?**


The traditional mission of safety net hospitals has been charity, providing the best healthcare for all individuals no matter their ability to pay. The focus has been on vulnerable populations that are low-income, uninsured, and other upstream circumstances that manifest downstream as poor health, poor health outcomes, and repeated high-cost interventions that fail to break cycles of perpetual health instability. Safety net hospitals are committed to serving their populations, even if only temporarily, through provision of subsidies and filling gaps that exist in patients’ lives. These interventions do not lead to the elimination of gaps, hence cyclical health instability persists. It is a new day in healthcare and what it means for people to be well. The focus is on improving health outcomes by addressing root causes of health instability such as unstable housing, income, education, and access to affordable healthy foods. This gives us pause to reflect on the traditional mission of safety net hospitals and the impact of charity in isolation. Are safety net hospitals missing an opportunity to mitigate and eliminate perpetual health instability? Can they shift the paradigm of healthcare for vulnerable populations to alter their quality-of-life course? To move forward, safety net hospitals have to change their mind set and existing narratives about what is possible for vulnerable populations to...
achieve. These historic giants in healthcare have an opportunity to use their assets and employ a methodology of disrup


tion and innovation to shift the mission of safety net healthcare from charity to equity.

**Scribes, Electronic Health Records, and the Expectation of Confidentiality**

Electronic health record (EHRs) have largely replaced obsolete paper medical charts. This replacement has produced an increased demand on physicians’ time and has compromised efficiency. In an attempt to overcome this perceived obstacle to productivity, physicians turned to medical scribes to perform the work required by EHRs. In doing so, they have introduced an uninvited participant in the physician-patient relationship and compromised patients’ confidentiality. Scribes may be a successful work around for physicians frustrated by EHRs, but patients’ confidentiality should not be sacrificed in the process.

**At the Bedside**
Edge-of-the-Field Ethics Consulting: What Are We Missing?

Ethics consultants’ grasp of ethical principles is ever improving. Yet, what still remains and will remain lacking is their ability to access factors that lie outside their conscious awareness and thus still effect suboptimal outcomes. This article will explore several ways in which these poor outcomes may occur. This discussion will include clinicians’ implicit biases, well-intentioned but nonetheless intrusive violations of patients’ privacy, and clinicians’ unwittingly connoting to patients and families that clinicians regard their moral values and conclusions as superior. I shall suggest several ways in which clinicians may seek to reduce these sources of bad outcomes or at least to do better when they occur.

**Features**

Psychiatric Diagnoses and Informed Consent

Although informed consent for treatment has become a cornerstone principle of psychiatric care, the process of diagnosis has remained largely in the hands of the physician alone. While the conferring of a psychiatric diagnosis has historically not been considered a form of medical intervention, the potential impact of a diagnosis for any particular patient may be substantial. This article explores the challenges involved in balancing respect for patients with the physician’s duty of truth-telling and clinical accuracy.

Response to "Psychiatric Diagnoses and Informed Consent"
David Brendel, *The Journal of Clinical Ethics* 29, no. 2 (Summer): 100-1.

A patient’s rights to informed consent and self-determination in psychiatric treatment are well enshrined, but the same rights have not yet been meaningfully extended to patients with regard to psychiatric diagnosis. Andrew Clark’s essay entitled “Psychiatric Diagnoses and Informed Consent” in The Journal of Clinical Ethics empowers both psychiatrists and patients to rethink who “owns” the process of clinical assessment and of bestowing diagnostic labels that may have far-reaching consequences. Clark’s article represents a noteworthy breakthrough in the field’s ongoing journey toward enhancing informed consent, personal dignity, and patients’ active involvement in their own care.

TTaPP: Together Take a Pause and Ponder: A Critical Thinking Tool for Exploring the Public/Private Lives of Patients

The broad use of social networking and user-generated content has increased the online footprint of many individuals. A generation of healthcare professionals have grown up with online search activities as part of their everyday lives. Sites like Facebook, Twitter, and Instagram have given the public new ways to share intimate details about their public and private lives and the lives of their friends and families. As a result, careproviders have the ability to find out more about their patients with just the tap of a key or the click of a mouse. This type of online searching for patient information is known as patient-targeted googling or PTG.

This article provides an overview of the emergence of PTG, identifies the potential benefits and possible pitfalls of engaging in PTG, and explores current ethical frameworks that guide decisions about PTG. The article describes the development of a critical thinking tool developed by the Behavioral Health Ethics Committee at CHI Health, that can serve as a best-practice model for other hospitals and health systems. Called TTaPP (Together Take a Pause and Ponder), this tool is designed to help healthcare professionals across settings practice collaborative critical thinking skills as they consider the ethical questions of whether or not to engage in PTG. Finally, this article suggests areas for further study, including ways to prompt collaboration and appropriate documentation by maximizing electronic medical records systems, exploring the effectiveness of the TTaPP tool as a way to promote a culture of collaborative critical thinking practices, and the attitudes of patients and the public regarding PTG.

Medical Futility in Concept, Culture, and Practice
This article elucidates the premises and limited meaning of medical futility in order to formulate an ethically meaningful definition of the term, that is, a medical intervention’s inability to deliver the benefit for which it is designed. It uses this definition to show the two ways an intervention could become medically futile, to recommend an even more limited usage of medical futility, and to explain why an intervention need not be futile in order to be withdrawn over patient-based objections. If an intervention retains some benefit, then patients or surrogates might legitimately consider that benefit in their case and request the intervention. Physicians might still be justified in declining it on the grounds that the burdens greatly outweigh the benefits, but not on the grounds of futility. Finally, the article uses bioethics research and healthcare litigation to clarify the meaning of futility in practice and recommends alternative language when possible.

**Action Guide for Addressing Ethical Challenges of Resource Allocation Within Community-Based Healthcare Organization**


This article proposes an action guide to making decisions regarding the ethical allocation of resources that affect access to healthcare services offered by community-based healthcare organizations. Using the filter of empirical data from a study of decision making in two community-based healthcare organizations, we identify potentially relevant conceptual guidance from a review of frameworks and action guides in the public health, health policy, and organizational ethics literature. We describe the development of this action guide. We used data from a prior empirical study of the values that influence decision making about the allocation of resources in particular types of community-based healthcare organizations. We evaluated, organized, and specified the conceptual guidance we found in 14 frameworks for ethical decision making. The result is an action guide that includes four domains that are relevant to the context of the decision to be made, eight domains that are relevant to the process of the decision to be made, and 15 domains that are relevant to the criteria of the decision to be made. We demonstrate the potential use of this action guide by walking through an illustrative resource allocation decision. The action guide provides community-based healthcare organizations with a conceptually grounded, empirically informed framework for ethical decision making.

**Treated Vulnerable Populations**

**Medical Decision Making for Medically Complex Children in Foster Care: Who Knows the Child’s Best Interests?**


Approximately one in 10 children in foster care are medically complex and require intensive medical supervision, frequent hospitalization, and difficult medical decision making. Some of these children are in foster care because their parents cannot care for their medical needs; other parents are responsible for their child’s medical needs due to abuse or neglect. In either case, there can be uncertainty about the role that a child’s biological parents should play in making serious medical decisions. Here we highlight some of the ethical challenges inherent in making these decisions for children in foster care, as seen through the lenses of a child welfare provider, an inpatient care physician, and a primary care pediatrician.

**Medically Complex Children in Foster Care: Do Research “Protections” Make This “Vulnerable Population” More Vulnerable?**


Children in foster care are considered a “vulnerable population” in clinical care and research, with good reason. These children face multiple medical, psychological, and social risks that oblige the child welfare and healthcare systems to protect them from further harms. An unintended consequence of the “vulnerable population” designation for children in foster care is that it may impose barriers on tracking and studying their health that creates gaps in knowledge that are key to their receipt of medical care and good outcomes. These gaps in knowledge have implications for justice, beneficence, and maleficence and serve to undermine “protection” of this population. Here we review the challenges of research regarding children in foster care, particularly medically complex children, and offer specific recommendations to include children in foster care in medical research.

**Ethics Consultation Practice**

**The Work of ASBH’s Clinical Ethics Consultation Affairs Committee: Development Processes Behind Our Educational Materials**


The authors of this article are previous or current members of the Clinical Ethics Consultation Affairs (CECA) Committee, a standing committee of the American Society for Bioethics and Humanities (ASBH). The committee is composed of seasoned healthcare ethics consultants (HCECs), and it is charged with developing and disseminating
education materials for HCECs and ethics committees. The purpose of this article is to describe the educational research and development processes behind our teaching materials, which culminated in a case studies book called **A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care** (hereafter, the Study Guide). In this article, we also enumerate how the Study Guide could be used in teaching and learning, and we identify areas that are ripe for future work.

**The Development and Rationale for CECA’s Case-Based Study Guide**


This article discusses the approach of the Clinical Ethics Consultation Advisory Committee (CECA) in developing **A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care**. This article addresses the processes used by the CECA, its use of pivot questions intended to encourage critical reflection, and the target audience of this work. It first considers the salience of case studies in general education and their relevance for training ethics consultants. Second, it discusses the enfolding approach used in presenting the case material designed to engage the trainee in the details of the case while stimulating critical reflection. And, third, this article briefly comments on the target audience with the caveat that even superbly developed cases are prone to misuse, although that prospect should not deter their development.

**Letter**

**Letter: Can Islamic Jurisprudence Justify Procurement of Transplantable Vital Organs in Brain Death?**


In their article, “An International Legal Review of the Relationship between Brain Death and Organ Transplantation,” in *The Journal of Clinical Ethics* 29, no. 1, Aramesh, Arima, Gardiner, and Shah reported on diverse international legislative approaches for justifying procurement of transplantable vital organs in brain death. They stated, “In Islamic traditions in particular, the notion of unstable life is a way to justify organ donation from brain-dead patients that we believe has not been fully described previously in the literature.” This commentary queries the extent to which this concept is valid in accordance with the primary source of Islamic law, that is, the Quran.

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**At the Bedside**

**Slowing Down Fast Thinking to Enhance Understanding**


Stress can make the comprehension of complex information more difficult, yet patients and their family members often must receive, process, and make decisions based on new, complex information presented in unfamiliar and stressful clinical environments such as the intensive care unit. Family members may be asked to make decisions regarding the donation of organs and genetic tissue soon after the death of a loved one, based on new, complex information, under tight time limits. How can we assist patients and families better process complex information while under stress, and to make better decisions for themselves or for a loved one?

**Features**

**“Buying-In” and “Cashing-Out”: Patients’ Experience and the Refusal of Life-Prolonging Treatment**


Surgical “buy-in” is an “informal contract between surgeon and patient in which the patient not only consents to the operative procedure but commits to the post-operative surgical care anticipated by the surgeon.” Surgeons routinely assume that patients wish to undergo treatment for operative complications so that the overall treatment course is “successful,” as in the treatment of a post-operative infection. This article examines occasions when patients buy-in to a treatment course that carries risk of complication, yet refuse treatment when complications arise. We coin this counter-phenomenon “cashing-out.” Cashing-out may elicit negative feelings among careproviders. We question why patients or families may wish to cash-out. One reason may be the changing epistemological position of patients as they experience a complication. The shift from the hypothetical discussion of complications during the initial informed-consent process to the experience of having a complication represents new knowledge. Patients and families may use this knowledge as the basis to revoke consent for some or all of the remaining treatment course. This article seeks to understand cashing-out in terms of the patients’ experiences. We hope to prompt recognition of this phenomenon across medical contexts and to provide impetus for further work to understand why patients may wish to cash-out.

**Impact of Cognitive Load on Family Decision Makers’ Recall and Understanding of Donation Requests for the Genotype-Tissue Expression (GTE) Project**


Genomic research projects that collect tissues from deceased organ and tissue donors must obtain the authorization of family decision makers under difficult circumstances that may affect the authorization process. Using a quasi-experimental design, the Ethical, Legal, and Social Issues (ELSI) sub-study of the Genotype-Tissue Expression (GTEx)
project compared the recall and understanding of the donation authorization process of two groups: family members who had authorized donation of tissues to the GTEx project (the comparison group) and family members who had authorized organ and tissue donations in years previous, who subsequently participated in two different mock-authorization processes that mimicked the GTEx authorization process (the intervention groups). Participants in the comparison and intervention groups were matched on key demographic characteristics.

We found that participants in the intervention groups who experienced a mock-authorization process demonstrated better recall of the tissue donation request than members of the comparison group. Our data indicate that the stress associated with the loss of a loved one limited the ability of family members to recall details about the GTEx project. However, we found a similar lack of knowledge in both the comparison and the intervention group participants, suggesting lack of knowledge may be due to the complexity and unfamiliarity of the information presented to them during the authorization process. We discuss these findings in the context of everyday clinical decision making in cognitively challenging conditions.

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An International Legal Review of the Relationship between Brain Death and Organ Transplantation

The “dead-donor rule” states that, in any case of vital organ donation, the potential donor should be determined to be dead before transplantation occurs. In many countries around the world, neurological criteria can be used to legally determine death (also referred to as brain death). Nevertheless, there is considerable controversy in the bioethics literature over whether brain death is the equivalent of biological death. This international legal review demonstrates that there is considerable variability in how different jurisdictions have evolved to justify the legal status of brain death and its relationship to the dead-donor rule.

In this article, we chose to review approaches that are representative of many different jurisdictions—the United States takes an approach similar to that of many European countries; the United Kingdom’s approach is followed by Canada, India, and influences many other Commonwealth countries; Islamic jurisprudence is applicable to several different national laws; the Israeli approach is similar to many Western countries, but incorporates noteworthy modifications; and Japan’s relatively idiosyncratic approach has received some attention in the literature. Illuminating these different justifications may help develop respectful policies regarding organ donation within countries with diverse populations and allow for more informed debate about brain death and the dead-donor rule.

Clinical Practice
The Bedside Capacity Assessment Tool: Further Development of a Clinical Tool to Assist with a Growing Aging Population with Increased Healthcare Complexities

Background: As the population of the United States ages, chronic diseases increase and treatment options become technologically more complicated. As such, patients’ autonomy, or the right of patients to accept or refuse a medical treatment, may become a more pressing and complicated issue. This autonomy rests upon a patient’s capacity to make a decision. As more older, cognitively and functionally impaired individuals enter healthcare systems, quality assessments of decision-making capacity must be made. These assessments should be done in a time-efficient manner at a patient’s bedside by the patient’s own physician. Thus, a clinically practical tool to assist in decision-making capacity assessments could help guide physicians in making more accurate judgments.

Objectives: To create a clinically relevant Bedside Capacity Assessment Tool (BCAT) to help physicians make timely and accurate clinical assessments of a patient’s decision-making capacity for a specific decision.

Setting: The Department of Medicine, Division of Geriatrics and Palliative Medicine, Zucker School of Medicine at Hofstra/Northwell.
Participants: Geriatric medicine fellows, palliative medicine fellows, and internal medicine residents (n = 30).

Measurements: Subjects used the BCAT to assess the decision-making capacity of patients described in 10 written, clinically complex capacity assessment vignettes. Subjects’ conclusions were compared to those of experts.

Results: The subjects’ and experts’ assessments of capacity had a 76.1 percent rate of agreement, with a range of 50 percent to 100 percent. With removal of three complex outlier vignettes, the agreement rate reached 83.2 percent.

Conclusion: The strong correlation between the two groups—one of physicians in training utilizing the BCAT and the other of specialists in this area—suggests that the BCAT may be a useful adjunct for clinicians who assess decision-making capacity in routine practice. The range indicates that further refinement and testing of this tool is necessary. The potential exists for this tool to improve capacity assessment skills for physicians in clinical practice.

Meaningful Use of Electronic Health Records for Quality Assessment and Review of Clinical Ethics Consultation


Evolving practice requires peer review of clinical ethics (CE) consultation for quality assessment and improvement. Many institutions have identified the chart note as the basis for this process, but to our knowledge, electronic health record (EHR) systems are not necessarily designed to easily include CE consultation notes. This article provides a framework for the inclusion of CE consultation notes into the formal EHR, describing a developed system in the Epic EHR that allows for the elaborated electronic notation of the CE chart note. The implementation of the “meaningful use” criteria for EHR, mandated by the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, requires that health professionals meet certain standards for quality, efficiency, and safety, all of which overlap with the goals of standardization, peer review, and quality improvement within CE consultation.

The Ethics of Bundled Payments in Total Joint Replacement: “Cherry Picking” and “Lemon Dropping”


The Centers for Medicare & Medicaid Services has initiated bundled payments for hip and knee total joint replacement in an effort to decrease healthcare costs and increase quality of care. The ethical implications of this program have not been studied. This article considers the ethics of patient selection to improve outcomes; specifically, screening patients by body mass index to determine eligibility for total joint replacement. I argue that this type of screening is not ethically defensible, and that the bundled payment program as structured is likely to lead to unfair restrictions on who receives total joint replacements.

Law

Colorado’s New Proxy Law: Moving from Statute to Guidelines


In 2016, the Colorado legislature passed an amendment to Colorado’s medical proxy law that established a process for the appointment of a physician to act as proxy decision maker of last resort for an unrepresented patient (Colorado HB 16-1101: Medical Decisions For Unrepresented Patients). The legislative process brought together a diverse set of stakeholders, not all of whom supported the legislation. Following passage of the statutory amendment, the Colorado Collaborative for Unrepresented Patients (CCUP), a group of advocates responsible for initiating the legislative process, coordinated a unique effort to engage these stakeholders in the creation of a set of voluntary guidelines to assist facilities and individual careproviders in the implementation of policies and procedures enabled by the statute. This article delineates the questions and concerns of stakeholders, describes how those issues were addressed within the guidelines, and proposes additional opportunities for research to assess the impact of the legislation in Colorado.

2017

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At the Bedside

New Ways to Cut through Ethical Gordian Knots


Clinicians and ethicists routinely encounter complex ethical dilemmas that seem intractable, which have been described as ethical Gordian knots. How can they best assist patients and surrogate decision makers who are entangled in struggles around the capacity to make life-or-death treatment decisions? In this article I describe unconventional and unorthodox approaches to help slice through these dilemmas.

Features

Comparativism and the Grounds for Person-Centered Care and Shared Decision Making

This article provides a new argument and a new value-theoretical ground for person-centered care and shared decision making that ascribes to it the role of enabling rational choice in situations involving clinical choice. Rather than referring to good health outcomes and/or ethical grounds such as patient autonomy, it argues that a plausible justification and ground for person-centered care and shared decision making is preservation of rationality in the face of comparative non-determinacy in clinical settings. Often, no alternative treatment will be better than or equal to every other alternative. In the face of such comparative non-determinacy, Ruth Chang has argued that we can make rational decisions by invoking reasons that are created through acts of willing. This article transfers this view to clinical decision making and argues that shared decision making provides a solution to non-determinacy problems in clinical settings. This view of the role of shared decision making provides a new understanding of its nature, and it also allows us to better understand when caregivers should engage in shared decision making and when they should not.

**Incapacitated Surrogates: A New and Increasing Dilemma in Hospital Care**


A power of attorney for healthcare (POAHC) form gives designated individuals legal status to make healthcare decisions when patients are unable to convey their decisions to medical staff. Completion of a POAHC form is crucial in the provision of comprehensive healthcare, since it helps to ensure that patients’ interests, values, and preferences are represented in decisions about their medical treatment. Because increasing numbers of people suffer from debilitating illness and cognitive deficits, healthcare systems may be called upon to navigate the complexities of patients’ care without clear directives from the patients themselves. Hence, the healthcare industry encourages all individuals to complete a POAHC form to ensure that persons who have the patients’ trust are able to act as their surrogate decision makers. However, sometimes POAHC agents, even when they are patients’ trusted agents, lack the capacity to make fully informed decisions that are in the patients’ best interests. We describe designated surrogate decision makers who have impaired or diminished judgment capacity as incapacitated surrogates. Decision making that is obviously flawed or questionable is a significant impediment to providing timely and appropriate care to patients. Moreover, failure to redress these issues in a timely and efficient manner can result in significant costs to an institution and a diminished quality of patient care. The authors offer a legal, ethical, and interdisciplinary framework to help navigate cases of incapacitated surrogates.

**Measuring Instrument for Ethical Sensitivity in the Therapeutic Sciences**


There are currently no instruments available to measure ethical sensitivity in the therapeutic sciences. This study therefore aimed to develop and implement a measure of ethical sensitivity that would be applicable to four therapeutic professions, namely audiology, occupational therapy, physiotherapy, and speech-language pathology. The study followed a two-phase, sequential exploratory mixed-methods design. Phase One, the qualitative development phase, employed six stages and focused on developing an instrument based on a systematic review: an analysis of professional ethical codes, focus group discussions, in-depth interviews, a review of public complaints websites, and an expert panel review. The development phase culminated in the Measuring Instrument for Ethical Sensitivity in the Therapeutic Sciences (MIEST), a pen-and-paper measure for studying ethical sensitivity in the therapeutic sciences.

Phase Two, the quantitative stage, focused on implementing the MIEST in two different stages. A total of 100 participants completed the instrument. MIEST scores were found to be comparable for all four professions, which confirmed the multidisciplinary usability of the instrument. Participants tended to base decisions on the ethical principle of beneficence. The MIEST is effective to assess and describe the ethical sensitivity of professionals in the four specified therapeutic sciences. The constructed vignettes also make the MIEST appropriate for use in problem-based learning programs.

**Make It Plain: Strengthening the Ethical Foundation of First-Person Authorization for Organ Donation**


One response to the chronic shortage of organs for transplant in the United States has been the passage of laws establishing first-person authorization for donation of organs, providing legal grounds for the retrieval of organs and tissues from registered donors, even over the objections of their next of kin. The ethical justification for first-person authorization is that it is a matter of respecting the donor’s wishes. The objection of some next of kin may be that the donor would not have wished for his or her loved ones to have their preferences overridden, had they considered that possibility. This article examines the basis of the conflict and suggests a remedy grounded in the provision of donor-intent options that have the ability to clarify the donor’s wishes.

**Cases from the Cleveland Clinic**

**Incarcerated Patients and Equitability: The Ethical Obligation to Treat Them Differently**


Prisoners are legally categorized as a vulnerable group for the purposes of medical research, but their vulnerability is not limited to the research context. Prisoner-patients may experience lower standards of care, fewer options for treatment, violations of privacy, and the use of inappropriate surrogates as a result of their status. This case study
Medical Education

Clinical Ethics Consultation

Ongoing Evaluation of Clinical Ethics Consultations as a Form of Continuous Quality Improvement

Ongoing evaluation of a clinical ethics consultation service (ECS) allows for continuous quality improvement, a process-based, data-driven approach for improving the quality of a service. Evaluations by stakeholders involved in a consultation can provide real-time feedback about what is working well and what might need to be improved. Although numerous authors have previously presented data from research studies on the effectiveness of clinical ethics consultation, few ECSs routinely send evaluations as an ongoing component of their everyday clinical activities. The primary purpose of this article is to equip and encourage others to engage in ongoing evaluation of their own ECS. Toward that end, the following resources are shared: (1) the survey tool used to gather the evaluation data, (2) the procedure used to elicit and collate responses, and (3) how the resulting data are used to support continuous quality improvement and justify the continued financial support of the ECS to hospital administration.

Moral Distress, Ethical Environment, and the Embedded Ethicist

Interest in understanding the experience of moral distress has steadily gained traction in the 30 years since Jameton first described the phenomenon. This curiosity should be of no surprise, since we now have data documenting the incidence across most caregiver roles and healthcare settings, both in the United States and internationally. The data have also amplified healthcare providers’ voices who report that the quality of the ethical environment is pivotal to preventing and containing the adverse effects caused by moral distress. Healthcare providers are asking for a moral space where ethics occurs at the bedside, in real time, applied to real cases. They are asking for ethics expertise to be available as part of the care team during their daily work, when treatment goals must be determined and decisions must be made. They are asking for an embedded ethicist who can help cultivate an ethical environment where formal ethics policy is properly applied to practice. This discussion advocates for an embedded ethics resource model that responds to contemporaneous ethics needs as a strategy to mitigate the effects of moral distress.

Medical Education

The Rise of Hospitalists: An Opportunity for Clinical Ethics

Translating ethical theories into clinical practice presents a perennial challenge to educators. While many suggestions have been put forth to bridge the theory-practice gap, none have sufficiently remedied the problem. We believe the ascendance of hospital medicine, as a dominant new force in medical education and patient care, presents a unique opportunity that could redefine the way clinical ethics is taught. The field of hospital medicine in the United States is comprised of more than 50,000 hospitalists—specialists in inpatient medicine—representing the fastest growing subspecialty in the history of medicine, and its members have emerged as a dominant new force around which medical education and patient care pivot. This evolution in medical education presents a unique opportunity for the clinical ethics community. Through their proximity to patients and trainees, hospitalists have the potential to teach medical ethics in real time on the wards, but most hospitalists have not received formal training in clinical ethics. We believe it is time to strengthen the ties between hospital medicine and medical ethics, and in this article we outline how clinical ethicists might collaborate with hospitalists to identify routine issues that do not rise to the level of an “ethics consult,” but nonetheless require an intellectual grounding in normative reasoning. We use a clinical vignette to explore how this approach might enhance and broaden the scope of medical education that occurs in the inpatient setting: A patient with an intra-abdominal abscess is admitted to the academic hospitalist teaching service for drainage of the fluid, hemodynamic support, and antimicrobial therapy. During the initial encounter with the hospitalist and his team of medical students and residents, the patient reports night sweats and asks if this symptom could be due to the abscess. How should the hospitalist approach this question?
At the Bedside

**Nine Lessons from Ashley and Her Parents**

Parents’ love for their child, even a child who has severe impairments, may give them much joy and quality in their life. This is also the case for caregivers of adults with severe cognitive impairments, such as end-stage dementia. How can clinicians work with these parents and caregivers and help them?

**Features**

**Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability**
Lisa Freitag and Joan Liaschenko, *The Journal of Clinical Ethics 28, no. 3 (Fall 2017): 189-96.*

The controversy over the so-called Ashley Treatment (AT), a series of medical procedures that inhibited both growth and sexual development in the body of a profoundly intellectually impaired girl, usually centers either on Ashley’s rights, including a right to an intact, unaltered body, or on Ashley’s parents’ rights to make decisions for her. The claim made by her parents, that the procedure would improve their ability to care for her, is often dismissed as inappropriate or, at best, irrelevant. We argue, however, that caregiving is a central issue in the controversy, as Ashley’s need for caregiving is a defining characteristic of her life. In this article, we analyze the ethics of the Ashley Treatment within the context of family caregiving. Through the physical and emotional work of caregiving, families participate in the formation and maintenance of personal identity, a process that Hilde Lindemann recently called “holding.” We argue that, in an intellectually disabled person such as Ashley, who depends on her family for every aspect of her care, the family’s contribution to identity is an essential source of personhood. We believe that the treatment can be justified if it is indeed an instance of appropriate family “holding” for Ashley.

**How We Become Who We Are: Ashley, Carla, and the Rest of Us**

Lisa Freitag and Joan Liaschenko’s thoughtful and important article goes directly to the under-examined heart of Ashley’s case, namely to what sustains her in a habitable and intelligible identity. Though quite sympathetic with their conclusion and line of argument, I try to trouble their proceedings a bit, largely by wondering how having a specific such identity, out of several that may be in-principle available, matters to someone with Ashley’s cognitive scope. I do this not simply to be contrary, but because their article also seems to me to raise issues in the ethics of bioethics—in particular, what I call the dilemma of ethical endeavor: How ought one publicly pursue deeply important and complex issues, the very raising of which may offend interlocutors who indeed have grounds for resentment. Making a habit of second guessing oneself may be part of the answer.

**Giving Voice to the Voiceless: The Colorado Response to Unrepresented Patients**

Medical decision making on behalf of unrepresented patients is one of the most challenging ethical issues faced in clinical practice. The legal environment surrounding these patients is equally complex. This article describes the efforts of a small coalition of interested healthcare professionals to address the issue in Colorado. A brief history of the effort is presented, along with discussion of the legal, ethical, practical, and political dimensions that arose in Colorado’s effort to address decision making for unrepresented patients through an extension of the existing Colorado Medical Treatment Decision Act (CRS 15-18). A discussion of lessons learned in the process is included.

**Re-Evaluating the Ethics of Uterine Transplantation**
*Danish Zaidi, The Journal of Clinical Ethics 28, no. 3 (Fall 2017): 212-6.*

In February 2016, the Cleveland Clinic initiated the first attempt at cadaveric uterine transplantation (UTx) in the United States. The transplantation was ultimately unsuccessful, but it opened doors for further research on both live and cadaveric UTx. While initial strides toward successful transplantation have been made, questions persist on the ethics of UTx: whether the uterus is a vital organ, whether we should prioritize live or cadaveric options, and how the procedure should be covered by health insurance. If we agree that the goal of the medical profession is both to treat and improve quality of life, then the question of whether or not infertility is considered a disease becomes inconsequential in the discussion. As such, the medical enterprise should move forward with research in UTx. In doing so, considering the ethical implications of UTx remains essential—and we must remember to pair innovation with regulation.

**May Medical Centers Give Nonresident Patients Priority in Scheduling Outpatient Follow-Up Appointments?**

Many academic medical centers are seeking to attract patients from outside their historical catchment areas for economic and programmatic reasons, and patients are traveling for treatment that is unavailable, of poorer quality, or more expensive at home. Treatment of these patients raises a number of ethical issues including whether they may be given priority in scheduling outpatient follow-up appointments in order to reduce the period of time they are away from home. Granting them priority is potentially unjust because medical treatment is generally allocated based on medical need and resource utilization, and then on a first-come, first-served basis. While it is difficult to compare the
opportunity cost of waiting for an appointment to different patients, nonresident patients incur higher expenditures for travel, room, and board than resident patients. Giving them priority in scheduling to reduce these costs may be justifiable. Preferentially scheduling nonresident patients may also indirectly benefit resident patients consistent with Rawls’s difference principle. This potential justification, however, rests on several empirical claims that should be demonstrated. In addition to reducing resident patients’ waiting times, medical centers should not prioritize nonresident patients over resident patients with more urgent medical needs. There is, therefore, a limited and circumscribed justification for prioritizing nonresident patients in scheduling follow-up appointments.

Cases and Analysis

**Responding to Moral Distress and Ethical Concerns at the Intersection of Medical Illness and Unmet Mental Health Needs**


Some of the most difficult clinical ethics consultations involve patients who have both medical and mental health needs, as these cases can result in considerable moral distress on the part of the bedside staff. In this article we examine the issues that such consults raise through the illustrative example of a particular case: several years ago our ethics consultation service received a request from a critical care attending physician who was considering a rarely performed psychosurgical intervention to address intractable and life-threatening agitation and aggression in an adolescent patient for whom standard treatments had proven unsuccessful. We consider strategies that may be useful in addressing not only the ethical dilemmas or the clinical problems, but also the emotional, social, and moral distress that arise in delivering care in such complex cases, in which standard routine practices of care have been exhausted. In addition, we explore the processes that led to this situation and suggest ways to promote early recognition and intervention for similar cases in the future.

**At the Intersection of Faith, Culture, and Family Dynamics: A Complex Case of Refusal of Treatment for Childhood Cancer**


Refusing treatment for potentially curable childhood cancers engenders much discussion and debate. I present a case in which the competent parents of a young Amish child with acute myeloid leukemia deferred authority for decision making to the child’s maternal grandfather, who was vocal in his opposition to treatment. I analyze three related concerns that distinguish this case from other accounts of refused treatment.

First, I place deference to grandparents as decision makers in the context of surrogate decision making more generally.

Second, the maternal grandfather’s ardent refusal of treatment and his rationale appeared to be inconsistent with the beliefs expressed by other family members and by members of the same Amish community, leading members of the medical team to question whether refusal of treatment should be treated differently when it appears to be based on the idiosyncratic beliefs of an individual rather than on community-wide values.

Third, the medical team perceived tension and dissension between the nonverbal behavior of some family members and the verbal statements made by the maternal grandfather, leading the team to question the parents’ true wishes and debate how to weigh nonverbal and indirect forms of communication.

Finally, building upon the conclusions of these queries, I explore whether, if the child’s prognosis was less favorable or if he were to relapse later, the maternal grandfather should have been permitted to drive a decision to refuse further treatment.

**The Angry Amish Grandfather: Cultural Competence and Empathy: A Case Commentary**


Crosscultural encounters are common in the delivery of healthcare, and cultural differences may contribute to misunderstandings and ethical conflict. Encounters between members of the Amish ethno-religious group and modern, science-based healthcare providers hold a high potential for misunderstanding and conflict because the Amish stridently maintain a countercultural outlook and they approach such encounters with suspicion and anxiety. This commentary on the case presented by Amy E. Caruso Brown, MD,1 involving a grandfather’s resistance to treating a child with leukemia commends this physician for successfully managing the case and deriving important insights from reflection upon it. It argues, however, that the level of conflict most likely would have been reduced if the care team had made more of an effort to listen to the grandfather and acknowledge the emotional trauma he had suffered.

**Research**

**The Ethics of Research in Lower Income Countries: Double Standards Are Not the Problem**


Discussion of the ethics of clinical trials in lower income countries has been dominated by concern over double standards. Most prominently, clinical trials of interventions that are less effective than the worldwide best treatment methods typically are not permitted in higher income countries. Commentators conclude that permitting such trials in lower income countries involves an ethical double standard. Despite significant attention to this concern, and its
influence over prominent guidelines for research in lower income countries, there has been little analysis of what constitutes an ethical double standard in clinical research. The present article attempts to address this gap in the literature. This analysis finds that ethical double standards involve a kind of disrespect, and yields a three-step decision procedure for evaluating when trials of less than the worldwide best methods raise this concern. Application of this procedure reveals that permitting these trials in lower income countries rarely involves an ethical double standard. Instead, the real challenge is determining when clinical trials of interventions that are less effective than the worldwide best represent a permissible and effective response to differences in access to healthcare between higher income and lower income countries. To protect research subjects, without blocking clinical trials that have the potential to improve health in lower income countries, research review committees and other stakeholders should focus on this issue, not on ethical double standards.

**Perspectives**

*Universal Health Care: The Cost of Being Human*


In this article I argue that the biological processes that make us human have error rates that distribute illness on a no-fault basis. I propose this as an ethical foundation for universal healthcare.

*Vaccine Exemptions and the Church-State Problem*


All of the 50 states of the United States have laws governing childhood vaccinations; 48 allow for religious exemptions, while 19 also offer exemptions based on some sort of personal philosophy. Recent disease outbreaks have caused these states to reconsider philosophical exemptions. However, we cannot, consistent with the U.S. Constitution, give preference to religion by creating religious exemptions only. The Constitution requires states to put religious and nonreligious claims on equal footing. Given the ubiquity of nonreligious objections to vaccination, I conclude that the best response is to remove all exemptions, as two states have already done. But removing exemptions should not end our concern for children. Removing exemptions only bars children from public schools; it still leaves them unvaccinated, a danger to others, and reliant on whatever nonpublic schooling is available. If public school attendance is not enough of an incentive for vaccine reluctant parents, perhaps we should look into stronger measures.

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At the Bedside

**Going from What Is, to What Should Be, to Care Better for Our Patients and Families**


This piece discusses ways in which clinicians may go beyond their usual practices. These include exploring the limits of old laws, consulting with colleagues and ethics committees earlier and more often, and giving patients’ family members new choices they didn’t have previously. This could include asking patients and family members whether clinicians should prioritize staying in the single, unconflicted role of serving patients and families, even when this might preclude simultaneously serving another interest, for example, that of a hospital.

**Features**

*Controversies in Cardiopulmonary Death*


We describe two unusual cases of cardiopulmonary death in mechanically ventilated patients in the neurological intensive care unit. After cardiac arrest, both patients were pulseless for a protracted period. Upon extubation, both developed agonal movements (gasperating respiration) resembling life. We discuss these cases and the literature on the ethical and medical controversies associated with determining time of cardiopulmonary death. We conclude that there is rarely a single moment when all of a patient’s physiological functions stop working at once. This can pose a challenge for determining the exact moment of death.

*How Do Healthcare Providers Feel About Family Presence During Cardiopulmonary Resuscitation?*


The presence of patients’ families during cardiopulmonary resuscitation (CPR) is a controversial topic, due to its repercussions for clinical practice. While family members’ presence may help them to overcome their grief, it could be detrimental, as it may case posttraumatic stress disorder (PTSD), and there is the possibility that family members may interfere with the procedure. For these reasons, families’ presence during CPR has rejected by some healthcare providers.

To research concerns about families’ presence among providers dealing with CPR in the Fundación Hospital Alcorcón (Madrid), I performed this study. Of the 190 providers surveyed, 115 submitted a complete questionnaire. The most frequently reported concerns were interference (78.3 percent of respondents), and PTSD (69.6 percent of respondents). Fewer pediatric providers were concerned about PTSD than other providers (41.2% percent versus 74.5 percent, p = 0.01). Providers were reluctant to offer families the option of being present unless they had
Developing Clinical Ethics Consultation and Committees

Hospital ethics committees are common, but not universal, in small hospitals. A needs assessment was completed at a 155-bed community hospital in order to adapt an academic tertiary center model for a clinical ethics committee to fit the needs of the small hospital community. Of 678 questionnaires distributed, 209 were completed. Data suggested that clinical staff frequently experienced ethical dilemmas. Significantly more nonphysicians indicated that

A Patient (Not) Alone

This case analysis examines questions that arise when an ethically appropriate recommendation initially appears to be in conflict with the legally appropriate recommendation. The case involves a dying, incapacitated octogenarian who had friends who were willing to share her values, but not to make decisions on her behalf. These circumstances put the patient in the unique position of being legally considered a “patient alone,” but who was ethically like a patient with surrogates—distinctions that are crucial when making end-of-life decisions under the New York Family Health Care Decisions Act. A strict interpretation of the law initially seemed to be in conflict with an ethically appropriate outcome. By gaining a deeper understanding of the patient from those who cared about her, however, and by considering a broader interpretation of the law, an outcome was reached that worked within the framework of the law and honored the patient’s reported values.

The Role of Relational Knowing in Advance Care Planning

Medical decision making when a patient cannot participate is complicated by the question of whose voice should be heard. The most common answer to this question is that “autonomy” is paramount, and therefore it is the voice of the unwell person that should be given priority. Advance care planning processes and practices seek to capture this sentiment and to allow treatment preferences to be documented and decision makers to be nominated. Despite good intentions, advance care planning is often deficient because it is unable to facilitate a relational approach to decision making in cases when the patient’s competence is reduced. In this article we present findings from a study of the ways in which older people and their significant others understand decision making in such circumstances. Critical to the participants’ understanding was the emergent concept of “relational knowing,” a concept that is poorly articulated in the advance care planning literature. Our findings suggest that the dominant understanding of decision making in conditions of impaired competence is incomplete and obscures much of what matters to people. We conclude that, having recognized a broader set of ethical concerns, it is necessary to develop a relational and narrative based approach that applies in appropriate settings.

Knowing About Others: On “The Role of Relational Knowing in Advance Care Planning”

Kate Robins-Browne and her colleagues have written a conceptually daring, empirically grounded article that is rich in scholarship and just conceivably might have a salutary effect on the theory and practice of advance care planning. It is, alas, just as easy to believe that its appreciation will be restricted to like-minded theorists. Writing from a posture of great admiration for this article’s agenda and achievements, I will consider why non-relationally-based understanding of deciding for others are so enduring, and what might be done about that.

Developing Clinical Ethics Consultation and Committees

Structure, Operation, and Experience of Clinical Ethics Consultation 2007-2013: A Report from the Massachusetts General Hospital Optimum Care Committee

We describe the structure, operation, and experience of the Massachusetts General Hospital ethics committee, formally called the Edwin H. Cassem Optimum Care Committee, from January 2007 through December 2013. Founded in 1974 as one of the nation’s first hospital ethics committees, this committee has primarily focused on the optimum use of life-sustaining treatments. We outline specific sociodemographic and clinical characteristics of consult patients during this period, demographic differences between the adult inpatient population and patients for whom the ethics committee was consulted, and salient features of the consults themselves. We include three case studies that illustrate important consult themes during this period. Our findings expand knowledge about the structure and workings of hospital ethics committees and illustrate how one ethics committee has developed and utilized policies on end-of-life care. More generally, we model a sociological approach to the study of clinical ethics consultation that could be utilized to contextualize institutional practices over time.

Development of a Clinical Ethics Committee De Novo at a Small Community Hospital by Addressing Needs and Potential Barriers

Hospital ethics committees are common, but not universal, in small hospitals. A needs assessment was completed at a 155-bed community hospital in order to adapt an academic tertiary center model for a clinical ethics committee to fit the needs of the small hospital community. Of 678 questionnaires distributed, 209 were completed. Data suggested that clinical staff frequently experienced ethical dilemmas. Significantly more nonphysicians indicated that
they would utilize a consultation service, if available, compared to physicians ($p = 0.0067$). The data also indicated that the majority of staff (>80 percent) desired more education in clinical ethics. Physicians preferred annual or biannual hospital-wide grand rounds, compared to nonphysicians, who preferred more frequent department-based teaching ($p < 0.001$). The data presented in this article were used to subsequently develop a clinical ethics support committee, the process of which is also described.

**Do Not Resuscitate, with No Surrogate and No Advance Directive: An Ethics Case Study**

Do-not-resuscitate (DNR) orders are typically signed by physicians in conjunction with patients or their surrogate decision makers in order to instruct healthcare providers not to perform cardiopulmonary resuscitation (CPR). Both the medical literature and CPR guidelines fail to address when it is appropriate for physicians to sign DNR orders without any knowledge of a patient’s wishes. We explore the ethical issues surrounding instituting a two-physician DNR for a dying patient with multiple comorbidities and no medical record on file, no advance directives, and no surrogate decision maker. Through this case we also highlight the issues of poor prognostication and the reversal of a DNR in such circumstances.

**Law**

**Legal Briefing: Unwanted Cesareans and Obstetric Violence**

A capacitated pregnant woman has a nearly unqualified right to refuse a cesarean section. Her right to say "no" takes precedence over clinicians’ preferences and even over clinicians’ concerns about fetal health. Leading medical societies, human rights organizations, and appellate courts have all endorsed this principle. Nevertheless, clinicians continue to limit reproductive liberty by forcing and coercing women to have unwanted cesareans. This “Legal Briefing” reviews recent court cases involving this type of obstetric violence. I have organized these court cases into the following six categories:
1. Epidemic of Unwanted Cesareans
2. Court-Ordered Cesareans
3. Physician-Coerced Cesareans
4. Physician-Ordered Cesareans
5. Cesareans for Incapacitated Patients
6. Cesareans for Patients in a Vegetative State or Who Are Brain Dead

**The Journal of Clinical Ethics, Volume 28, Number 1, Spring 2017**

**At the Bedside**

**Fourteen Important Concepts Regarding Moral Distress**

I suggest that we may want to strive, over time, to change our present professional-cultural view, from one that sees an expression of moral distress as a threat, to a professional-cultural view that welcomes these challenges. Such an effort to better medicine would not only include dissenting clinicians, but patients (and their loved ones) as well.

**Special Section on Moral Distress**

**Harnessing the Promise of Moral Distress: A Call for Re-Orientation**

Despite over three decades of research into the sources and costs of what has become an "epidemic" of moral distress among healthcare professionals, spanning many clinical disciplines and roles, there has been little significant progress in effectively addressing moral distress. We believe the persistent sense of frustration, helplessness, and despair still dominating the clinical moral distress narrative signals a need for re-orientation in the way moral distress is understood and worked with. Most fundamentally, moral distress reveals moral investment and energy. It is the troubled call of conscience, an expression of fidelity to moral commitments seen as imperiled or compromised.

It is crucial that we find ways to empower clinicians in heeding this call—to support clinicians’ moral agency and voice, foster their moral resilience, and facilitate their ability to contribute to needed reform within the organizations and systems in which they work. These objectives must inform creative expansion in the design of strategies for addressing moral distress in the day-to-day of clinical practice. We include suggestions about promising directions such strategies might take in the hope of spurring further innovation within clinical environments.

**Focus More on Causes and Less on Symptoms of Moral Distress**

In this commentary on Carse and Rushton’s call for reorientation of moral distress, we state agreement with the authors that the discourse of moral distress should refocus on the moral components of integrity. We then explain how our philosophical taxonomy of moral distress, mentioned by the authors, appeals to moral integrity. In this process, we clarify our taxonomy’s appeal to Aristotle’s concept of *akrasia*. We conclude by offering support of Carse and Rushton’s challenge to organizations to strengthen moral integrity by fostering resilience.
Using Moral Distress for Organizational Improvement

Moral distress is a major problem for nurses, other clinicians, and the health system itself. But if properly understood and responded to, it is also a promising guide for healthcare improvement. When individuals experience moral distress or burnout, their reports must be seen as crucial data requiring careful attention to the individuals and to the organization. Distress and burnout will often point to important opportunities for system improvements, which may in turn reduce the experience of distress. For this potential virtuous cycle to happen, individuals must be able to articulate their concerns without fear of retribution, and organizational leaders must be able to listen in an undefensive, improvement-oriented manner.

Looking at the Positive Side of Moral Distress: Why It’s a Problem

Moral distress, is, at its core, an organizational problem. It is experienced on a personal level, but its causes originate within the system itself. In this commentary, we argue that moral distress is not inherently good, that effective interventions must address the external sources of moral distress, and that while there is a place for resilience in the healthcare professions, it cannot be an effective antidote to moral distress.

Moral Distress: Conscious and Unconscious Feelings

In analyzing moral distress, perhaps greater attention should be given to the possible implicit sources of feelings of distress, as well as explicit sources.

Features

When Not to Rescue: An Ethical Analysis of Best Practices for Cardiopulmonary Resuscitation and Emergency Cardiac Care

It is now a default obligation to provide cardiopulmonary resuscitation (CPR), in the absence of knowledge of a patient’s or surrogate’s wishes to the contrary. We submit that it is time to re-evaluate this position. Attempting CPR should be subject to the same scrutiny demanded of other medical interventions that involve balancing a great benefit against grievous harms.

A Framework for Ethical Decision Making in the Rehabilitation of Patients with Anosognosia

Currently, the number of patients diagnosed with impaired self-awareness of their own deficits after brain injury—anosognosia—is increasing. One reason is a growing understanding of this multifaceted phenomenon. Another is the development and accessibility of alternative measurements that allow more detailed diagnoses. Anosognosia can adversely affect successful rehabilitation, as often patients lack confidence in the need for treatment. Planning such treatment can become a complex process full of ethical dilemmas.

To date, there is no systematic way to deal with different aspects of anosognosia rehabilitation planning. This is the first article to present a framework for ethical decision making in establishing rehabilitation plans that are focused on increasing patients’ self-awareness of their own deficits after brain injury. It concentrates especially on addressing the ethical dilemmas that may arise, and describes stepwise procedures that can be applied to distinct theoretical approaches, as well as diagnostic and rehabilitation methods. To show the flexibility of the use of this framework, alternative approaches are discussed.

Case and Analysis

Family Loyalty as a Cultural Obstacle to Good Care: The Case of Mrs. Indira

What is the responsibility of the physician when a capacitated patient assigns decision-making authority to a surrogate who does not act in the patient’s best interest?

Complexities in Caregiving: Comforts, Cultures, Countries, Conversations, and Contracts

As depicted in the case of Mrs. Indira, decision making by patients and surrogates may be complicated by multiple factors, including care, comfort, country, and culture.

Law

Legal Briefing: New Penalties for Ignoring Advance Directives and Do-Not-Resuscitate Orders

Patients in the United States have been subject to an ever-growing “avalanche” of unwanted medical treatment. This is economically, ethically, and legally wrong. As one advocacy campaign puts it: “Patients should receive the medical treatments they want. Nothing less. Nothing more.” First, unwanted medical treatment constitutes waste (and often fraud or abuse) of scarce healthcare resources. Second, it is a serious violation of patients’ autonomy and self-determination. Third, but for a few rare exceptions, administering unwanted medical treatment contravenes settled legal rules and principles. This “Legal Briefing” describes a central and growing role for the law. Specifically, courts and agencies have increasingly imposed penalties on healthcare providers who deliberately or negligently...
disregard advance directives and DNR (do-not-resuscitate) orders. I group these legal developments into the following five categories:

1. Five Types of Unwanted Medical Treatment
2. State and Federal Duties to Follow Advance Directives
3. *Doctors Hospital of Augusta v. Alicea*
4. Other Lawsuits for Ignoring Advance Directives
5. Administrative Penalties for Ignoring Advance Directives.

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At the Bedside

**New Paradigms in Medical Ethics**

*Edmund G. Howe*

As new technologies develop, new ethical paradigms may be needed. This article considers several examples, such as stopping venoarterial extracorporeal membrane oxygenation (VA-ECMO), treating patients who are in a locked-in-like state who have awareness, purposefully deceiving patients who have dementia, meeting the needs of transgender persons, showing loved ones patients’ wounds, and doing research on controlled substances. I suggest that clinicians should identify the practices underlying their value assumptions so they can alter their assumptions when this might improve the care they offer to their patients.

Features

**A Survey of Physicians’ Attitudes toward Decision-Making Authority for Initiating and Withdrawing VA-ECMO: Results and Ethical Implications for Shared Decision Making**

*Ellen C. Meltzer, Natalia S. Ivascu, Meredith Stark, Alexander V. Orfanos, Cathleen A. Acres, Paul J. Christos, Thomas Mangione, and Joseph J. Fins*

**Objective:** Although patients exercise greater autonomy than in the past, and shared decision making is promoted as the preferred model for doctor-patient engagement, tensions still exist in clinical practice about the primary locus of decision-making authority for complex, scarce, and resource-intensive medical therapies: patients and their surrogates, or physicians. We assessed physicians’ attitudes toward decisional authority for adult venoarterial extracorporeal membrane oxygenation (VA-ECMO), hypothesizing they would favor a medical locus.

**Design, Setting, Participants:** A survey of resident/fellow physicians and internal medicine attendings at an academic medical center, May to August 2013.

**Measurements:** We used a 24-item, internet-based survey assessing physician-respondents’ demographic characteristics, knowledge, and attitudes regarding decisional authority for adult VA-ECMO. Qualitative narratives were also collected.

**Main Results:** A total of 179 physicians completed the survey (15 percent response rate); 48 percent attendings and 52 percent residents/fellows. Only 32 percent of the respondents indicated that a surrogate’s consent should be required to discontinue VA-ECMO; 56 percent felt that physicians should have the right to discontinue VA-ECMO over a surrogate’s objection. Those who self-reported as “knowledgeable” about VA-ECMO, compared to those who did not, more frequently replied that there should not be presumed consent for VA-ECMO (47.6 percent versus 33.3 percent, \( p = 0.007 \)), that physicians should have the right to discontinue VA-ECMO over a surrogate’s objection (76.2 percent versus 50 percent, \( p = 0.02 \)) and that, given its cost, the use of VA-ECMO should be restricted (81.0 percent versus 54.4 percent, \( p = 0.005 \)).

**Conclusions:** Surveyed physicians, especially those who self-reported as knowledgeable about VA-ECMO and/or were specialists in pulmonary/critical care, favored a medical locus of decisional authority for VA-ECMO. VA-ECMO is complex, and the data may (1) reflect physicians’ hesitance to cede authority to presumably less knowledgeable patients and surrogates, (2) stem from a stewardship of resources perspective, and/or (3) point to practical efforts to avoid futility and utility disputes. Whether these results indicate a more widespread reversion to paternalism or a more circumscribed usurping of decisional authority occasioned by VA-ECMO necessitates further study.

**Covert Administration of Medication to Persons with Dementia: Exploring Ethical Dimensions**

*Jenny M. Young and David Unger*

The literature, although sparse, reports that covert administration of all types of medications is prevalent in nursing homes. Whether it is ever ethically defensible, however, to administer medications covertly to persons with significant dementia is a complex and contentious question. Some scholars contend that deception is inherently wrong and is never acceptable, while others believe that deception is intrinsic to providing care to persons with dementia. With an aim to begin to reconcile these polarized positions and to objectively study this contentious issue, the authors undertake an ethical analysis of the covert administration of medications by utilizing the principles of respect for autonomy, nonmaleficence, beneficence, and justice. Our approach examines covert administration within the context of all persons with significant dementia who are administered medications, and is aimed at providing
ethical and practical guidance to clinicians who, when confronted with a patient who refuses medication, must choose the "least bad" option from among various courses of action, all of which have ethical implications. Components of a possible guideline for practice are proposed.

**Covert Medications: Act of Compassion or Conspiracy of Silence?**  
*Robert C. Macauley*

As the population in the United States gets older, more people suffer from dementia, which often causes neuropsychiatric symptoms such as agitation and paranoia. This can lead patients to refuse medications, prompting consideration of covert administration (that is, concealing medication in food or drink). While many condemn this practice as paternalistic, deceptive, and potentially harmful, the end result of assuming the "moral high ground" can be increased suffering for patients and families. This article addresses common criticisms of covert medication and presents a detailed algorithm by which to determine whether the practice is ethically permissible in specific cases. It also explores why so little attention has been paid in the U.S. to this presumably common practice, and reviews professional statements from Europe that endorse the practice. Finally, it presents a compelling argument for the role of Ulysses clauses in advance care planning, not only for patients with psychiatric illness but also for those who may suffer from dementia, which is far more common.

**Stakeholders’ Views on Barriers to Research on Controversial Controlled Substances**  
*Evelyn Rhodes, Michael Andreae, Tyler Bourgise, Debbie Indyk, Rosamond Rhodes, and Henry Sacks*

Many diseases and disease symptoms still lack effective treatment. At the same time, certain controversial Schedule I drugs, such as heroin and cannabis, have been reputed to have considerable therapeutic potential for addressing significant medical problems. Yet, there is a paucity of U.S. clinical studies on the therapeutic uses of controlled drugs. For example, people living with HIV/AIDS experience a variety of disease- and medication-related symptoms. Their chronic pain is intense, frequent, and difficult to treat. Nevertheless, clinical trials of compassionate management for their chronic symptoms, which should be a research priority, are stymied.

We employed qualitative methods to develop an understanding of the barriers to research on potential therapeutic uses of Schedule I drugs so that they might be addressed. We elicited the perspectives of key stakeholder groups that would be involved in such studies: people living with HIV/AIDS, clinicians, and members of institutional review boards. As we identified obstacles to research, we found that all of the stakeholder groups arrived at the same conclusion, that clinical research on the therapeutic potential of these drugs is ethically required.

**The Evolution of American Hospital Ethics Committees: A Systematic Review**  
*Andrew Courtwright and Martha Jurchak*

During the 1970s and 1980s, legal precedent, governmental recommendations, and professional society guidelines drove the formation of hospital ethics committees (HECs). The Joint Commission on Accreditation of Health Care Organization’s requirements in the early 1990s solidified the role of HECs as the primary mechanism to address ethical issues in patient care. Because external factors drove the rapid growth of HECs on an institution-by-institution basis, however, no initial consensus formed around the structure and function of these committees. There are now almost 40 years of empirical studies on the composition, administration, and activities of HECs in the United States. We conducted a systematic review of the available empirical literature on HECs to describe their evolution. As HECs changed over time, they increased their total number of members and percentage of members from nursing and the community. Although physicians increasingly chaired these committees, their presence as a percentage of overall members declined. The percentage of administrative members remained steady, although committees became increasingly likely to have at least one administrative member. HECs were also increasingly likely to report to an administrative body or to the board of trustees or directors rather than to the medical staff. Finally, consultation volume increased steadily over time. There has not, however, been a national survey of the composition of ethics committees, their administration, or volume of consultation in more than 10 years, despite increasing calls for professional standards and quality improvement assessments among HECs.

**Cultivating Administrative Support for a Clinical Ethics Consultation Service**  
*Courtenay R. Bruce, Mary A. Majumder, Ashley Stephens, Janet Malek, and Amy McGuire*

Hospital administrators may lack familiarity with what clinical ethicists do (and do not do), and many clinical ethicists report receiving inadequate financial support for their clinical ethics consultation services (CECSSs). Ethics consultation is distinct in that it is not reimbursable by third parties, and its financial benefit to the hospital may not be quantifiable. These peculiarities make it difficult for clinical ethicists to resort to tried-and-true outcome-centered evaluative strategies, like cost reduction or shortened length of stay for patients, to show a "need" for ethics consultation. Likewise, it can be difficult for clinical ethicists to "speak the same language" as healthcare administrators and managers, which, in turn, means that CECSSs run the risk of being unable to demonstrate value to those who pay for the service.

The purpose of this descriptive article is to provide practical guidance to clinical ethicists and program directors on how to cultivate administrative support for a CECSS. Specifically, we discuss two elements that clinical ethicists leaders must critically appraise and successfully argue to meet the expectations of administrators—the value of a CECSS and its fit in clinical workflow.
What’s Knowledge Got to Do with It? Ethics, Epistemology, and Intractable Conflicts in the Medical Setting

Bryan Kibbe and Paul J. Ford

This article utilizes the case of Ms H. to examine the contrasting ways that surrogate decision makers move from simply hearing information about the patient to actually knowing and understanding the patient’s medical condition. The focus of the case is on a family’s request to actually see the patient’s wounds instead of being told about the wounds, and the role of clinical ethicists in facilitating this request. We argue that clinical ethicists have an important role to play in the work of converting information into knowledge and that this can serve as a valuable way forward in the midst of seemingly intractable conflicts in the medical setting.

Medical Futility: A Contemporary Review

Ellen Coonan

As medical technology has advanced, the question of medical futility has become a topic of intense debate both within the medical community and within society as a whole. However, a unanimous definition thereof is yet to be decided—some commentators are sceptical as to whether an agreement will ever be reached—and this continues to lead to difficulties, tension, and even legal action when a treating physician disagrees with a patient and/or a patient’s family regarding care and treatment options. Although living in a pluralistic society presents one of the major reasons as to why, despite 30 years of intense discussion, no consensus has been made; the issue of medical futility will always be complex as it is, by nature, multifaceted, and numerous elements—including possible risks, evidence of the probability of benefit, the wishes of the patient (and family), professional standards, and cost—interact. Nevertheless, the global medical community has seen the development of two distinctly different approaches to medical futility: one in which the autonomy of patients is of paramount importance in the decision whether or not to pursue a treatment; and one in which beneficence and primum non nocere—first do no harm—are almost entirely the clinician’s prerogative, and whereby he/she has a duty to refuse any treatment for which the potential risks outweigh the potential benefits for the patient. Recently, however, there has been a rejection of this dichotomous view of medical futility and the apparent “power struggle” between physician and patient, and a positive movement towards a more collaborative decision-making process that highlights the necessity of communication, aiming to result in the obtainment of the best possible outcome for each patient as an individual.

Moral Agency, Moral Imagination, and Moral Community: Antidotes to Moral Distress

Terri Traudt, Joan Liaschenko, and Cynthia Peden-McAlpine

Moral distress has been covered extensively in the nursing literature and increasingly in the literature of other health professions. Cases that cause nurses’ moral distress that are mentioned most frequently are those concerned with prolonging the dying process. Given the standard of aggressive treatment that is typical in intensive care units (ICUs), much of the existing moral distress research focuses on the experiences of critical care nurses. However, moral distress does not automatically occur in all end-of-life circumstances, nor does every critical care nurse suffer its damaging effects. What are the practices of these nurses? What specifically do they do to navigate around or through the distressing situations? The nursing literature is lacking an answer to these questions. This article reports a study that used narrative analysis to explore the reported practices of experienced critical care nurses who are skilled at and comfortable working with families and physicians regarding the withdrawal of aggressive treatment. A major finding was that these nurses did not report experiencing the damaging effects of moral distress as described in the nursing literature. The verbal communication and stated practices relevant to this finding are organized under three major themes: (1) moral agency, (2) moral imagination, and (3) moral community. Further, a total of eight subthemes are identified. The practices that constitute these themes and subthemes are further detailed and discussed in this article. Understanding these practices can help mitigate critical care nurses’ moral distress.

Towards a New Narrative of Moral Distress: Realizing the Potential of Resilience

Cynda Hylton Rushton and Alisa Carse
Terri Traudt, Joan Liaschenko, and Cynthia Peden-McAlpine's study contributes to a much-needed reorientation in thinking about and working with the challenges of moral distress. In providing a vital example of nurses able to navigate morally distressing situations in positive and constructive ways, and offering an analysis of the component elements of these nurses' success, the study helps identify promising directions we might take in addressing the epidemic of moral distress. It also invites important questions, concerning the challenges faced by clinicians who do not who work in healthy "moral communities," who lack the ethical competencies, and who don't have the presumptive authority and recognition enjoyed by the seasoned clinicians studied here. We explore some of these questions, and suggest ways we might build on the insights of Traudt and colleagues' study.

**Special Section: Physicians' Exercise of Conscience: Commentaries on the AMA's Code of Medical Ethics**

**Report by the American Medical Association's Council on Ethical and Judicial Affairs on Physicians' Exercise of Conscience**

BJ Crigger, Patrick W. McCormick, Stephen L. Brotherton, and Valarie Blake

As practicing clinicians, physicians are expected to uphold the ethical norms of their profession, including fidelity to patients and respect for patients' self-determination. At the same time, as individuals, physicians are moral agents in their own right and, like their patients, are informed by and committed to diverse cultural, religious, and philosophical traditions and beliefs. In some circumstances, the expectation that physicians will put patients' needs and preferences first may be in tension with the need to sustain the sense of moral integrity and continuity that grounds a physician's personal and professional life.

This article examines the implications for patients, physicians, and the medical profession when tensions arise between a physician's professional commitments and his or her deeply held personal moral beliefs. It offers guidance on when a physician's professional commitments should outweigh personal beliefs as well as when physicians should have freedom to act according to the dictates of conscience while still protecting patients' interests.

**Accommodating Conscientious Objection in Medicine—Private Ideological Convictions Must Not Trump Professional Obligations**

Udo Schuklenk

The opinion of the American Medical Association (AMA) Council on Ethical and Judicial Affairs (CEJA) on the accommodation of conscientious objectors among medical doctors aims to balance fairly patients' rights of access to care and accommodating doctors' deeply held personal beliefs. Like similar documents, it fails. Patients will not find it persuasive, and neither should they. The lines drawn aim at a reasonable compromise between positions that are not amenable to compromise. They are also largely arbitrary. This article explains why that is the case. The view that conscientious objection accommodation has no place in modern medicine is defended.

**Professional Ethics, Personal Conscience, and Public Expectations**

Claudia E. Haupt

Examining to what extent physicians are, or ought to be, defined by the profession when giving advice to patients, this commentary seeks to offer a better understanding of the potential conflicts that the American Medical Association’s (AMA’s) “Opinion 1.1.7, Physician Exercise of Conscience,” addresses. This commentary conceptualizes the professions as knowledge communities, and situates the physician-patient relationship within this larger conceptual framework. So doing, it sheds light on how and when specialized knowledge is operationalized in professional advice-giving. Physicians communicate the knowledge community’s insights to the patient. Thus, departures from professional knowledge as a matter of the professional’s personal conscience are appropriately circumscribed by the knowledge community.

**Who Judges Harm?**

Nadia N. Sawicki

The American Medical Association’s (AMA’s) “Opinion 1.1.7, Physician Exercise of Conscience” attempts to help physicians strike a reasonable balance between their own conscientious beliefs and their patients' medical interests in an effort to minimize harms to both. However, some ambiguity still remains as to whether the severity of harms experienced by physicians and patients is to be assessed externally (by policy makers or by a professional body like the AMA), or internally by the subjects of those harms. Conflicts between conscientious physicians' self-assessments of the moral harm associated with various actions and the AMA's external assessments of such harms are likely to lead to challenges in the implementation of some provisions of its opinion. This commentary argues, however, that provisions (b) and (e) of the opinion, which describe the information physicians should provide about their own scope of practice and about the existence of controversial procedures, are less likely to conflict with physicians' subjective assessments of moral harm, and therefore will face fewer challenges in implementation.

**Action Steps and Solutions for Physicians' Exercise of Conscience**

Eliza Blanchard and Lynn Stoller

Conscience can influence physicians' interactions with patients in myriad ways and, by extension, can influence the interactions and internal dynamics of a health care team. The AMA's opinion around physicians' exercise of conscience appropriately balance the obligations physicians have to their patients and profession, and the rights of
physicians as moral agents to exercise their conscience. While the opinion is an effective starting point, further
guidance is necessary to clarify the process by which physicians should identify, manage, and, if necessary, report
their conscientious refusals to patients, supervisors, or colleagues. In addition to laying out a proposed process for
identifying and managing issues of conscience, this article will use relevant and timely examples to help clarify how a
physician could apply this process in an instance of conscientious refusal.

Conscientious Objection: Widening the Temporal and Organizational Horizons
Armand H. Matheny Antommaria

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the interactions and internal dynamics of a health care team. The AMA’s opinion around physicians’ exercise of
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identifying and managing issues of conscience, this article will use relevant and timely examples to help clarify how a
physician could apply this process in an instance of conscientious refusal.

Thinking about Conscience
BJ Crigger

The path to consensus about physicians’ exercise of conscience was not linear. It looped back on itself as new
insights illuminated earlier deliberations and in turn led to further insights. In particular, coming to agreement about
physicians’ responsibility in regard to referral charted a route through many course corrections.

Law

Legal Briefing: Stopping Nonbeneficial Life-Sustaining Treatment without Consent
Thaddeus Mason Pope and Kristin Kemmerling

In the United States, authoritative legal guidance remains sparse on whether or when clinicians may stop life-
sustaining treatment without consent. Fortunately, several significant legislative and judicial developments over the
past two years offer some clarity. We group these legal developments into the following seven categories:
1. Lawsuits for Damages
2. Amendments to the Texas Advance Directives Act
3. Constitutional Attack on TADA
4. Legislation Prohibiting Clinicians
5. Legislation Authorizing Clinicians
6. Cases from Canada
7. Cases from the United Kingdom.

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At the Bedside
What Do We Owe Medical Students and Medical Colleagues Who Are Impaired?
Edmund G. Howe

Physicians who are impaired, engage in unprofessional behavior, or violate laws may be barred from further
practice. Likewise, medical students may be dismissed from medical school for many infractions, large and small. The
welfare of patients and the general public must be our first priority, but when we assess physicians and students who
have erred, we should seek to respond as caringly and fairly as possible. This piece will explore how we may do this at
all stages of the proceedings physicians and students may encounter. This may include helping them to resume their
medical careers if and when this would be sufficiently safe and beneficial for patients.

Features

Untangling Uncertainty: A Study of the Discourses Shaping Clinical Ethics Consultation as a Professional
Practice
Salla Saxén

This qualitative social scientific interview study delves into the ways in which professional vision is constructed in
clinical ethics consultation (CEC). The data consist of 11 semi-structured interviews that were conducted with clinical
ethics consultants currently working in hospitals in one major urban area in the U.S. The interviews were analyzed with
the qualitative research method of critical discourse analysis, with a focus on identifying the cultural structures of
knowledge that shape CEC as a professional practice. The discourses were first identified as belonging to two higher
discourse categories, order and agency. Order was divided into three lower categories, emotional, managerial, and
rational order, and discourses of agency into the lower categories of exploration, technique, deliberation, and
distancing. An additional discourse of neutral interaction was identified as a bridging discourse, activated to level
tensions emerging out of conflicting goals and agencies embedded in CEC practice. This analysis brings out as its main
observation that clinical ethics consultants draw on and shift between potentially ideologically conflicting social positions
that can create built-in tensions within the professional domain. The study calls attention to these tensions and
suggests for the professional group to discuss the possibility of defining priorities between different kinds of order, identified in this study, that shape the CEC domain.

**How Can Clinical Ethics Committees Take on Organizational Ethics? Some Practical Suggestions**

*James E. Sabin*

Although leaders in the field of ethics have for many years pointed to the crucial role that organizations play in shaping healthcare ethics, organizational ethics remains a relatively undeveloped area of ethics activity. Clinical ethics committees are an important source of potential expertise, but new skills will be required. Clinical ethics committees seeking to extend their purview to organizational issues will have to respond to three challenges—how to gain sanction and support for addressing controversial and sensitive issues, how to develop an acceptable process, and how to make a difference on the ground. The article presents practical suggestions for how clinical ethics committees meet these challenges.

**What Is Everyday Ethics? A Review and a Proposal for an Integrative Concept**

*Natalie Zizzo, Emily Bell, and Eric Racine*

“Everyday ethics” is a term that has been used in the clinical and ethics literature for decades to designate normatively important and pervasive issues in healthcare. In spite of its importance, the term has not been reviewed and analyzed carefully. We undertook a literature review to understand how the term has been employed and defined, finding that it is often contrasted to “dramatic ethics.” We identified the core attributes most commonly associated with everyday ethics. We then propose an integrative model of everyday ethics that builds on the contribution of different ethical theories. This model proposes that the function of everyday ethics is to serve as an integrative concept that (1) helps to detect current blind spots in bioethics (that is, shifts the focus from dramatic ethics) and (2) mobilizes moral agents to address these shortcomings of ethical insight. This novel integrative model has theoretical, methodological, practical, and pedagogical implications, which we explore. Because of the pivotal role that moral experience plays in this integrative model, the model could help to bridge empirical ethics research with more conceptual and normative work.

**Medical Education and Professionalism**

**The Medical Ethics Curriculum in Medical Schools: Present and Future**

*Alberto Giubilini, Sharyn Milnes, and Julian Savulescu*

In this review article we describe the current scope, methods, and contents of medical ethics education in medical schools in Western English speaking countries (mainly the United Kingdom, the United States, and Australia). We assess the strengths and weaknesses of current medical ethics curricula, and students’ levels of satisfaction with different teaching approaches and their reported difficulties in learning medical ethics concepts and applying them in clinical practice. We identify three main challenges for medical ethics education: counteracting the bad effects of the “hidden curriculum,” teaching students how to apply ethical knowledge and critical thinking to real cases in clinical practice, and shaping future doctors’ right character through ethics education. We suggest ways in which these challenges could be addressed. On the basis of this analysis, we propose practical guidelines for designing, implementing, teaching, and assessing a medical ethics program within a four-year medical course.

**Medical Boards and Fitness to Practice: The Case of Teleka Patrick, MD**

*Katrina A. Bramstedt*

**Background:** Medical boards and fitness-to-practice committees aim to ensure that medical students and physicians have “good moral character” and are not impaired in their practice of medicine.

**Method:** Presented here is an ethical analysis of stalking behavior by physicians and medical students, with focus on the case of Teleka Patrick, MD (a psychiatry resident practicing medicine while under a restraining order due to her alleged stalking behavior).

**Conclusions:** While a restraining order is not generally considered a criminal conviction, stalking behavior is clearly unprofessional and a marker of inappropriate character and fitness, yet the reporting obligations for such matters are complex. Medical schools and training programs that fail to assess, record, and report matters of moral conduct such as this potentially allow impaired students to graduate and enter the work force (unless a robust licensing process identifies them). Patrick’s case should be a wake-up call for medical schools and medical boards to better integrate the professionalism domain into their operations. Further, the professionalism of students and doctors need to be integrated into the legal domain, so that those who are unfit to practice are, in fact, prevented from doing so. Guidance for integration is provided.

**Clinical Ethics Consultation**

**Gender and Race in the Timing of Requests for Ethics Consultations: A Single-Center Study**

*Bethany Spielman, Christine Gorka, Keith Miller, Carolyn A. Pointer, and Barbara Hinze*

**Background:** Clinical ethics consultants are expected to “reduce disparities, discrimination, and inequities when providing consultations,” but few studies about inequities in ethics consultation exist.1 The objectives of this study were (1) to determine if there were racial or gender differences in the timing of requests for ethics consultations related to limiting treatment, and (2) if such differences were found, to identify factors associated with that difference and the role, if any, of ethics consultants in mitigating them.
Features

At the Bedside

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How Clinicians Can Reduce “Bullied Acquiescence”

Edmund G. Howe

Clinicians and patients and their families may disagree about a course of treatment, and the ensuing conflict may seem intractable. The parties may request mediation, or use mediation-based approaches, to help resolve the conflict. In the process of mediation, and at other times, parties in conflict may feel so pressured to accept a resolution that they acquiesce unwillingly—and such resolutions often unravel. In this article I investigate how “bullied acquiescence” might happen, and how to avoid it.

The Effectiveness of Standardized Patient Simulation in Training Hospital Ethics Committees

David Y. Harari and Robert C. Macauley

Clinical simulation using standardized patients has become standard in medical education—and is now being incorporated into some graduate programs in bioethics—for both formative and summative evaluation. In most hospitals, though, clinical ethics consultation is done by the ethics committee (or a subset of it). This study is the first,
to our knowledge, to examine the effectiveness of standardized patient simulation in training hospital ethics committees to deal with ethically complex and emotionally fraught clinical situations. Following a substantial revision of the institution’s nonbeneficial treatment policy, ethics committee members underwent a simulation to determine whether a specific requested treatment should be withheld on the basis of futility. Pre- and post-intervention surveys showed improvement in all domains, although the small sample size limited the power of the study, with only one measure showing a statistically significant difference. An interesting incidental finding was that one-quarter of committee members voted against a determination of futility, even though the case clearly met the definition set forth in the policy. This highlights the emotional challenges in implementing an ethically rigorous, unanimously accepted policy that ultimately determines the timing and manner of a patient’s death.

**Clinical Recommendations in Medical Practice: A Proposed Framework to Reduce Bias and Improve the Quality of Medical Decisions**

*David Alfandre*

Patients rely on, benefit from, and are strongly influenced by physicians’ recommendations. In spite of the centrality and importance of physicians’ recommendations to clinical care, there is only a scant literature describing the conceptual process of forming a clinical recommendation, and no discrete professional standards for making individual clinical recommendations. Evidence-based medicine and shared decision making together are intended to improve medical decision making, but there has been limited attention to how a recommendation is discretely formulated from either of those processes or how patients’ preferences ought to be considered and how much weight they should hold. Moreover, physicians’ bias has been reported to strongly influence how a recommendation is derived, thereby undermining the quality of healthcare decisions and patients’ trust. To demonstrate a potential for improving the quality of decisions, this article proposes a conceptual framework for how physicians should reach a clinical recommendation and apply the process in practice. For preference-sensitive clinical decisions—that is, clinical decisions when patients’ values and preferences are relevant—the process for reaching a recommendation should be transparent to patients and should be based solely on the medical evidence and patients’ values and preferences. When patients’ preferences for care do not prioritize health, physicians decide whether their recommendation will prioritize a welfare-enhancing versus an autonomy-enhancing approach. When there are gaps in understanding how physicians derive their clinical recommendations and how to further improve the quality of the decisions, the author calls for further empiric research.

**The Role of Communication and Interpersonal Skills in Clinical Ethics Consultation: The Need for a Competency in Advanced Ethics Facilitation**

*Wayne Shelton, Cynthia Geppert, and Jane Jankowski*

Clinical ethics consultants (CECs) often face some of the most difficult communication and interpersonal challenges that occur in hospitals, involving stressed stakeholders who express, with strong emotions, their preferences and concerns in situations of personal crisis and loss. In this article we will give examples of how much of the important work that ethics consultants perform in addressing clinical ethics conflicts is incompletely conceived and explained in the American Society of Bioethics and Humanities *Core Competencies for Healthcare Ethics Consultation* and the clinical ethics literature.

The work to which we refer is best conceptualized as a specialized type of interviewing, in which the emotional barriers of patients and their families or surrogates can be identified and addressed in light of relevant ethical obligations and values within the context of ethics facilitation.

**A Case of Attempted Suicide in Huntington’s Disease: Ethical and Moral Considerations**

*Kristin Furfari, Nichole Zehnder, and Jean Abbott*

A 62-year-old female with Huntington’s disease presented after a suicide attempt. Her advance directive stated that she did not want intubation or resuscitation, which her family acknowledged and supported. Despite these directives, she was resuscitated in the emergency department and continued to state that she would attempt suicide again. Her suicidality in the face of a chronic and advancing illness, and her prolonged consistency in her desire to take her own life, left careproviders wondering how to provide ethical, respectful care to this patient.

Tension between the ethical principles of autonomy and beneficence is central in this case. The patient’s narrative demonstrated that her suicide was an autonomous decision, free from coercion or disordered thinking from mental illness. Beneficence then would seem to necessitate care aligned with the patient’s desire to end her life, which created ethical uneasiness for her family and careproviders.

The case highlights several end-of-life ethical considerations that have received much recent attention. With ongoing discussions about the legalization of aid in dying across the country, caregivers are challenged to understand what beneficence means in people with terminal illnesses who want a say in their death. This case also highlights the profound moral distress of families and careproviders that arises in such ethically challenging scenarios.

**Mediation**

**Story of a Mediation in the Clinical Setting**

*Haavi Morreim*
Conflicts in the clinical setting can spiral downward with remarkable speed, as parties become ever more incensed and entrenched in their positions. Productive conversations seem unlikely at best. Nevertheless, such situations can sometimes be turned into collaborative problem solving with equally remarkable speed. For this to happen, those providing conflict-resolution services such as mediation need to bring, not just a set of skills, but also some key norms: the process must be voluntary for all; the mediator must abjure giving advice or taking sides, and must honor the privacy of privately offered thoughts.

This article describes a conflict that had reached the point of a hospital’s requesting judicial coercion. However, a conflict-resolution process was then initiated that, in the end, led to amicable resolution and mended relationships, obviating the need for court orders. This article describes that conflict and the resolution process in detail, along the way annotating specific strategies that are often highly effective.

Cases from MedStar Washington Hospital Center

The Case of Ms D: A Family’s Request for Posthumous Procurement of Ovaries
Laura Guidry-Grimes

The MedStar Washington Hospital Center clinical ethics team became involved in a case when the family requested the posthumous removal of a patient’s ovaries for future reproductive use. This case presents a novel question for clinical ethicists, since the technology for posthumous female reproduction is still in development. In the bioethics literature, the standard position is to refuse to comply with such a request, unless there is explicit consent or evidence of explicit conversations that demonstrate the deceased would have wanted this option pursued. Ms D’s case, we suggest, offers an exception to this default position; complying with the family’s request could have been ethically permissible in this case, had it been medically feasible.

Analysis: OB/GYN-Genetics
Melissa Fries

Ovarian salvage from a patient with brain death is not available and will not preserve viable ova for future reproduction. Previous interest in assisted reproductive technology is only the first step in this process, which requires careful assessment of maternal risks and potential for recurrent genetic disease.

Analysis: Fertility Preservation
Veronica Gómez-Lobo

This commentary considers the viability of ovarian tissue cryopreservation (OTC) in the case of an adult who qualified for brain death. Although there has been some success with OTC in achieving pregnancy when the tissue is reimplemented in the original donor, attempting OTC in the case under discussion would have not been medically feasible.

Analysis: A Legal Perspective
Jack Schwartz

This commentary summarizes the uncertain state of the law regarding consent for posthumous gamete retrieval. The emergence of a legal framework will be aided by the kind of ethical analysis prompted by this family’s request for removal and preservation of a deceased patient’s ovaries.

Perspectives
Ethical Considerations of Whole-Eye Transplantation
Wesley N. Sivak, Edward H. Davidson, Chiaki Komatsu, Yang Li, Maxine R. Miller, Joel S. Schuman, Mario G. Solari, Gerard Magill, and Kia M. Washington

Whole eye transplantation (WET) remains experimental. Long presumed impossible, recent scientific advances regarding WET suggest that it may become a clinical reality. However, the ethical implications of WET as an experimental therapeutic strategy remain largely unexplored. This article evaluates the ethical considerations surrounding WET as an emerging experimental treatment for vision loss. A thorough review of published literature pertaining to WET was performed; ethical issues were identified during review of the articles.

Let’s Not Forget about Clinical Ethics Committees!
Franco A. Carnevale

The aim of this article is to highlight the under-recognized merits of clinical ethics committees (CECs), to help ensure that the development of roles for clinical ethics consultants do not unwittingly compromise the valuable contributions that CECs can continue to provide.

I argue that CECs can offer distinctive contributions to the clinical ethics consultation process that can complement and enrich the input provided by a clinical ethics consultant. These distinctions and complementarities should be further examined and developed. This will help to optimize the synergistic contributions that CECs and clinical ethics consultants can make to promote the ethical treatment of patients and their families.

Moving Clinical Deliberations on Administrative Discharge in Drug Addiction Treatment Beyond Moral Rhetoric to Empirical Ethics
Izaak L. Williams

Patients’ admission to modern substance use disorder treatment comes with the attendant risk of being discharged from treatment—a widespread practice. This article describes the three mainstream theories of addiction
that operate as a reference point for clinicians in reasoning about a decision to discharge a patient from treatment. The extant literature is reviewed to highlight the pathways that patients follow after administrative discharge. Little scientific research has been done to investigate claims and hypotheses about the therapeutic function of AD, which points to the need for empirical ethics to inform clinical addictions practice.

Law

**Legal Briefing: Mandated Reporters and Compulsory Reporting Duties**

*Thaddeus Mason Pope*

This issue’s “Legal Briefing” column, one product of a Greenwall Foundation grant, reviews recent developments concerning compulsory reporting duties. Most licensed clinicians in the United States are “mandated reporters.” When these clinicians discover certain threats to the safety of patients or the public, they are legally required to report that information to specified government officials. Over the past year, several states have legislatively expanded the scope of these reporting duties. In other states, new court cases illustrate the vigorous enforcement of already existing duties. I have organized all these legal developments into the following eight categories:

1. Overview of Mandatory Reporting Duties
2. Controversy over the Benefits of Mandatory Reporting
3. New and Expanded Duties to Report
4. Criminal Penalties for Failing to Report
5. Civil Liability for Failing to Report
6. Disciplinary Penalties for Failing to Report
7. Legal Immunity for Good-Faith Reporting
8. Protection against Employers’ Retaliation

2015

The Journal of Clinical Ethics, Volume 26, Number 4, Winter 2015

At the Bedside

*Mediation Approaches at the Beginning or End of Life*

Edmund G. Howe

Features

*The “Commitment Model” for Clinical Ethics Consultations: Society’s Involvement in the Solution of Individual Cases Stakeholders’ Perspectives on Preclinical Testing for Alzheimer’s Disease*

Jalayne J. Arias, Jeffrey Cummings, Alexander Rae Grant, and Paul J. Ford

*Patient Decision Aids: A Case for Certification at the National Level in the United States*

Urbashi Poddar, Shannon Brownlee, Dawn Stacey, Robert J. Volk, John W. Williams, and Glyn Elwyn

Special Section: Mediation Techniques for Managing Clinical Conflict

*Teaching and Learning the Techniques of Conflict Resolution for Challenging Ethics Consultations*

Edward J. Bergman and Autumn Fiester

*Identifying Sources of Clinical Conflict: A Tool for Practice and Training in Bioethics Mediation*

Edward J. Bergman

*Contentious Conversations: Using Mediation Techniques in Difficult Clinical Ethics Consultations*

Autumn Fiester

*A Second Opinion: A Case Narrative on Clinical Ethics Mediation*

Michael S. Weinstein

*Patient-Centered Care and the Mediator’s Skills*

Mary K. Walton

*In the Ethos of the Safety Net: An Expanded Role for Clinical Ethics Mediation*

Jolion McGreevy

*Mediation Training for the Physician: Expanding the Communication Toolkit to Manage Conflict*

Joshua B. Kayser

*Preventing and De-Escalating Ethical Conflict: A Communication-Training Mediation Model*

Tomer T. Levin and Patricia A. Parker

*Intensive Care, Intense Conflict: A Balanced Approach*

Erin Talati Paquette and Irini N. Kolaitis

Cases from the Cleveland Clinic

*“She Just Doesn’t Know Him Like We Do”: Illuminating Complexities in Surrogate Decision Making*

Margot M. Eves and Bryn S. Esplin

Perspective

*Medical Decision Making for Patients Without Proxies: The Effect of Personal Experience in the Deliberative Process*
The Journal of Clinical Ethics, Volume 26, Number 3, Fall 2015

At the Bedside

How to Help Parents, Couples, and Clinicians When an Extremely Premature Infant Is Born
Edmund G. Howe

Features

COAST (Coordinating Options for Acute Stroke Therapy: An Advance Directive for Stroke
Ilana Spokoyny, Lynette Cederquist, Brian Clay, and Brett C. Meyer
Assessing Advance Care Planning: Examining Autonomous Selections in an Advance Directive
Craig M. Klugman and Nicole M. Tolwin
Informed Consent, Deaf Culture, and Cochlear Implants
Lauren Pass and Abraham D. Graber

Clinical Ethics Consultation

Case Complexity and Quality Attestation for Clinical Ethics Consultants
Bethany Spielman, Jana Craig, Christine Gorka, and Keith Miller

Pediatrics

Prenatal Consultation for Extremely Preterm Neonates: Ethical Pitfalls and Proposed Solutions
Jennifer C. Kett
Ethical Bargaining and Parental Exclusion: A Clinical Case Analysis
Laura Guidry-Grimes and Elizabeth Victor

Case Analysis

The Least Bad Option: Unilateral Extubation after Declaration of Death by Neurological Criteria
Sally E. Bliss and Robert C. Macauley

Commentary

Clarifying an Expanded Use of Continuous Sedation Until Death: A Reply to the Commentary by McCammon and Piemonte
Samuel H. LiPuma and Joseph P. DeMarco

Letter

Response to Stephens and Heitman
Jason Adam Wasserman

The Journal of Clinical Ethics, Volume 26, Number 2, Summer 2015

At the Bedside

How to Retain the Trust of Patients and Families When We Will Not Provide the Treatment They Want
Edmund G. Howe

Features

A Justifiable Asymmetry
Daniel Brudney and Mark Siegler
On Not Taking “Yes” for an Answer
Alexander M. Capron
Moral Reasoning among HEC Members: An Empirical Evaluation of the Relationship of Theory and Practice in Clinical Ethics Consultation
Jason Adam Wasserman, Shannon Lindsey Stevenson, Cassandra Claxton, and Ernest F. Krug, III
Reasoning Backwards by Design: Commentary on “Moral Reasoning among HEC Members”
Ashley L. Stephens and Elizabeth Heitman
Expanding the Use of Continuous Sedation Until Death: Moving Beyond the Last Resort for the Terminally Ill
Samuel H. LiPuma and Joseph P. DeMarco
Continuous Sedation Until Death Should Not Be an Option of First Resort
Susan D. McCammon and Nicole M. Piemonte
"Let Me Keep My Dead Husband’s Sperm": Ethical Issues in Posthumous Reproduction
Nikoletta Panagiotopoulou and Stamatios Karavolos

Cases from the Harvard Ethics Consortium

The Value of Virginity
Christine Mitchell
When Bleeding Is Vital: Surgically Ensuring the “Virginal” State
Sohaila Bastami

A Hymen Epiphany
Farrah Jarral

On Hymenoplasty
Mary-Jo DelVecchio Good

Hymen Restoration: “My” Discomfort, “Their” Culture, and Women’s Missing Voice
Sylvie Schuster

The Value of Virginity and the Value of the Law: Accommodating Multiculturalism
Pablo de Lora

Is Hymenoplasty Anti-Feminist?
Gretchen Heinrichs

Doctoring the Genitals: Towards Broadening the Meaning of Social Medicine
Richard A. Shweder

Law

Legal Briefing: Adult Orphans and the Unbefriended: Making Medical Decisions for Unrepresented Patients without Surrogates
Thaddeus Mason Pope

Letters

Possible Unintended Consequences of Including Equal-Priority Surrogates
Steven Perry and Arvind Venkat

Response to Perry and Venkat
Autumn Fiester

The Journal of Clinical Ethics, Volume 26, Number 1, Spring 2015

Professionalism: One Size Does Not Fit All
Edmund G. Howe

When a child is born with or acquires special needs, the parents may find some parental tasks more difficult. They may not know how to make their tasks easier, or that some parents find it exceptionally rewarding and meaningful to raise their children with special needs. This piece explores how clinicians might share this potentially life-altering information. It also explores when and why clinicians might want to make one-of-a-kind exceptions to their usual professional practices.

A Quality of Life Quandary: A Framework for Navigating Parental Refusal of Treatment for Co-Morbidities in Infants with Underlying Medical Conditions
Sarah N. Kunz, Ryan M. McAdams, Douglas S. Diekema, and Douglas J. Opel

Parental refusal of a recommended treatment is not an uncommon scenario in the neonatal intensive care unit. These refusals may be based upon the parents’ perceptions of their child’s projected quality of life. The inherent subjectivity of quality of life assessments, however, can exacerbate disagreement between parents and healthcare providers. We present a case of parental refusal of surgical intervention for necrotizing enterocolitis in an infant with Bartter syndrome and develop an ethical framework in which to consider the appropriateness of parental refusal based upon an infant’s projected quality of life.

Witnesses to Mute Suffering: Quality of Life, Intellectual Disability, and the Harm Standard
Lisa C. Freitag

Decisions to override a parental request to withhold or withdraw treatment in the neonatal intensive care unit are often made based on the harm standard, with death being cast as the ultimate harm. However, often the treatment itself is not without harm, and the suffering engendered is undergone by an infant who is neither able to understand it nor express its presence. We can draw upon anticipated future quality of life to justify the present suffering, but are in a quandary when that future is not guaranteed or is likely to hold little but further suffering. I propose that conflicts over continuing treatment are based both on disagreements about the desirability of possible futures, and on differing perceptions of the infant’s current level of suffering. Those of us who witness the suffering of these tiny, mute infants all bear some responsibility to insure that their suffering is not without purpose.

Home Birth of Infants with Congenital Anomalies: A Case Study and Ethical Analysis of Careproviders’ Obligations
Jane Jankowski and Paul Burcher

This article presents the case of a mother who is planning a home birth with a midwife with the shared knowledge that the fetus would have congenital anomalies of unknown severity. We discuss the right of women to choose home birth, the caregivers’ duty to the infant, and the careproviders' dilemma about how to respond to this request. The ethical duties of concerned careproviders are explored and reframed as professional obligations to the mother, infant, and their profession at large. Recommendations are offered based on this case in order to clarify the
considerations surrounding not only home birth of a fetus with anticipated anomalies, but also to address the ethical obligations of caregivers who must navigate the unique tension between respecting the mother’s wishes and the duty of the careproviders to deliver optimal care.

**Of Missing Voices and the Obstetric Imaginary: Commentary on Jankowski and Burcher**

*Melissa Cheyney*

In this commentary, I respond to an ethical analysis of a case study, reported by Jankowski and Burcher, in which a woman gives birth to an infant with a known heart anomaly of unknown severity, at home, attended by a midwife. Jankowski and Burcher argue that the midwife who attended this family acted unethically because she knowingly operated outside of her scope of practice. While I agree that the authors’ conclusions are well supported by the portion of the story they were able to gather, the fact that the midwife and mother declined to engage in the ethics consult that informs their piece means that critical segments of the narrative are left untold. Some important additional considerations emerge from these silences.

I explore the implicit assumptions of the biotechnical embrace, the roles of the political economy of hope and the obstetric imaginary in driving prenatal testing, and institutional blame for the divisiveness of the home-hospital divide in the United States. The value of Jankowski and Burcher’s case study lies in its ability to highlight the intersections and potential conflicts between the principles of beneficence, patients’ autonomy, and professional ethics, and to begin to chart a course for us through them.

**Hinduism and Death with Dignity: Historic and Contemporary Case Examples**

*Rajan Dewar, Nancy Cahners, Christine Mitchell, and Lachlan Forrow*

An estimated 1.2 to 2.3 million Hindus live in the United States. End-of-life care choices for a subset of these patients may be driven by religious beliefs. In this article, we present Hindu beliefs that could strongly influence a devout person’s decisions about medical care, including end-of-life care. We provide four case examples (one sacred epic, one historical example, and two cases from current practice) that illustrate Hindu notions surrounding pain and suffering at the end of life. Chief among these is the principle of karma, through which one reaps the benefits and penalties for past deeds. Deference to one’s spouse or family is another important Hindu value, especially among Hindu women, which can impact the decision-making process and challenge the Western emphasis on autonomy. In addition, the Hindu embrace of astrology can lead to a desire to control the exact time of death. Confounding any generalizations, a Hindu patient may reject or accept treatments based on the individual patient’s or family’s interpretation of any given tradition. Through an awareness of some of the fundamental practices in Hinduism and the role of individual interpretation within the tradition, clinicians will be better able to support their Hindu patients and families at the end of life.

**Medical Professionalism in China and the United States: A Transcultural Interpretation**

*Jing-Bao Nie, Kirk L. Smith, Yali Cong, Linying Hu, and Joseph D. Tucker*

As in other societies, medical professionalism in the Peoples’ Republic of China has been rapidly evolving. One of the major events in this process was the endorsement in 2005 of the document, “Medical Professionalism in the New Millennium: A Physician Charter,” by the Chinese Medical Doctor Association (hereafter, the Charter). More recently, a national survey, the first on such a large scale, was conducted on Chinese physicians’ attitudes toward the fundamental principles and core commitments put forward in the Charter. Based on empirical findings from that study and comparing them to the published results of a similar American survey, the authors offer an in-depth interpretation of significant cross-cultural differences and important transcultural commonalities. The broader historical, socio-economic, and ethical issues relating to salient Chinese cultural practices such as family consent, familism (the custom of deferring decisions to family members), and the withholding of medical information, as well as controversial topics such as not respecting patients’ autonomy, are examined. The Chinese Survey found that Chinese physicians supported the principles of the Charter in general. Here we argue that Chinese culture and traditional medical ethics are broadly compatible with the moral commitments demanded by modern medical professionalism. Methodologically and theoretically—recognizing the problems inherent in the hoary but still popular habit of dichotomizing cultures and in relativism—a transcultural approach is adopted that gives greater (due) weight to the internal moral diversity present within every culture, the common ground shared by different cultures, and the primacy of morality. Genuine cross-cultural dialogue, including a constructive Chinese-American dialogue in the area of medical professionalism, is not only possible, but necessary.

**Re-Evaluating Ethical Concerns in Planned Emergency Research Involving Critically Ill Patients: An Interpretation of the Guidance Document from the United States Food and Drug Administration**


**Background:** U.S. federal regulations require that certain ethical elements be followed to protect human research subjects. The location and clinical circumstances of a proposed research study can differ substantially and can have significant implications for these ethical considerations. Both the location and clinical circumstances are particularly relevant for research in intensive care units (ICUs), where patients are often unable to provide informed consent to participate in a proposed research intervention.
Purpose: Our goal is to elaborate on the updated 2013 U.S. Food and Drug Administration (FDA) guidance document regarding an exemption from the requirement of obtaining informed consent from patients or their surrogates and to address certain elements within that document, thereby assisting clinicians in developing a framework for emergency research in accordance with the regulatory bodies at their own institutions and in the United States.

Methods: Review of the 2011 and updated FDA guidance document on exemption from informed consent.

Results: The current process of obtaining informed consent within ICUs needs to be revisited, especially for research in which timely informed consent is not likely. In particular, the process of obtaining informed consent may not be appropriate or even ethical for critically ill patients in extremis who require an intervention for which there is no current acceptable standard of care and clinical equipoise exists. We provide clinicians with a viewpoint that further elaborates on the FDA guidance document.

Limitations: The viewpoints provided herein are those of the authors and are therefore inherently limited by the personal views of a selected few. Other clinicians or researchers may not interpret the FDA guidelines in a similar manner. Moreover, the discussion of a guideline document is a limitation in and of itself. The guidelines set forth by the FDA are precisely that—guidelines. Therefore, they may not be followed as outlined in the guidance document within one’s own institution. Our goal is that, by elaborating on the guidelines for planned research involving human subjects in the ICU, institutional regulatory bodies may gain a better understanding in drafting their own document when faced with a clinician or a researcher who wishes to conduct planned research in an ICU.

Conclusions: We believe that the interpretations provided will allow clinicians to safely undertake planned research in ICUs without endangering the main tenets of ethical research involving human participants. This research is needed for the advancement of care in the critically ill.

The Ethics of Physicians’ Web Searches for Patients’ Information
Nicholas Genes and Jacob Appel

When physicians search the web for personal information about their patients, others have argued that this undermines patients’ trust, and the physician-patient relationship in general. We add that this practice also places other relationships at risk, and could jeopardize a physician’s career.

Yet there are also reports of web searches that have unambiguously helped in the care of patients, suggesting circumstances in which a routine search of the web could be beneficial. We advance the notion that, just as nonverbal cues and unsolicited information can be useful in clinical decision making, so too can online information from patients. As electronic records grow more voluminous and span more types of data, searching these resources will become a clinical skill, to be used judiciously and with care—just as evaluating the literature is, today.

But to proscribe web searches of patients’ information altogether is as nonsensical as disregarding findings from physical exams—instead, what’s needed are guidelines for when to look and how to evaluate what’s uncovered, online.

Legal Briefing: Coerced Treatment and Involuntary Confinement for Contagious Disease
Thaddeus Mason Pope and Heather Michelle Bughman

This issue’s “Legal Briefing” column covers recent legal developments involving coerced treatment and involuntary confinement for contagious disease. Recent high profile court cases involving measles, tuberculosis, human immunodeficiency virus, and especially Ebola, have thrust this topic back into the bioethics and public spotlights. This has reignited debates over how best to balance individual liberty and public health. For example, the Presidential Commission for the Study of Ethical Issues has officially requested public comments, held open hearings, and published a 90-page report on “ethical considerations and implications” raised by “U.S. public policies that restrict association or movement (such as quarantine).”1 Broadly related articles have been published in previous issues of JCE.2 We categorize recent legal developments on coerced treatment and involuntary confinement into the following six categories:

1. Most Public Health Confinement Is Voluntary
2. Legal Requirements for Involuntary Confinement
3. New State Laws Authorizing Involuntary Confinement
4. Quarantine Must Be as Least Restrictive as Necessary
5. Isolation Is Justified Only as a Last Resort
6. Coerced Treatment after Persistent Noncompliance.

2014

The Journal of Clinical Ethics, Volume 25, Number 4, Winter 2014

New Approaches with Surrogate Decision Makers
Edmund G. Howe

Who’s at the Table? Moral Obligations to Equal-Priority Surrogates in Clinical Ethics Consultations
Meghan O’Brien and Autumn Fiester
Special Issue on Place of Birth, Guest Edited by Elizabeth Bogdan-Lovis, Charlotte de Vries, and Raymond G. de Vries

When a Mother Wants to Deliver with a Midwife at Home
Edmund G. Howe

Planned Home Birth in the United States and Professionalism: A Critical Assessment
Frank A. Chervenak, Laurence B. McCullough, Amos Grünebaum, Birgit Arabin, Malcolm I. Levene, and Robert L. Brent

Ethics and the Architecture of Choice for Home and Hospital Birth
Elizabeth Bogdan-Lovis and Raymond G. de Vries

Revisiting “The Maximin Strategy in Modern Obstetrics”
Howard Brody and Carol Sakala

A Reconsideration of Home Birth in the United States
Howard Minkoff and Jeffrey Ecker

The Absolute Power of Relative Risk in Debates on Repeat Cesareans and Home Birth in the United States
Eugene Declercq

Moral Science: Ethical Argument and the Production of Knowledge about Place of Birth
Raymond G. de Vries, Yasaswi Paruchuri, Kathleen Lorenz, and Saraswathi Vedam

Women’s Perceptions of Childbirth Risk and Place of Birth
Mary Regan and Katie McElroy

Exceptional Deliveries: Home Births as Ethical Anomalies in American Obstetrics
Claire L. Wendland

Being Safe: Making the Decision to Have a Planned Home Birth in the United States
Judith A. Lothian

Facilitating Women’s Choice in Maternity Care
Marianne Nieuwenhuijze and Lisa Kane Low

Personal Perspective: One Obstetrician’s Look at a Polarizing Birth Arena
Annette E. Fineberg

Personal Perspective: Seeking an Alternative Baseline for Birth
Darcia Narváez

Personal Perspective: Individual versus Professional Preferences
Julie Sharon-Wagschal

Personal Perspective: The Industry Take-Over of Home Birth and Death
Merilynne Rush

Personal Perspective: On the Need for a Real Choice
Steve Calvin

Legal Briefing: Home Birth and Midwifery
Thaddeus Mason Pope and Deborah Fisch

The Journal of Clinical Ethics, Summer 2013, Volume 24, Number 2

Why Careproviders May Conclude that Treating a Patient Is Futile
Edmund G. Howe

Repetitive Foreign Body Ingestion: Ethical Considerations
Sarah Lytle, Susan J. Stagno, and Barb Daly

The Intensity and Frequency of Moral Distress Among Different Healthcare Disciplines
Susan Houston, Mark A. Casanova, Marygrace Leveille, Kathryn L. Schmidt, Sunni A. Barnes, Kelli R. Trungale, and Robert L. Fine

“He Got His Last Wishes”: Ways of Knowing a Loved One’s End-of-Life Preferences and Whether Those Preferences Were Honored
Angelina R. Wittich, Beverly Rosa Williams, F. Amos Bailey, Lesa L. Woodby, and Kathryn L. Burgio

Making Decisions for Hospitalized Older Adults: Ethical Factors Considered by Family Surrogates
Jenna Fritsch, Sandra Petronio, Paul R. Helft, and Alexia M. Torke

The Threshold Moment: Ethical Tensions Surrounding Decision Making on Tracheostomy for Patients in the Intensive Care Unit
Arvind Venkat

A Response to Dubler’s Commentary on “Surmounting Elusive Barriers: The Case for Bioethics Mediation”
Edward J. Bergman
The Art of the Chart Note in Clinical Ethics Consultation and Bioethics Mediation: Conveying Information that Can Be Understood and Evaluated
Nancy Neveloff Dubler

Legal Briefing: The New Patient Self-Determination Act
Thaddeus Mason Pope

The Journal of Clinical Ethics, Spring 2013, Volume 24, Number 1

The Best Place for “Bare-Knuckled Ethics”
Edmund G. Howe

Surmounting Elusive Barriers: The Case for Bioethics Mediation
Edward J. Bergman

Commentary on Bergman: “Yes . . . But”
Nancy Neveloff Dubler

The Chiaroscuro of Accountability in the Second Edition of the Core Competencies for Healthcare Ethics Consultation
Lisa Rasmussen

Prescribing for Coworkers: Practices and Attitudes of Faculty and Residents
Carson Strong, Stephanie Connelly, and Laura R. Sprabery

The Ethics of Reality Medical Television
Thalia Margalit Krakower, Martha Montello, Christine Mitchell, and Robert D. Truog

Not a “Reality” Show
Terence Wrong and Erica Baumgart

First, Do No Harm
Neal Baer

Watching Boston Med
Walter M. Robinson

Legal Briefing: Shared Decision Making and Patient Decision Aids
Thaddeus Mason Pope and Melinda Hexum

2012

The Journal of Clinical Ethics, Winter 2012, Volume 23, Number 4

A Different Approach to Patients and Loved Ones Who Request “Futile” Treatments
Edmund G. Howe

Complex Discharges and Undocumented Patients: Growing Ethical Concerns
Kayhan Parsi and Nina Hossa

When Negative Rights Become Positive Entitlements: Complicity, Conscience, and Caregiving
Andrew G. Shuman, Adam A. Khan, Jeffrey S. Moyer, Mark E. Prince, and Joseph J. Fins

A New Standard for Incapacitated Patient Decision Making: The Clinical Standard of Surrogate Empowerment
Marc Tunzi

Bedside Resource Stewardship in Disasters: A Provider’s Dilemma Practicing in an Ethical Gap
Michelle Daniel

Resource Stewardship in Disasters: Alone at the Bedside
Jeffrey T. Berger

Tragic Choices in Humanitarian Health Work
Matthew R. Hunt, Christina Sinding, and Lisa Schwartz

Endoscopy During a Missile Attack: A Military Dilemma for Physicians
Stephen Malnick, Orit Faraj, and Alan Jotkowitz

Making “Social” Safer: Are Facebook and Other Online Networks Becoming Less Hazardous for Health Professionals?
Daniel R. George

Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment
Thaddeus Mason Pope and Melinda Hexum

The Journal of Clinical Ethics, Volume 23, Number 3, Fall 2012

An Ethical Priority Greater than Life Itself
Edmund G. Howe
The Journal of Clinical Ethics, Volume 23, Number 1, Spring 2012

How Careproviders Can Acquire and Apply Greater Wisdom
Edmund G. Howe

Clinical Wisdom in Psychoanalysis and Psychodynamic Psychotherapy: A Philosophical and Qualitative Analysis
Cynthia Baum-Baicker and Dominic A. Sisti

Response: Clinical Wisdom and Evidence-Based Medicine Are Complementary
Julian De Freitas, Omar S. Haque, Abilash A. Gopal, and Harold J. Bursztajn

Clinical Wisdom and Evidence-Based Medicine Are (Indeed) Complementary: A Reply to Bursztajn and Colleagues
Cynthia Baum-Baicker and Dominic A. Sisti

Attending to Clinical Wisdom
Jodi Halpern

Her Own Decision: Impairment and Authenticity in Adolescence
Amy T. Campbell, Sabrina F. Derrington, D. Micah Hester, and Cheryl D. Lew

Supporting Her Autonomy: The Obligations of Guardians and Physicians in Adolescents’ Refusals of Care
Jennifer K. Walter

Intraoperative Conversion to Open Technique: Is Informed Consent Implied?
Chirag B. Patel and Davide Cattano

Anesthesiological Ethics: Can Informed Consent Be Implied?
Jeffrey P. Spike

Surrogate Medical Decision Making on Behalf of a Never-Competent, Profoundly Intellectually Disabled Patient Who Is Acutely Ill
Arvind Venkat

Care versus Treatment at the End of Life for Profoundly Disabled Persons
Jeffrey P. Spike

Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients without Surrogates (Part 1)
Thaddeus Mason Pope and Tanya Sellers

2011

The Journal of Clinical Ethics, Volume 22, Number 4, Winter 2011

How Mediation (and Other) Approaches May Improve Ethics Consultants’ Outcomes
Edmund G. Howe

Consensus, Clinical Decision Making, and Unsettled Cases
David M. Adams and William J. Winslade

The Role of the Clinical Ethics Consultant in “Unsettled” Cases
David M. Adams

The Roles of the Ethics Consultant
William J. Winslade

Confronting Ambiguity: Identifying Options for Infants with Trisomy 18
Sabrina F. Derrington and April R. Dworetz

“Facilitated Consensus,” “Ethics Facilitation,” and Unsettled Cases
Mark P. Aulisio

Commentary on “Consensus, Clinical Decision Making, and Unsettled Cases”
Albert R. Jonsen

Final Comments
David M. Adams and William J. Winslade

Ill-Placed Democracy: Ethics Consultations and the Moral Status of Voting
Autumn M. Fiester

Commentary on Fiester’s “Ill-Placed Democracy: Ethics Consultations and the Moral Status of Voting”
Nancy Neveloff Dubler

Clinical Ethics Consultation’s Dilemma, and a Solution
Lisa M. Rasmussen
The Journal of Clinical Ethics, Volume 22, Number 3, Fall 2011

**Ethical Challenges When Patients Have Dementia**
Edmund G. Howe

**Incapable Sex: A Case Study**
Bethan J. Everett

**Training Currently Practicing Members of the Ethics Consultation Service: One Institution’s Experience**
Rebecca L. Volpe

**Accuracy of a Decision Aid for Advance Care Planning: Simulated End-of-Life Decision Making**
Benjamin H. Levi, Steven R. Heverley, and Michael J. Green

**Advance Care Directives: Realities and Challenges in Central California**
Marc Tunzi

**Introduction to “Exemplary Cases in Clinical Ethics”**
Leslie LeBlanc

**Clinical Ethics Case Report: Questionable Capacity and the Guidance of Living Wills**
Ari VanderWalde

**Exemplary Cases in Clinical Ethics: Commentary on the Case of Mr. A.**
Jeffrey Spike

**Mind the Gap: The Lack of Common Language in Healthcare Ethics**
Michael A. Kekewich, Dorothyann Curran, Jennifer L. Cornick, and Thomas C. Foreman

John J. Mitchell, Jr.

**Legal Briefing: Futile or Non-Beneficial Treatment**
Thaddeus Mason Pope

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The Journal of Clinical Ethics, Volume 22, Number 2, Summer 2011

**Helping Patients by Involving Their Families**
Edmund G. Howe

**Responsive Care Management: Family Decision Makers in Advanced Cancer**
Mary Ann Meeker

**Trusting Families: Responding to Mary Ann Meeker, “Responsive Care Management: Family Decision Makers in Advanced Cancer”**
James Lindemann Nelson

**Revisiting the Best Interest Standard: Uses and Misuses**
Douglas S. Diekema

**The Best Interest Standard: Both Guide and Limit to Medical Decision Making on Behalf of Incapacitated Patients**
Thaddeus Mason Pope

**Between Uncertainty and Certainty**
Lena Hoff and Göran Hermerén

**A Systematic Review of Activities at a High-Volume Ethics Consultation Service**
Courtenay R. Bruce, Martin L. Smith, Sabahat Hizlan, and Richard R. Sharp

**Report of the AMA Council on Ethical and Judicial Affairs: Professionalism in the Use of Social Media**
Rebecca Shore, Julia Halsey, Kavita Shah, Bette-Jane Crigger, and Sharon P. Douglas

**Online Professionalism: Social Media, Social Contracts, Trust, and Medicine**
Lois Snyder

**Medical Professionalism: A Tale of Two Doctors**
Tristan Gorrindo and James E. Groves

**Nonclinical Use of Online Social Networking Sites: New and Old Challenges to Medical Professionalism**
Lindsay A. Thompson and Erik W. Black

**Blurring Boundaries and Online Opportunities**
Jeanne M. Farnan and Vineet M. Arora

**Physician, Monitor Thyself: Professionalism and Accountability in the Use of Social Media**
Tara Lagu and S. Ryan Greysen

**Social Media and Interpersonal Relationships: For Better or Worse?**
Norman Quist

**Certifying Clinical Ethics Consultants: Who Pays?**
Marianne Burda
The Journal of Clinical Ethics, Volume 22, Number 1, Spring 2011

How Can Careproviders Most Help Patients during a Disaster?
Edmund G. Howe

Imagining the Unthinkable, Illuminating the Present
Jeffrey T. Berger, Guest Editor, Special Section: Clinical Ethics in Catastrophic Situations: Mapping a Standard of Care—Imagining the Unthinkable

An Ethical Framework for the Responsible Management of Pregnant Patients in a Medical Disaster
Frank A. Chervenak and Laurence B. McCullough

Non-Pharmaceutical Interventions to Limit the Transmission of a Pandemic Virus: The Need for Complementary Programs to Address Children’s Diverse Needs
Armand H. Matheny Antommaria and Emily A. Thorell

Unaltered Ethical Standards for Individual Physicians in the Face of Drastically Reduced Resources Resulting from an Improvised Nuclear Device Threat
J. Jaime Caro, C. Norman Coleman, Ann Knebel, and Evan G. DeRenzo

Attending to Social Vulnerability When Rationing Pandemic Resources
Dorothy E. Vawter, J. Eline Garrett, Karen G. Gervais, Angela Witt Prehn, and Debra DeBruin

Ethical Care for Infants with Conditions Not Curable with Intensive Care
Bethan J. Everett and Susan G. Albersheim

Priority Setting Up Close
Barbara Russell and Deb deVlaming

Personal Perspective: “Evidence-Debased Medicine” and the Integrity of the Medical Profession
Richard L. Elliott

Legal Briefing: Healthcare Ethics Committees
Thaddeus Mason Pope

Letter: Ethical Issues Related to Direct Nursing Care Time, Compared to Time Spent Charting in Intensive Care Units
Peter Roffey and Duraiyah Thangathurai

Letter: Esprit de Corps
Evan G. DeRenzo and Jack Schwartz

2010

The Journal of Clinical Ethics, Volume 21, Number 4, Winter 2010

A Possible Application of Care-Based Ethics to People with Disabilities during a Pandemic
Edmund G. Howe

Bedside Ethics and Health System Catastrophe: Imagine If You Will . . .
Jeffrey T. Berger, Guest Editor

Family Participation in the Care of Patients in Public Health Disasters
Tia Powell

Sufficiency of Care in Disasters: Ventilation, Ventilator Triage, and the Misconception of Guideline-Driven Treatment
Griffin Trotter

Pandemic Preparedness Planning: Will Provisions for Involuntary Termination of Life Support Invite Active Euthanasia?
Jeffrey T. Berger

Should Palliative Care Be a Necessity or a Luxury during an Overwhelming Health Catastrophe?
Philip M. Rosoff

Taking Seriously the “What Then?” Question: An Ethical Framework for the Responsible Management of Medical Disasters
Laurence B. McCullough

The Elephant in the Room: Collaboration and Competition among Relief Organizations during High-Profile Disasters
Italo Subbarao, Matthew K. Wynia, and Frederick M. Burkle, Jr.

Medical School Oath-Taking: The Moral Controversy
Robert M. Veatch and Cheryl C. Macpherson

Allocating Scarce Medical Resources to the Overweight
Adrian Furnham, Niroosha Loganathan, and Alastair McClelland

Legal Briefings: Crisis Standards of Care and Legal Protection during Disasters and Emergencies
Religious Belief and Surrogate Medical Decision Making
Stewart Eskew and Christopher Meyers

The Journal of Clinical Ethics, Volume 20, Number 1 Spring 2009

Increasing Consensus with Patients and their Loved Ones
Edmund G. Howe

Increasing Rates of Organ Donation: Exploring the Institute of Medicine’s Boldest Recommendation
James M. DuBois

Translating the IOM’s “Boldest Recommendation” into Accepted Practice
Stephen P. Wall, Nancy N. Dubler, and Lewis R. Goldfrank, on Behalf of the New York City Uncontrolled Donation after Cardiac Death Study Group

Public Policy Should Facilitate Organ Donation for Transplantation: A Commentary on “Increasing Rates of Organ Donation: Exploring the IOM’s Boldest Recommendation”
Ronald B. Miller

Commentary on DuBois
Nneka O. Mokwunye, Evan G. DeRenzo, Virginia A. Brown, and John J. Lynch

Comment on DuBois’s Article, “Increasing Rates of Organ Donation: Exploring the IOM’s Boldest Recommendation”
Sigrid Fry-Revere and Bahar Bastani

Response to Commentaries on “Increasing Rates of Organ Donation”
James M. DuBois

Ethics Consultation and “Facilitated” Consensus
David M. Adams

Consensus and Independent Judgment in Clinical Ethics: Or What Can an Eighteenth-Century French Mathematician Teach Us about Ethics Consultation?
Lynn A. Jansen

Difficult Patients, Overmedication, and Groupthink
Francis Dominic Degnin

Groupthink and Caregivers’ Projections: Addressing Barriers to Empathy
Jodi Halpern

A Process and Format for Clinical Ethics Consultation
Robert D. Orr and Wayne Shelton

Seeking Excellence in Hospital Care: Evolving Toward a Systems Approach
Evan G. DeRenzo

Legal Trends in Bioethics
Sigrid Fry-Revere, Alison Mathey, Deborah Chen, and Nathaniel B. Revere

2008

The Journal of Clinical Ethics, Volume 19, Number 4, Winter 2008

Child Abuse: How Society and Careproviders Should Respond
Edmund G. Howe

Clinical Ethics and Domestic Violence: An Introduction
Norman Quist

The Veil of Silence around Family Violence: Is Protecting Patients’ Privacy Bad for Health?
Felicia Cohn

State Codes on Intimate Partner Violence: Victimization Reporting Requirements for Healthcare Providers
Family Violence Prevention Fund

Deadly Sins and Cardinal Virtues in the Clinical Management of Intimate Partner Violence
Gregory Luke Larkin

A Health-Based Child Protection System: Studying a Change in Paradigm
Richard D. Krugman, Stephanie Stronks-Knapp, Mischa Haroutunian, and Jessica M. Yeatemeyer

Social Problem or Medical Condition? A Response to Krugman’s Proposal
Barbara Katz Rothman and Rebecca Tiger

Ethical Dilemmas in Coding Domestic Violence
William Rudman, Susan Hart-Hester, C. Andrew Brown, Shannon Pittman, Esther Choo, and Felicia Cohn

The Spectrum of Religion and Science in Clinical Encounters
Mark F. Carr
The Journal of Clinical Ethics, Volume 19, Number 1, Spring 2008

When, If Ever, Should Careproviders Give Moral Advice?
Edmund G. Howe

Of More than One Mind: Obstetrician-Gynecologists’ Approaches to Morally Controversial Decisions in Sexual and Reproductive Healthcare
Farr A. Curlin, Shira N. Dinner, and Stacy Tessler Lindau

Commentary on “Of More than One Mind”
Edmund D. Pellegrino

Professional Responsibility and Individual Conscience: Protecting the Informed Consent Process from Impermissible Bias
Frank A. Chervenak and Laurence B. McCullough

Beliefs, Boundaries, and Self-Knowledge in Professional Practice
David Kozishek and Elizabeth Bogdan-Lovis

Ethical Issues Concerning Disclosures of HIV Diagnoses to Perinatally Infected Children and Adolescents
Robert Klitzman, Stephanie Marhefka, Claude Mellins, and Lori Wiener

Disclosure of HIV Status to an Infected Child: Medical, Psychological, Ethical, and Legal Perspectives in an Era of “Super-Vertical” Transmission
Charles D. Mitchell, F. Daniel Armstrong, Kenneth W. Goodman, and Anita Cava

Disclosure of HIV Status to an Infected Child: Confidentiality, Duty to Warn, and Ethical Practice
James R. Corbin

Placebo Use in Clinical Practice: Report of the American Medical Association Council on Ethical and Judicial Affairs
Nathan A. Bostick, Robert Sade, Mark A. Levine, and Dudley M. Stewart, Jr.

Placebos: Current Clinical Realities
Rachel Sherman and John Hickner

Clinical Placebo Interventions Are Unethical, Unnecessary, and Unprofessional
Asbjørn Hróbjartsson

Commentary on “The Case of Mr. A.B.”: Dilemmas for a Reason
G. Caleb Alexander

Legal Trends in Bioethics
Sigrid Fry-Revere, Sheeba Koshy, Greyson C. Ruback, and John Leppard, IV

2007

The Journal of Clinical Ethics, Volume 18, Number 4, Winter 2007

When Family Members Disagree
Edmund G. Howe

Beyond Schiavo
Arthur L. Caplan and Edward J. Bergman

Commentary on “Beyond Schiavo”: Beyond Theory
Nancy Neveloff Dubler

A Commentary on Caplan and Bergman: Ethics Mediation — Questions for the Future
Robert Arnold, Mark Aulisio, Ann Begler, and Deborah Seltzer

Mediation and Moral Aporia
Autumn Fiester

Hope, Uncertainty, and Lacking Mechanisms
Norman Quist

How Much Emotion Is Enough?
Annie Janvier

Real Life Informs Consent
Felicia Cohn

What Parents Face with Their Child’s Life-Threatening Illness: Comment on “How Much Emotion Is Enough?” and “Real Life Informs Consent”
Edward J. Krill

Reflections on Love, Fear, and Specializing in the Impossible
David M. Browning, Elaine C. Meyer, Dara Brodsky, and Robert D. Truog

Emotion, Suffering, and Hope: Commentary on “How Much Emotion Is Enough?”
Jason D. Higginson
Let’s Value, But Not Idealize, Emotions
Jodi Halpern

Jewish Law and End-of-Life Decision Making: A Case Report
Craig D. Blinderman

When Surrogates’ Responsibilities and Religious Concerns Intersect
Jeffrey T. Berger

A Tale of Two Daughters: Jewish Law and End-of-Life Decision Making
Dena S. Davis

Commentary on “Jewish Law and End-of-Life Decision Making”
Fred Rosner

The Case of Mr. A.B.
Peter Sloane and Evan G. DeRenzo

Comment on the Case of Mr. A.B.
Paul S. Appelbaum

Legal Trends in Bioethics
Sigrid Fry-Revere, Sheeba Koshy, and John Leppard, IV

The Journal of Clinical Ethics, Volume 18, Number 3, Fall 2007

How Should Careproviders Respond When the Medical System Leaves a Patient Short?
Edmund G. Howe

Autonomy and the Family as Surrogates for DNR Decisions: A Qualitative Analysis of Dying Cancer Patients’ Talk
Jaklin Eliott and Ian Olver

What Families Say about Surrogacy: A Response to “Autonomy and the Family as (In)appropriate Surrogates for DNR Decisions”
James L. Nelson and Hilde Lindemann

The Armchair Ethicist: It’s All about Location
Douglas S. Diekema

Response from Eliott and Olver
Jaklin Eliott and Ian Olver

Ethics Consultation: Continuing its Analysis
Barbara J. Russell and Deborah A. Pape

Professional Clinical Ethicist: Knowing Why and Limits
Paul J. Ford

Memento . . . Life Imitates Art: The Request for an Ethics Consultation
Sheila Otto

Memory Identity and Capacity
Jeffrey P. Spike

Decision-Making Capacity, Memory and Informed Consent, and Judgment at the Boundaries of the Self
Omar Sultan Haque and Harold Bursztajn

The Challenges of Amnesia in Assessing Capacity, Assigning a Proxy, and Deciding to Forego Life-Prolonging Medical Treatment
Catherine Myser

Lisa Lehmann

Legal Trends in Bioethics
Sigrid Fry-Revere and Sheeba Koshy

The Journal of Clinical Ethics, Volume 18, Number 2, Summer 2007

“I’m Still Glad You Were Born” — Careproviders and Genetic Counseling
Edmund G. Howe

The Role of Substituted Judgment in the Aftermath of a Suicide Attempt
Robert C. Macauley

Commentary: Support for Case-Based Analysis in Decision Making after a Suicide Attempt
Tia Powell

Flipping the Default: A Novel Approach to Cardiopulmonary Resuscitation in End-Stage Dementia
Angelo E. Volandes and Elmer D. Abbo
Proactive Ethics Consultation in the ICU: A Comparison of Value Perceived by Healthcare Professionals and Recipients
Felicia Cohn, Paula Goodman-Crews, William Rudman, Lawrence J. Schneiderman, and Ellen Waldman

Uncertainty and Moral Judgment: The Limits of Reason in Genetic Decision Making
Mary Terrell White

Pride and Prejudice: Avoiding Genetic Gossip in the Age of Genetic Testing
Darlyn Pirakitikulr and Harold J. Bursztajn

Legal Trends in Bioethics
Sigrid Fry-Revere, with the research assistance of John Joseph Leppard, IV, Molly Elgin, William Bryce Hankins, III, and Scott Ryan Grandt

The Journal of Clinical Ethics, Volume 18, Number 1, Spring 2007
Taking Patients’ Values Seriously
Edmund G. Howe

How Much Risk Can Medicine Allow a Willing Altruist?
David Steinberg

Living Donor Transplantation: The Perfect Balance of Public Oversight and Medical Responsibility
Maryam Valapour

Reply to Valapour, “Living Donor Transplantation: The Perfect Balance of Public Oversight and Medical Responsibility”
David Steinberg

What Should We Do with Patients Who Buy a Kidney Overseas?
Marie-Chantal Fortin, Delphine Roigt, and Hubert Doucet

As Sure As Eggs? Responses to an Ethical Question Posed by Abramov, Elchalal, and Schenker
Deborah Sarah Ferber

Is Subfertility a Medical Condition?
Jeroen D. Kok

Some Reflections on IVF, Emotions, and Patient Autonomy
Deborah Sarah Ferber

Ethical Considerations in Clinical Care of the “VIP”
Thomas Schenkenberg, Neil K. Kochenour, and Jeffrey R. Botkin

Ethics Consultants’ Recommendations for Life-Prolonging Treatment of Patients in Persistent Vegetative State: A Follow-up Study
Ellen Fox, Frona C. Daskal, and Carol Stocking

Legal Trends in Bioethics
Sigrid Fry-Revere

2006

The Journal of Clinical Ethics, Volume 17, Number 4, Winter 2006
Do We Undervalue Feelings in Patients Who Are Cognitively Impaired?
Edmund G. Howe

Report of the American Medical Association Council on Ethical and Judicial Affairs: Withholding Information from Patients: Rethinking the Propriety of “Therapeutic Privilege”
Nathan A. Bostick, Robert Sade, John W. McMahon, and Regina Benjamin

The Grand Inquisitor’s Choice: Comment on the CEJA Report on Withholding Information from Patients
Darlyn Pirakitikulr and Harold J. Bursztajn

The End of Therapeutic Privilege?
Nicole Sirotin and Bernard Lo

Comment on the CEJA Guidelines: Treating Patients Who Deny Reality
Edmund G. Howe

When Patients Do Not Have a Proxy: A Procedure for Medical Decision Making When There Is No One to Speak for the Patient
Isoo Hyun, Cynthia Griggins, Margaret Weiss, Dorothy Robbins, Allyson Robichaud, and Barbara Daly

A Mother’s Death: The Story of “Margaret’s” Children
Christine Mitchell

The Ethics of Palliative Care in Psychiatry
The Journal of Clinical Ethics, Volume 17, Number 3, Fall 2006

Beyond Respect for Autonomy
   Edmund G. Howe

The Case of A.R.: The Ethics of Sibling Donor Bone Marrow Transplantation Revisited
   Douglas J. Opel and Douglas S. Diekema

A Compounding of Errors: The Case of Bone Marrow Donation between Non-Intimate Siblings
   Lainie Friedman Ross and Walter Glannon

Duty and Altruism: Alternative Analyses of the Ethics of Sibling Bone Marrow Donation
   Rebecca Pentz

The Courage to Stand Up: The Cultural Politics of Nurses’ Access to Ethics Consultation
   Elisa J. Gordon and Ann B. Hamric

Healthcare Organizations as Moral Communities
   Mila Ann Aroskar

Nurses and Ethics Consultation: Growing Beyond a Rock and a Hard Place
   Kathy Mayle

Physician-Nurse Relationships and their Effect on Ethical Nursing Practice
   Teresa A. Savage

Supporting Pregnant Women through Difficult Decisions: A Case of Prenatal Diagnosis of Osteogenesis Imperfecta
   Marilyn E. Coors and Susan F. Townsend

Individuals, Systems, and Professional Behavior
   Evan G. DeRenzo

The Journal of Clinical Ethics, Volume 17, Number 2, Summer 2006

Patients May Benefit from Postponing Assessment of Mental Capacity
   Edmund G. Howe

An Intimate Collaboration: Prognostic Communication with Advanced Cancer Patients
   Paul R. Helft

Are Organ Donors after Cardiac Death Really Dead?
   James L. Bernat

The Truth about “Donation after Cardiac Death”
   Robert D. Truog and Thomas I. Cochrane

Donation after Cardiac Death: Consent Is the Issue, Not Death
   Maryam Valapour

How a Model Based on Linguistic Theory Can Improve the Assessment of Decision-Making Capacity for Persons with Dementia
   Daniel J. Brauner and Susan E. Merel

How Can Medical Training and Informed Consent Be Reconciled with Volume-Outcome Data?
   David S. Wendler and Seema Shah

Religious and Spiritual Concerns in Genetic Testing and Decision Making: An Introduction for Pastoral and Genetic Counselors
   Mary Terrell White
Evaluating the Outcomes of Ethics Consultation
J.M. Craig and Thomas May

Clinical Ethics and the Managerial Revolution in American Healthcare
Ann E. Mills, Mary V. Rorty, and Patricia H. Werhane

A Part of Life, A Part of Me, and “The Quality of Life”
Ilia Volkov

The Journal of Clinical Ethics, Volume 17, Number 1, Spring 2006

Throwing Jello: A Primer on Helping Patients
Edmund G. Howe

Physicians’ Legal Defensiveness in End-of-Life Treatment Decisions: Comparing Attitudes and Knowledge in States with Different Laws
S. Van McCrary, Jeffrey W. Swanson, Jack Coulehan, K. Faber-Langendoen, Robert S. Olick, and Catherine Belling

Interest in Physician-Assisted Suicide among Oregon Cancer Patients
Linda Ganzini, Tomasz M. Beer, Matthew Brouns, Motomi Mori, and Yi-Ching Hsieh

“Physician-Assisted Suicide among Oregon Cancer Patients”: A Fading Issue
Colleen C. Denny and Ezekiel J. Emanuel

Response to Denny and Emanuel
Linda Ganzini

The Duty to Re-Contact for Newly Appreciated Risk Factors: Fragile X Premutation
Gregory F. Guzauskas and Robert Roger Lebel

Child-to-Parent Bone Marrow Donation for Treatment of Sickle Cell Disease
Lisa Anderson-Shaw and Kristina Orfali

Diagnosing PVS and Minimally Conscious State: The Role of Tacit Knowledge and Intuition
Mary Terrell White

Advance Health Planning and Treatment Preferences among Recipients of Implantable Cardioverter Defibrillators: An Exploratory Study
Jeffrey T. Berger, Matthew Gorski, and Todd Cohen

When a Village is Not Enough
Christine Mitchell and Robert Truog

Sick to Death
Grace Good

The Case Manager’s View
Suzanne M. Burke

“We Need to Meet”
Jennifer Repper-DeLisi and Susan M. Kilroy

Was My Patient Fortunate or Forsaken?
Robin Dauterive

Talking with Lorraine’s Mother and Sister, Five Months after Her Death
Ellen M. Robinson, Grace Good, and Suzanne Burke

The Journal of Clinical Ethics, Volume 16, Number 4, Winter 2005

Shame, Slap Jack, and Families that Should Lie
Edmund G. Howe

The District of Columbia Amends its Health-Care Decisions Act: Bioethics Committees in the Arena of Public Policy
Douglas B. Mishkin and Gail Povar

Families and Bioethics: Old Problems, New Themes
James Lindemann Nelson

Voice: Cognitive Impairment and Medical Decision Making
Tia Powell

On the Mend: Alzheimer’s and Family Caregiving
Hilde Lindemann

Imaginary Fathers: A Sentimental Perspective on the Question of Identifying Sperm Donors
Catherine Belling

Like a Motherless Child: Fetal Eggs and Families
Laura Purdy
The Journal of Clinical Ethics, Volume 16, Number 1, Spring 2005

Patients’ Interests in their Family Members’ Well-Being: An Overlooked, Fundamental Consideration within Substituted Judgments
Jeffrey T. Berger

Autonomy and the Role of the Family in Making Decisions at the End of Life
Jonathan M. Breslin

Application of Systems Principles to Resolving Ethical Dilemmas in Medicine
George F. Blackall, Michael J. Green, and Steve Sims

Dawning of Awareness: The Experience of Surrogate Decision Making at the End of Life
Jane Chambers-Evans and Franco A. Carnavale

Evolution of a Living Donor Liver Transplantation Advocacy Program
Lisa Anderson-Shaw, Mary Lou Schmidt, Jeanine Elkin, William Chamberlin, Enrico Benedetti, and Guiliano Testa

Wanted Dead or Alive? Kidney Transplantation in Inmates Awaiting Execution
Jacob M. Appel

Recommendations for the Ethical Conduct of Quality Improvement
Ellen Fox and James A. Tulsky

Ethical Evaluation of “Retainer Fee” Medical Practice
Mervin H. Needell and John S. Kenyon

Urine Trouble: Practical, Legal, and Ethical Issues Surrounding Mandated Drug Testing of Physicians
Martin Donohoe

2004

The Journal of Clinical Ethics, Volume 15, Number 4, Winter 2004

Disability
Edmund G. Howe

Introduction to a Special Section on Disability Ethics
Teresa A. Savage, Carol J. Gill, and Kristi L. Kirschner

Brain Trauma and Surrogate Decision Making: Dogmas, Challenges, and Response
James Lindemann Nelson and Joel Frader

Depolarizing and Complicating the Ethics of Treatment Decision Making in Brain Injury: A Disability Rights Response to Nelson and Frader
Carol J. Gill

A Response to Gill
James Lindemann Nelson and Joel Frader

Ethical Issues in Rehabilitation in the Home-Care Setting
Marilyn Martone

Clinical (Mis)Judgments of Quality of Life after Disability
Sunil Kothari

Acquired Brain Injury: Reflections of Two Professionals with ABI
Judy Panko Reis and Bill Baumann

The Trauma of Discharge Planning following Brain Injury
Rebecca Brashler

Hypothetical Autonomy and Actual Autonomy: Some Problem Cases Involving Advance Directives
Michael J. Wreen

Surrogates’ Decisions regarding CPR and the Fallacy of Substituted Judgment
Gwen M. Sayers, Nigel Beckett, Helen Waters, and Caroline Turner

Feeding Patients with Advanced Dementia: A Jewish Ethical Perspective
Alan Jotkowitz
Griffin Trotter

Parents, Lies, and Videotape: Covert Video Surveillance in Pediatric Care
Wayne Vaught

Covert Video Surveillance in Pediatric Care: The Fiduciary Relationship with a Child
Steven R. Leuthner

Care and Justice: The Impact of Gender and Profession on Ethical Decision Making in the Healthcare Arena
Susan L. Zickmund

Culture and Medical Intervention
Michael Boylan

Use of Videos by Directors of Medical Ethics Courses
Delaney Ruston, Jesse Canchola, and Bernard Lo

The Journal of Clinical Ethics, Volume 15, Number 1, Spring 2004

What Research Practices in China May Teach the U.S.
Edmund G. Howe

Introductory Comments
M. Roy Schwarz and David T. Stern

Tests Involving Humans: Old and New in China
Zhen Cheng

Ethical Principles for the Conduct of Research Involving Human Subjects: Historical Considerations
Robert J. Levine

When Experiments Go Wrong: The U.S. Perspective
Alexander M. Capron

Clinical Trials in China: Protection of Subjects’ Rights and Interests
Lü Yuan

Informed Consent in Research Involving Human Subjects
Ben-Fu Li

Special Challenges to the Informed Consent Doctrine in the U.S.
Mark Siegler, Megan E. Collins, and David C. Cronin

Conflict of Interests in Research Ethics: A Chinese Perspective
Ren-Zong Qiu

Clinical Trials in Traditional Chinese Medicine
Zhufan Xie

Research with Vulnerable Participants
Bernard Lo

Evaluation of the Informed Consent Process in a Randomized Controlled Clinical Trial in China: The Sino-U.S. NTD Project
Hong Wang, J. David Erickson, Zhu Li, and Robert J. Berry

The Individual and the Community in International Genetic Research
Patricia A. Marshall

Future Challenges from the U.S. Perspective: Trust as the Key to Clinical Research
David T. Stern

Closing Remarks
M. Roy Schwarz

2003

The Journal of Clinical Ethics, Volume 14, Number 4, Winter 2003

Death-Defying Empathy
Edmund G. Howe

At the Interface of Cultures
Farhat Moazam and Riffat Moazam Zaman

A Defense of the Philosopher-Ethicist as Moral Expert
Christopher Meyers

Moral Reasoning of Members of Hospital Ethics Committees: A Pilot Study
Arthur Dobrin

Ethics Consultation: In the Service of Practice
Mark P. Aulisio and Robert M. Arnold
Introduction: The Case of Ms G
   The Editor

The Challenge of Clinical Empathy
   Maria Merritt

Reading Experience: Jodi Halpern’s From Detached Concern to Empathy
   Martha Montello

Empathy as Epistemological Tool: Commentary on Jodi Halpern’s From Detached Concern to Empathy
   Mary B. Mahowald

Catastrophic Emotions and Respect for Autonomy
   Agnieszka Jaworska

Practicing Medicine in the Real World: Challenges to Empathy and Respect for Patients
   Jodi Halpern

Dear Bonzo
   Carl Elliot, Tod Chambers, and Britt Elliot

Peter Singer and Beastiality
   Edmund G. Howe

On Judicial Obstruction of Sound Surrogate Decision Making: A Comment on California’s Wendland Case
   Norman L. Cantor

The Journal of Clinical Ethics, Volume 14, Number 3, Fall 2003

Overcoming the Downside of Asymmetry
   Edmund G. Howe

Correlates of Children’s Competence to Make Healthcare Decisions
   Janet A. Deatrick, Susan B. Dickey, Ron Wright, Susan M. Beidler, Mary Emily Cameron, Haley Shimizu, and Kim Mason

Making Wishes Known: The Role of Acquired Speech and Language Disorders in Clinical Ethics
   Walter S. Davis and Alesia Ross

Opportunities for Advance Directives to Influence Acute Medical Care
   Paul R. Dexter, Fredric D. Wolinsky, Gregory P. Gramelspacher, George J. Eckert, and William M. Tierney

Exploring Asymmetry in the Relationship between Patients and Physicians
   Antonella Surbone and Jerome Lowenstein

A Bridge to Nowhere
   Christine Mitchell and Robert D. Trough, Editors

Mrs. T’s Story: An Interview
   Rebecca Horr, Lauren Kattany, and Ellen M. Robinson

The Nurses’ Story about Mr. T
   Lauren Kattany and Rebecca Horr

Comments from the Optimum Care Committee Consultant
   Ned Cassem

Ethical Issues Raised by LVADs and Mr. T’s Story
   Ellen M. Robinson and Martha Jurchak

Hope or Truth: Commentary on the Case of Mr. T
   Edmund G. Howe

Legal Trends in Bioethics
   Anne Lederman Flamm

The Journal of Clinical Ethics, Volume 14, Number 1-2, Spring-Summer 2003

When Careproviders Should Give Advice, Disclose Personal Information, and Reveal Their Feelings
   Edmund G. Howe

The Antemortem Use of Heparin in Non-Heart-Beating Organ Transplantation: A Justification Based on the Paradigm of Altruism
   David Steinberg

Does the Public Support Organ Donation Using Higher Brain-Death Criteria?
   James M. DuBois and Tracy Schmidt

Asking for Organs: Different Needs and Different Values
   Ann Freeman Cook, Helena Hoas, and Carla Grayson

The Moral Irrelevance of Proximity to Death
   Lynn A. Jansen
Why “Doctor, if this Were your Child, What Would You Do?” Deserves an Answer
Lainie Friedman Ross

Revisiting “Doctor, if this Were your Child, What Would You Do?”
Robert Truog

Answering Parents’ Questions
William Ruddick

Responding to the Need Behind the Question, “Doctor, if this Were your Child, What Would You Do?”
Jodi Halpern

The Paradox of Questions and Answers: Possibilities for a Doctor-Patient Relationship
Norman Quist

Seeking Blinded Consent
Christine Mitchell and Robert Truog

Complications to Consent
David Brendel

Looking into a Distorted Mirror
“Jay Carter”

Public Dialogue and the Boundaries of Moral Community
Steven Joffe

Lessons from “Jay Carter”
Edmund G. Howe

Beyond Wishful Thinking: Facing the Harm that Psychotherapists Can Do by Writing about their Patients
Jodi Halpern

Legal Trends in Bioethics
Deborah K. Cruze and Anne L. Flamm

2002

The Journal of Clinical Ethics, Volume 13, Number 4, Winter 2002

Challenging Patients’ Personal, Cultural, and Religious Beliefs
Edmund G. Howe

Bringing Moral Order to the Ordinary: Outpatient Ethics Takes Shape
Robert Lyman Potter and Christy Kaiser

Outpatient Ethics: “And the Walls Came Tumbling Down”
Michael Felder

Medical Ethics in the Outpatient Setting: Ethics in Practice
Thomas H. Gallagher

Keeping the Patient in the Loop: Ethical Issues in Outpatient Referral and Consultation
Jay A. Jacobson

Doubling the Guard: Ethics and Law at the Privacy Gate
Mary Beth Blake

Ethical Considerations of Genetic Testing
David A. Fleming

Ethical Considerations of Electronic Communication in the Clinical Outpatient Setting
Perry A. Pugno

Moral Distress and the Nurse Practitioner
Nelda S. Godfrey and Katharine V. Smith

Enhanced Listening Skills: Gifts from the Hmong
Charles Numrich, Gregory Plotnikoff, Deu Yang, Chu Yongyuan Wu, and Phua Xiong

Factors that Predict Better Informed Consent
Clarence H. Braddock, III, Mark A. Micek, Kelly Fryer-Edwards, and Wendy Levinson

Quality Improvement and Ethics: Performance Improvement in an Oncology Practice
John E. Hennessy and Marcus Neubauer

Practicing Accountability in Professional Ethics
Joseph d’Oronzio

Outside Outpatient Ethics: Is It Ethical for Physicians to Serve Ringside?
Griffin Trotter

Legal Trends in Bioethics
Anne L. Flamm
The Journal of Clinical Ethics, Volume 11, Number 3, Fall 2000

**Can Assisted Suicide Be Regulated?**
David Orentlicher and Lois Snyder

**Narrative Unity and the Unraveling of Personal Identity: Dialysis, Dementia, Stroke, and Advance Directives**
Jeffrey Spike

**Legal Trends in Bioethics**
Heidi P. Forster

**Doing Ethics Consultations Better**
Edmund G. Howe

**Why Ethicists Should Stop Writing Cases**
Tod Chambers

**Patient Vignettes in Bioethics Literature**
Christopher D. Herrera

**Should Children with Severe Cognitive Impairment Receive Solid Organ Transplants?**
Robert D. Orr, Joyce K. Johnston, Stephen Ashwal, and Leonard L. Bailey

**Are Patients Willing to Participate in Medical Education?**
Peter A. Ubel and Ari Silver-Isenstadt

**Living Poorly or Dying Well: Culture and Decisions about Life-Supporting Treatment for American and Japanese Patients**
Susan O. Long

**Revisiting the Truth-Telling Debate: A Study of Disclosure Practices at a Major Cancer Center**
Mary R. Anderlik, Rebecca D. Pentz, Kenneth R. Hess

**Assisted Suicide and the Duty to Die**
Griffin Trotter

**Feeding the Moral Sense: The Case of Jim Blair**
Jack Coulehan

**Legal Trends in Bioethics**
Dena S. Davis and Heidi Forster

**Letters**
Robert M. Veatch; Edward V. Spudis

The Journal of Clinical Ethics, Volume 11, Number 2, Summer 2000

**Pediatricians’ Most Difficult Decision**
Edmund G. Howe

**From the Files of a Pediatric Ethics Committee**
Christine Mitchell and Robert D. Truog

**Loving Noncompliance: Determining Medical Neglect by Parents of HIV-Positive Children**
Rick Bourne

**Comment: Collaborative Decision Making with HIV-Infected Mothers**
Verle Headings

**Responding to Parental Requests to Forgo Pediatric Nutrition and Hydration**
Judith Johnson and Christine Mitchell

**FUTILITY IN PEDIATRICS: FROM CASE TO POLICY**
Robert D. Truog

**Comment: Will Futility Policies Make a Difference?**
Robert D. Orr

**Ethical Issues in Pediatric Research**
Walter M. Robinson

**Comment: Research Involving Children: Clarifying Roles and Authority**
Nuala Kenny and Paul Miller

**Suffering in Children at the End of Life: Recognizing an Ethical Duty to Palliate**
Joanne Wolfe

**Including the Family’s Interests in Medical Decision Making in Pediatrics**
George Hardart

**Comment: Supporting the Child within the Family**
Paula Rauch
The Hazards of "Hanging Crepe" or Stating Overly Pessimistic Prognoses
David B. Waisel

From Case to Policy: Institutional Ethics at a Children’s Hospital
Jeffrey P. Burns

Comment: Should All Ethics Committee Members Be Institutionalized?
O.J. Sahler

Legal Trends in Bioethics
Dena S. Davis

The Journal of Clinical Ethics, Volume 11, Number 1, Spring 2000

Leaving Laputa: What Doctors Aren’t Taught about Informed Consent
Edmund G. Howe

Iatrogenic Cardiopulmonary Arrests in DNR Patients
James A. Christensen and James P. Orlowski

The Role of the Clinical Ethicist in Conflict Resolution
Robert D. Orr and Dennis M. deLeon

The Effect of Clinical Medical Ethics Consultation on Healthcare Costs
Bernard J. Heilicser, David Meltzer, and Mark Siegler

Residents’ and Patients’ Perspectives on Informed Consent in Primary Care Clinics
Douglas G. Kondo, F. Marian Bishop, and Jay A. Jacobson

Report of a Study to Examine the Process of Ethics Case Consultation
Martha Jurchak

Thoughts of Hastening Death Among Hospice Patients
Barbara J. Daly, Jennifer Hooks, Stuart J. Youngner, Barbara Drew, and MaryJo Prince-Paul

Respecting the Autonomy of the Biologically Driven
Jeffrey D. Tiemstra

“The Aesthetics of Dementia Care”: Some Final Thoughts from Tom Kitwood
Leonard D. Ferenz

Controlled NHBD Protocol for a Fully Conscious Person: When Death Is Intended as an End in Itself and It Has Its Own End
Jeffrey Spike

Intention, Action, and the Dead Donor Rule: Commentary on Spike
James M. DuBois

Decisions by Conscious Persons about Controlled NHBD after Death: Eyes Wide Open
Michael A. DeVita and Thomas May

Meaningful Life and Respecting Brute Autonomy: Commentary on Spike
Reginald Peniston

Author’s Response: The Limits of Persuasion
Jeffrey Spike

Legal Trends in Bioethics
Dena S. Davis

1999

The Journal of Clinical Ethics, Volume 10, Number 4, Winter 1999

Organizational Ethics’ Greatest Challenge: Factoring in Less-Reachable Patients
Edmund G. Howe

Dementia and Advance-Care Planning: Perspectives from Three Countries on Ethics and Epidemiology
Joanne Lynn, Joan Teno, Rebecca Dresser, Dan Brock, Hilde Lindemann Nelson, James Lindemann Nelson, Rita Kielstein, Yoshinosuke Fukuchi, Dan Lu, and Haruka Itakura

End-of-Life Decision Making: When Patients and Surrogates Disagree
Peter B. Terry, Margaret Vettese, John Song, Jane Forman, Karen B. Haller, Deborah J. Miller, Rebecca Stallings, and Daniel P. Sulmasy

Optimizing Ethics Services and Education in a Teaching Hospital: Rounds Versus Consultation
Eugene V. Boisaubin and Michele A. Carter

Death and Remembrance: Addressing the Costs of Learning Anatomy through the Memorialization of Donors
Kathleen Marie Dixon
Emotions, Ethics, and Decisions in Primary Care
Julia Connelly

Toward an Ethical Standard for Coerced Mental Health Treatment: Least Restrictive or Most Therapeutic?
Douglas P. Olsen

Assessing Competency Without Judging Merit
Thomas May

Do Patients’ Treatment Decisions Match Advance Statements of Their Preferences?
Melinda A. Lee, David M. Smith, Darien S. Fenn, and Linda Ganzini

Optimizing Discussions about Resuscitation: Development of a Guide Based on Patients’ Recommendations
Mary S. Carlsen, Clair Pomeroy, and D. Gay Moldow

Avoiding Conflicts of Interest in Surrogate Decision Making: Why Ethics Committees Should Assign Surrogacy to a Separate Committee
Richard Steven Levine

Disclosure of Operating Practices by Managed-Care Organizations to Consumers of Healthcare: Obligations of Informed Consent
Vikram Khanna, Henry Silverman, and Jack Schwartz

Ethics by the Numbers: Monitoring Physicians’ Integrity in Managed Care
Elizabeth Alexander and Howard Brody

Physicians’ Responsibilities in the Care of Suicidal Patients: Three Case Studies
Jeffrey Spike

Decision Making in the Nursery: An Ethical Dilemma
Charlotte Jones and John M. Freeman

Legal Trends in Bioethics
Dena S. Davis and Heide P. Forster

The Journal of Clinical Ethics, Volume 9, Number 2, Summer 1998

Deconstructing Equity, Autonomy, and Ethical Analysis
Edmund G. Howe

Cultural Differences among Health Professionals: A Case Illustration
Henry S. Perkins, Josie D. Supik, and Helen P. Hazuda

Barriers to Completion of Healthcare Proxy Forms: A Qualitative Analysis of Ethnic Differences
R. Sean Morrison, Luis H. Zayas, Michael Mulvihill, Shari A. Baskin, and Diane E. Meier

Cultural Discrimination in Mechanisms for Health Decisions: A View from New York
Jeffrey T. Berger

The Family in Medical Decision Making: Japanese Perspectives
Michael D. Fetters

Heart Transplantation Selection Criteria: Attitudes of Ethnically Diverse Medical Students
Michael S. Wilkes and Stuart Slavin

The Ethics of Placebo-Controlled Trials for Perinatal Transmission of HIV in Developing Countries
Peter A. Clark

The “Best Proven Therapeutic Method” Standard in Clinical Trials in Technologically Developing Countries
Robert J. Levine

Cultural Diversity and Informed Consent
Ellen Agard, Daniel Finkelstein, and Edward Wallach

Respect for Autonomy and a Couple’s Decision
Monica d’Agostino

A Study of Healthcare Professionals’ Perspectives about a Cross-Cultural Ethical Conflict Involving a Hmong Patient and Her Family
Kathleen A. Culhane-Pera and Dorothy E. Vawter

Commentary: “Missing” Patients by Seeing Only Their Cultures
Edmund G. Howe

Futility and the Goals of Medicine
Rosamond Rhodes

Non-Simultaneous Deaths of Parallel Personhoods Crashing through a Denver S & L
Edward V. Spudis

Resisting the Siren: Commentary
The Journal of Clinical Ethics, Volume 9, Number 1, Spring 1998

Caring for Patients with Dementia: An Indication for “Emotional Communism”
Edmund G. Howe

Ethics and Alzheimer’s Disease: Widening the Lens
Martha B. Holstein

Toward a Theory of Demetia Care: Ethics and Interaction
Tom Kitwood

Voices of Alzheimer’s Disease Sufferers: Treatment Based on Personhood
Steven R. Sabat

Living with Alzheimer’s Disease: The Creation of Meaning among Persons with Dementia
Karen A. Lyman

Reasons and Feelings, Duty and Dementia
James Lindemann Nelson

Persons with Dementia as “Liability Magnets”: Ethical Implications
Marshall B. Kapp

The Fear of Forgetfulness: A Grassroots Approach to an Ethics of Alzheimer’s Disease
Stephen G. Post

Personhood, Spirituality, and Hope in the Care of Human Beings with Dementia
David B. McCurdy

Legal Trends in Bioethics
Dena S. Davis

1997

The Journal of Clinical Ethics, Volume 8, Number 4, Winter 1997

“Possible Mistakes”
Edmund G. Howe

When a Physician Harms a Patient by a Medical Error: Ethical, Legal, and Risk-Management Considerations

Errors in Medicine: Nurturing Truthfulness
Françoise Baylis

A Study of the Ethical Duty of Physicians to Disclose Errors
Matthew P. Sweet and James L. Bernat

Holding Owen
David Schiedermayer

Musings on Medical Mistakes: A Four-Piece Ensemble in Search of an Orchestra
Paul J. Reitemeier

Dialogue to Action: Lessons Learned from Some Family Members of Deceased Patients at an Interactive Program in Seven Utah Hospitals
Jay A. Jacobson, L.P. Francis, Margaret P. Battin, David J. Green, C. Grammes, J. VanRiper, and J. Gully

A New Role for Institutional Ethics Committees: Organizational Ethics
Edward M. Spencer

Use of the Hippocratic Oath: A Review of Twentieth Century Practice and a Content Analysis of Oaths Administered in Medical Schools in Medical Schools in the U.S. and Canada in 1993
Robert D. Orr, Norman Pang, Edmund D. Pellegrino, and Mark Siegler

Humanistic Problem Solving: The Case of Mr. T
William J. Winslade

Ethics Consultation: Iatrogenic Liver Failure, Transplantation, and Prisoners
Jeffrey Spike

Legal Trends in Bioethics
Dena S. Davis

The Journal of Clinical Ethics, Volume 8, Number 3, Fall 1997

Deceiving Patients for Their Own Good
The Journal of Clinical Ethics, Volume 8, Number 2, Summer 1997

**Induction Procedures for Psychogenic Seizures: Ethical and Clinical Considerations**
Edmund G. Howe

**Managed Care: A House of Mirrors**
Martin L. Smith, Susan J. Stagno, Michelle Dolske, Joanne Kosalko, Carolyn McConnell, Larita Kasper, and Richard Lederman

**Semantic and Moral Debates about Hastening Death: A Survey of Bioethicists**
Peter A. Ubel and David A. Asch

**Patients with DNR Orders in the Operating Room: Surgery, Resuscitation, and Outcomes**

**A Computerized System for Entering Orders to Limit Treatment: Implementation and Evaluation**
Daniel P. Sulmasy and Eric S. Marx

**Ethical and Legal Aspects of Teratogenic Medications: The Case of Isotretinoin**
John C. Moskop, Michael L. Smith, and Kenneth De Ville

**Attitudes of Women from Vulnerable Populations toward Physician-Assisted Death: A Qualitative Approach**
Elizabeth Morrow

**The Quality of Mercy: Reflections on Provider-Assisted Suicide**
Kathleen Marie Dixon

**A Paradox about Capacity, Alcoholism, and Noncompliance**
Jeffrey Spike

**Biological Drivenness: A Relative Indication for Paternalism**
Edmund G. Howe

**Legal Trends in Bioethics**
Dena S. Davis

---

**Everyday Heroes, Part 2: Should Careproviders Ever Be Quintilian?**
Edmund G. Howe

**Stability of Treatment Preferences: Although Most Preferences Do Not Change, Most People Change Some of Their Preferences**
Nitsa Kohut, Mehran Sam, Keith O'Rourke, Douglas K. MacFadden, Irving Salit, and Peter A. Singer

**Understanding the Practice of Ethics Consultation: Results of an Ethnographic Multi-Site Study**
Susan E. Kelly, Patricia A. Marshall, Lee M. Sanders, Thomas A. Raffin, and Barbara A. Koenig

**The Effect of Ethnicity on ICU Use and DNR Orders in Hospitalized AIDS Patients**
James A. Tulsky, Barrie R. Cassileth, and Charles L. Bennett

**Children's Refusal of Gynecologic Examinations for Suspected Sexual Abuse**
David Muram, Margaret M. Aiken, and Carson Strong

**What's Love Got to Do with It? The Altruistic Giving of Organs**
Jeffrey Spike

**The Role of Emotions in Decisional Competence, Standards of Competency, and Altruistic Acts**
Henry Silverman

**A Noncompliant Patient?**
Kathryn L. Moseley and Sandra Truesdell

**Care, Support, and Concern for Noncompliant Patients**
Philip R. Muskin

**Max Weber on Ethics Case Consultation: A Methodological Critique of the Conference on Evaluation of Ethics Consultation**
Francis Dominic Degnin

**Goals of Ethics Consultation: Toward Clarity, Utility, and Fidelity**
Judith Andre

**Speaking Truth to Employers**
Judith Andre

**Legal Trends in Bioethics**
Dena S. Davis

**Letter**
Howard L. Field
The Journal of Clinical Ethics, Volume 7, Number 3, Fall 1996

Deadly Sins, Continued: Treating Patients with Addictions
Edmund G. Howe

Putting Advance-Care Planning into Action
Joan M. Teno and Joanne Lynn

Death with Kantian Dignity
Hilde Lindemann Nelson

Professional Healthcare Workers’ Attitudes Toward Treating Patients with Multidrug-Resistant Tuberculosis
Jeremy Sugarman, Peter Terry, Ruth R. Faden, Denise E. Holmes, Linda Fogarty, and Reed E. Pyeritz

Introduction to Section: Feminist Approaches to Bioethics
Rosemarie Tong

Women and Health Research: Working for Change
Françoise Baylis

The Interrelationship of Ethical Issues in the Transition from Old Paradigms to New Technologies
Timothy R. Cooper, William D. Caplan, Joseph A. Garcia-Prats, and Baruch A. Brody

Clinical Practice Guidelines: Toward Attributes for Ethical Validity
Barbara K. Redman

Should a Patient Who Attempted Suicide Receive a Liver Transplant?
Jameson Forster, William G. Bartholome, and Romano Delcore

Anubis and the Feather of Truth: Judging Transplant Candidates Who Engage in Self-Damaging Behavior
Colin E. Atterbury

Exclusionary Criteria and Suicidal Behavior: Comment on “Should a Patient Who Attempted Suicide Receive a Liver Transplant?”
Mark P. Aulisio and Robert M. Arnold

Legal Trends in Bioethics
Dena S. Davis

The Journal of Clinical Ethics, Volume 7, Number 2, Summer 1996

The Three Deadly Sins of Ethics Consultation
Edmund G. Howe

Evaluating Ethics Consultation: Framing the Questions
James A. Tulsky and Ellen Fox

Concepts in Evaluation Applied to Ethics Consultation Research
Ellen Fox

What Are the Goals of Ethics Consultation? A Consensus Statement
John C. Fletcher and Mark Siegler

Evaluating Outcomes in Ethics Consultation Research
Ellen Fox and Robert M. Arnold

Obstacles and Opportunities in the Design of Ethics Consultation Evaluation
James A. Tulsky and Carol B. Stocking

Evaluation Research and the Future of Ethics Consultation
Ellen Fox and James A. Tulsky

Introduction to Section: Feminist Approaches to Bioethics
Rosemarie Tong

Working within Contradiction: The Possibility of Feminist Cosmetic Surgery
Anna Kirkland and Rosemarie Tong

Philosophy, Gender Politics, and In Vitro Fertilization: A Feminist Ethics of Reproductive Healthcare
Linda LeMoncheck

Bioethics Committees and JCAHO Patients’ Rights Standards: A Question of Balance
Bruce V. Corsino

Responding to JCAHO Standards: Everybody’s Business
The Journal of Clinical Ethics, Volume 7, Number 1, Spring 1996

Implementing Feminist Perspectives in Clinical Care
Edmund G. Howe

An Introduction to Feminist Approaches to Bioethics: Unity in Diversity
Rosemarie Tong

Knowledge at the Bedside: A Feminist View of What’s Happening with This Patient
Hilde Lindemann Nelson

Partiality and the Pediatrician
Rosalind Ekman Ladd

Aging as Death Rehearsal: The Oppressiveness of Reason
Sally Gadow

Care-Based Reasoning, Caring, and the Ethic of Care: A Need for Clarity
Sara T. Fry, Aileen R. Killen, and Ellen M. Robinson

The Stability of DNR Orders on Hospital Readmission
The SUPPORT Investigators

Public Awareness of the Nature of CPR: A Case for Values-Centered Advance Directives
Charles F. Thurber

Do You Understand? An Ethical Assessment of Researchers’ Description of the Consenting Process
Sandra L. Titus and Moira A. Keane

Conflicts of Interest, Conflicting Interests, and Interesting Conflicts, Part 2
Sue Shevlin Edwards, Janicemarie K. Vinicky, and James P. Orlowski

The Ethics of Mandatory HIV Testing in Newborns
Jeffrey T. Berger, Fred Rosner, and Peter Farnsworth

Rethinking the Testing of Babies and Pregnant Women for HIV Infection
Ronald Bayer

W Is “Informed Right of Refusal” the Same as “Informed Consent”?
Robert D. Truog

Legal Trends in Bioethics
Dena S. Davis

Letters
Arnold Golodetz; Lawrence J. Schneiderman

The Journal of Clinical Ethics, Volume 6, Number 4, Winter 1995

Managed Care: “New Moves,” Moral Uncertainty, and a Radical Attitude
Edmund G. Howe

Comments on the AMA Report “Ethical Issues in Managed Care”
Steven H. Miles and Robert Koepf

Interests, Obligations, and Justice: Some Notes Toward an Ethic of Managed Care
Edmund D. Pellegrino

A Response to “Comments on the AMA Report ‘Ethical Issues in Managed Care’”
Charles W. Plows

The Threat of the New Managed Practice of Medicine to Patients’ Autonomy
Frank A. Chervenak and Laurence B. McCullough

Managed Care and the New Medical Paternalism
Daniel P. Sulmasy

Disposable Doctors: Incentives to Abuse Physician Peer Review
John H. Fielder
Physician Advocacy for Patients Under Managed Care
David Orentlicher

Medical Ethics in the Era of Managed Care: The Need for Institutional Structures Instead of Principles for Individual Cases
Ezekiel J. Emanuel

The Patient as Commodity: Managed Care and the Question of Ethics
Laurie Zoloth-Dorfman and Susan Rubin

Conflicts of Interest, Conflicting Interests, and Interesting Conflicts
Janicemarie K. Vinicky, Sue Shevlin Edwards, and James P. Orlowski

Inner Turmoil: An Important Consideration in Conflicts of Interest
Edmund G. Howe

Surrogates and Uncertainty
Ralph Baergen

More Regarding “Circular Questioning”
Jeffrey D. Tiemstra

Legal Trends in Bioethics
Dena S. Davis

The Journal of Clinical Ethics, Volume 6, Number 3, Fall 1995

Influencing a Patient’s Religious Beliefs: Mandate or No-Man’s Land?
Edmund G. Howe

Jewish Medical Ethics
Fred Rosner

Halakhic Dilemmas in Modern Medicine
Michael A. Grodin

Face to Face, Not Eye to Eye: Further Conversations on Jewish Medical Ethics
Laurie Zoloth-Dorfman

A Question of Context: A Response to Fred Rosner
Dena Davis

Religious Leaders’ Attitudes and Beliefs about Genetics Research and the Human Genome Project
Kinh Luan Dinh Phan, David John Doukas, and Michael D. Fetters

Religious Attitudes Toward Genetics: Opening a Larger Debate
Michael A. Grodin

Ethical Reasoning in Clinical Genetics: A Survey of Cases and Methods
Timothy C. Callahan, Sharon J. Durfy, and Albert R. Jonsen

Ensuring a Stillborn: The Ethics of Fetal Lethal Injection in Late Abortion
Joan C. Callahan

On Learning from Mistakes
John C. Fletcher

Certainty and Agnosticism about Lethal Injection in Late Abortion
Bethany Spielman

Is It Appropriate to Pray in the Operating Room?
H. Phil Gross

Prayer, Piety, and Professional Propriety: Limits on Religious Expression in Hospitals
Teo Forcht Dagi

Dialogue between Faith and Science: The Role of the Hospital Chaplain
William J. O'Brien, III

Legal Trends in Bioethics
Dena Davis

The Journal of Clinical Ethics, Volume 6, Number 2, Summer 1995

Transforming or Vampiric? When Careproviders Share Their Subjective Realities with Their Patients
Edmund G. Howe

The “Futility Debate” and the Management of Gordian Knots
Bruce E. Zawacki

Progress in the Futility Debate
Robert D. Truog

Is Refusal of Futile Treatment Unjustified Paternalism?
Nancy S. Jecker
The Problem of Medically Futile Treatment: Falling Back on a Preventive Ethics Approach
Stephen Wear and Gerald Logue

Decedents' Reported Preferences for Physician-Assisted Death: A Survey of Informants Listed on Death Certificates in Utah
Jay A. Jacobson, Evelyn M. Kasworm, Margaret P. Battin, Jeffrey R. Botkin, Leslie P. Francis, and David Green

Empirical Studies on Euthanasia and Assisted Suicide
Ezekiel J. Emanuel

The Limitation of Empirical Research in Ethics
Edmund D. Pellegrino

Circular Questioning by Ethics Committees: Who's Asking the Doctors?
Jeffrey D. Tiemstra

Of Circles and Lines, Metaphors and Narratives: Toward a Systems Theory of Ethics Consultation
Jan Marta

The Ghost Walks Again: Unpacking the Assumption of Circular Questioning
Ellen W. Bernal and Guillermo Argueta-Bernal

Incidental Findings: Patients' Knowledge, Rights, and Preferences
Lisa S. Parker and Rachel Ankeny Majeske

Genetic Counseling, Non-Directiveness, and Clients' Values: Is What Clients Say, What They Mean?
Benjamin S. Wilfond and Diane Baker

Genetic Counseling: Making Room for Beneficence
Jeffrey R. Botkin

Substituted Judgment: In Search of a Foolproof Method; A Response to Baergen
David Gary Smith and Sally Nunn

Legal Trends in Bioethics
Dena Davis

The Journal of Clinical Ethics, Volume 6, Number 1, Spring 1995

Impossible Choices: When Patients and Careproviders Face Impossible Decisions
Edmund G. Howe

Should People Do unto Others as They Would Not Want Done unto Themselves?
Christine Harrison, D. William Molloy, Peteris Darzins, and Michel Bédard

The Best-Interest Standard: Surrogate Decision Making and Quality of Life
James F. Drane and John L. Coulehan

Revising the Substituted Judgment Standard
Ralph Baergen

Time and Language in Bioethics: When Patient and Proxy Appear to Disagree
John Arthur McClung

Futility and Bargaining Power
Bethany Spielman

Pain Relief for Dying Persons: Dealing with Physicians’ Fears and Concerns
Melissa L. Buchan and Susan W. Tolle

Physician Aid in Dying and the Relief of Patients’ Suffering: Physicians’ Attitudes Regarding Patients’ Suffering and End-of-Life Decisions
Frederick Y. Huang and Linda L. Emanuel

Physicians’ Ethical Responsibilities under Co-Pay Insurance: Should Potential Fiscal Liability Become Part of Informed Consent?
J.F. Turner, T. Mason, D. Anderson, A. Gulati, and J.A. Sbarbaro

Religion, Race, and Reason: The Case of LJ
Tia Powell

LJ’s Religious Craziness
Annette Dula

The Fiction of Neutrality
Marian Gray Secundy and Colleen Sundstrom

An Algorithm for Determining Best Interest?
Muriel R. Gillick

Recognizing and Respecting Family Judgment
Valerie Swigart

The Hermeneutical Project and Clinical Ethics
Robert Lyman Potter
Some Thoughts on AIDS and Death
Alvin Novick

Legal Trends in Bioethics
Dena S. Davis

Letter
Laurence J. Schneiderman, Richard Kronick, Robert D. Langer, Robert M. Kaplan, and John P. Anderson

1994

The Journal of Clinical Ethics, Volume 5, Number 4, Winter 1994

Some Prices of Epiphany and the Occasional Need to Stigmatize Patients to Offset Them
Edmund G. Howe

Literature, Medical Ethics, and “Epiphanic Knowledge”
Ann Hunsaker Hawkins

Healthcare Rationing through Global Budgeting: The Ethical Choices
Robert M. Veatch

What’s Missing from Current Clinical Trial Guidelines? A Framework for Integrating Science, Ethics, and the Community Context
Heather J. Sutherland, Eric M. Meslin, and James E. Till

Clinical Practice Guidelines as Tools of Public Policy: Conflicts among Purpose, Issues of Autonomy, and Justice
Barbara K. Redman

Make My Case: Ethics Teaching and Case Presentations
Mark Kuczewski, Mark R. Wisclair, Robert M. Arnold, Rosa Lynn Pinkus, and Gretchen M. E. Aumann

It Ain’t Necessarily So: Clinicians, Bioethics, and Religious Studies
Dena S. Davis

The Physicians’ Role in Completing Advance Directives: Ensuring Patients’ Capacity to Make Healthcare Decisions in Advance
Neil S. Wenger and Jodi Halpern

Clinical Ethics Consultations with Children
Robert D. Orr and Ronald M. Perkin

The Physician-Assisted Suicide and Euthanasia Debate: An Annotated Bibliography of Representative Articles
Joseph J. Fins and Matthew D. Bacchetta

Literature as Mirror or Lamp? Commentary on “Literature, Medical Ethics, and ‘Epiphanic Knowledge’ ”
Ann Hudson Jones

Global Budgeting in the Real World
Jay A. Gold

The Ethics of Global Budgeting: Some Historically Based Observations
Robert Baker

Thinking about Cases as Stories
Ronald A. Carson

One of These Mornings I’m Going to Rise Up Singing: The Necessity of the Prophetic Voice in Jewish Bioethics
Laurie Zoloth-Dorfman

Bioethics and the Old-Time Religion: Response to Dena Davis
Benjamin Freedman

Setting Up a Straw Man: Commentary on Dena Davis
Fred Rosner

Appropriate and Inappropriate Use of Advance Directives
Linda Emanuel

The Capacity to Make Decisions in Advance and Borderline Personality Disorder
Linda Ganzini, Melinda A. Lee, and Ronald T. Heintz

Clear, Convincing, and Authentic Advance Directives in the Context of Managed Care?
Harold Bursztajin and Archie Brodsky

Legal Trends in Bioethics
Dena S. Davis

The Journal of Clinical Ethics, Volume 5, Number 3, Fall 1994
Approaches (and Possible Contraindications) to Enhancing Patients’ Autonomy
   Edmund G. Howe

Patients’ Perceptions of the Quality of Informed Consent for Common Medical Procedures
   Daniel P. Sulmasy, Lisa S. Lehmann, David M. Levine, and Ruth R. Faden

Discussions about the Use of Life-Sustaining Treatments: A Literature Review of Physicians’ and
Patients’ Attitudes and Practices
   Rita T. Layson, Harold M. Adelman, Paul M. Wallach, Mark P. Pfeifer, Sarah Johnston, Robert A. McNutt,
   and the End Of Life Study Group

Should Hospital Policy Require Consent for Practicing Invasive Procedures on Cadavers? The
Arguments, Conclusions, and Lessons from One Ethics Committee’s Deliberations
   Henry S. Perkins and Anna M. Gordon

Issues of Consent: The Use of the Recently Deceased for Endotracheal Intubation Training
   Gregory J. Hayes

Reconsidering “Psychosurgery”: Issues of Informed Consent and Physician Responsibility
   Susan J. Stagno, Martin L. Smith, and Samuel J. Hassenbusch

Hawkeye Pierce and the Questionable Relevance of Medical Etiquette to Contemporary Medical Ethics
   and Practice
   Jeremy Sugarman

Can a Patient Refuse a Psychiatric Consultation to Evaluate Decision-Making Capacity?
   Neil S. Wenger and Jodi Halpern

Iatrogenic Ethical Problems: A Commentary on “Can a Patient Refuse a Psychiatric Consultation to
Evaluate Decision-Making Capacity?”
   Alan A. Stone

Authenticity and Autonomy in the Managed-Care Era: Forensic Psychiatric Perspectives
   Harold J. Bursztajn and Archie Brodsky

Patients’ Perceptions of Consent
   Ian Shenk

Informed Consent: Pondering a New Piece of the Puzzle
   Jay A. Jacobson

Changing the Paradigm for Informed Consent
   Teo Forcht Dagi

Commentary on Discussions About Life-Sustaining Treatments
   Ezekiel J. Emanuel

“How Do You Catch a Cloud and Pin It Down?” (with apologies to Rogers and Hammerstein): A
Commentary on Layson and Colleagues
   Gail J. Povar

Politically Correct Ethical Thinking and Intubation Practice on Cadavers
   James P. Orlowski

Life versus Death: Exposing a Misapplication of Ethical Reasoning
   Kenneth V. Iserson

Autonomy, Informed Consent, and Psychosurgery
   Edward M. Hundert

Legal Trends in Bioethics
   Dena S. Davis

Letters
   Jeffrey Berger
Warren L. Holleman, David C. Edwards, and Christine C. Matson

Should Hospital Ethics Committees Do Research?
Jeremy Sugarman

Helping Ken and Marie Pines
Frederick O. Bonkovsky

Commentary on “Helping Ken and Marie Pines”
Michael A. Grodin

Deciding Whether to Intervene
Edmund G. Howe

Veatch and Brain Death: A Plea for Soul
Rebecca D. Pentz

Letter from Abroad: Leaves from a Research Diary
Dena S. Davis

Calling It Quits: Stopping Futile Treatment and Caring for Patients
Nancy S. Jecker

The Multiple Facets of Futility
Howard Brody

The Role of Empirical Research in Medical Ethics: Asking Questions or Answering Them?
Clarence H. Braddock III

The Quantifiability of Medical Futility
Janicemarie K. Vinicky and James P. Orlowski

Trees and Heads: The Objective and the Subjective in Painful Procedures
Henry L. Bennett

Conscious Forgetting and Subconscious Remembering of Pain
Louis Tinnin

Amnesia Instead of Anesthesia: Not Always a Question of Consent
Robert D. Truog and David Waisel

The Euthanasia Debate and Empirical Evidence: Separating Burdens to Others from One’s Own Quality of Life
Peter A. Ubel and Robert M. Arnold

To Save the Logic, the Facts Must Fit
Edmund D. Pellegrino

Should Ethics Committees Study Themselves?
Marion Danis

Book Review of Life Before Birth: The Moral and Legal Status of Embryos and Fetuses
Baruch A. Brody

Book Review of The Culture of Pain
Elizabeth Lipton Cobbs

Book Review of When Others Must Choose: Deciding for Patients without Capacity
M. Rose Gasner

Book Review of Birth, Suffering, and Death: Catholic Perspectives at the Edges of Life
Lonnie D. Kliever

Elena O. Nightingale

Book Review of Spare Parts: Organ Replacement in American Society
Peter A. Ubel

Book Review of If I Were a Rich Man Could I Buy a Pancreas? and other essays on the ethics of health care
Paul A. Menzel

Letters
Howard Brody; Edward P. Lewis; Martha Jurchak; Thomas A. Preston

The Journal of Clinical Ethics, Volume 5, Number 1, Spring 1994

Clinical Dilemmas When Patients Want Assistance in Dying
Edmund G. Howe

When Abstract Moralizing Runs Amok
John Lachs

Ad Hominem Run Amok: A Response to John Lachs
Daniel Callahan

The Skilled Specialist’s Ethical Duty to Treat
Frederick A. Paola and Israel Freeman

Ethics Committees and Family Ghosts: Case Studies
Timothy J. Keay

Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?
  Joan M. Teno, Joanne Lynn, Russell S. Phillips, Donald Murphy, Stuart J. Youngner, Paul Bellamy,
  Alfred F. Connors, Jr., Norman A. Desbiens, William Fulkerson, and William A. Knaus

Nurses’ Perspectives on Implementation of the Patient Self-Determination Act
Henry J. Silverman, Sara T. Fry, and Niti Armistead

Neuromuscular Paralysis and Withdrawal of Mechanical Ventilation
Lisa Kirkland

To Breathe or Not to Breathe
Robert D. Truog and Jeffrey P. Burns

Distinguishing between Effect and Benefit
Carl A. Riddick and Lawrence J. Schneiderman

The Physician’s Duty to Treat in Emergencies: Accepting Patients in Transfer
Ellen Fox

Commentary on “The Skilled Specialist’s Ethical Duty to Treat”
Reginald L. Peniston

Ethics Consultation Is Not Therapy
Ellen W. Bernal

First-Person Plural: Community and Method in Ethics Consultation
Susan Rubin and Laurie Zoloth-Dorfman

Confronting the “Near Irrelevance” of Advance Directives
Rebecca Dresser

Advance Directives: What Is It Reasonable to Expect from Them?
Dan W. Brock

Outcomes Research and Advance Directives
Jeremy Sugarman

Legal Trends in Bioethics
Dena S. Davis

Feminism’s Healing Effect: A Review of Feminist Perspectives in Medical Ethics
Leslie Bender

A Feminist Challenge to Practices of Medicine: A Review of No Longer Patient: Feminist Ethics and Health Care
K.A. Wallace

Feminism and Reproductive Technologies: A Review of Living Laboratories: Women and Reproductive Technologies
Joan C. Callahan

Letters
George L. Spaeth; Charles H. Kite

1993

The Journal of Clinical Ethics, Volume 4, Number 4, Winter 1993

Preventive Ethics and Alleviating Care Providers’ Stress
  Edmund G. Howe

Preventive Ethics: Expanding the Horizons of Clinical Ethics
  Lachlan Forrow, Robert M. Arnold, and Lisa S. Parker

Impairments and Impediments in Patients’ Decision Making: Reframing the Competence Question
  E. Haavi Morreim

Brain Death in Pregnant Women
  Jay E. Kantor and Iffath Abbasi Hoskins

The Psychiatric Admission Index: Deciding When to Admit a Patient
  H. Tristram Engelhardt, Jr., and John H. Coverdale

The Effect on Researchers of Handling Human Fetal Tissue
  Bernard E. Tuch, Stewart M. Dunn, and Vivianne de Vahl Davis
Case 1: Rational Suicide or Involuntary Commitment of a Patient Who Is Terminally Ill
Virginia L. Byer, Evan G. DeRenzo, and Edward J. Matricardi

The Case of Ms. A and Her Nurse Therapist
David J. Mayo

A Model System Works: Looking Deeper than Suicide
Stuart J. Youngner

On Promoting Rational Treatment, Not Rational Suicide
Tia Powell and Donald B. Kornfeld

Case 2: Decisions to Refuse Treatment by Depressed, Medically Ill Patients
Richard C. Christensen and S. Van McCrary

Depression, Suicide, and the Right to Refuse Life-Sustaining Treatment
Linda Ganzini, Melinda A. Lee, Ronald T. Heintz, and Joseph D. Bloom

Commentary on “Impairments and Impediments in Patients’ Decision Making”
Thomas G. Gutheil

Incubators and Organ Donors
Jacqueline J. Glover

Have We Lost Our Senses? Problems with Maintaining Brain-Dead Bodies Carrying Fetuses
Joel E. Frader

Clinical Management of Brain Death during Pregnancy
Frank A. Chervenak and Laurence B. McCullough

Commentary on “The Psychiatric Admission Index”
Paul Chodoff

An Algorithm in a Different World
Alan A. Stone

Is Admission to a Psychiatric Hospital an Ethical Alternative to Home-Based Treatment?
Ian R.H. Fallool

Cases and Social Reality: Making the Decision to Admit
H. Tristram Engelhardt, Jr., and John H. Coverdale

The Psychological and Moral Consequences of Participating in Human Fetal-Tissue Research
Stuart J. Youngner

Legal Trends in Bioethics
Dena S. Davis

Book Review of Rationing America’s Medical Care: The Oregon Plan and Beyond
Leonard M. Fleck

Book Review of Balancing Act: The New Medical Ethics of Medicine’s New Economics
Mary Ann Baily

Book Review of Ethics in Nursing
Mila Ann Aroskar

Book Review of The Patient’s Ordeal
Hugh Mullan

Book Reviews of Suffering and Beneficent Community: Beyond Libertarianism and The Nature of Suffering and the Goals of Medicine
Ian Shenk

Book Review of Doctors’ Stories: The Narrative Structure of Medical Knowledge
Marian Gray Secundy

Book Review of Psychiatric Ethics
Elissa P. Benedek

Letters
Anne Hunsaker Hawkins; William L. Allen and S. Van McCrary; Robert M. Veatch; Shimon Glick

The Journal of Clinical Ethics, Volume 4, Number 3, Fall 1993

The Relevance of Suffering and Identifying with Others When Allocating Resources, and Clinical Implications of the Elasticity of the Law
Edmund G. Howe

Outcome Predictors in the Early Withdrawal of Life Support: Issues of Justice and Allocation for the Severely Brain Injured
Steven A. Toms

Conflict in Medical Ethics Cases: Seeking Patterns of Resolution
Bethany J. Spielman
<table>
<thead>
<tr>
<th>Title</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phone Fees: A Justification of Physician Charges</strong></td>
<td>Susan S. Braithwaite and Nancy O. Unferth</td>
</tr>
<tr>
<td><strong>Requirements for Ethics, Socioeconomic, and Legal Education in Postgraduate Medical Programs</strong></td>
<td>Kenneth V. Iserson and Carol Stocking</td>
</tr>
<tr>
<td><strong>Clinical Ethics Training for Staff Physicians: Designing and Evaluating a Model Program</strong></td>
<td>Bruce David White and Richard M. Zaner</td>
</tr>
<tr>
<td><strong>Confidentiality in the Age of AIDS: A Case Study in Clinical Ethics</strong></td>
<td>Martin L. Smith and Kevin P. Martin</td>
</tr>
<tr>
<td><strong>Gathering Information and Casuistic Analysis</strong></td>
<td>Athena Beldecos and Robert M. Arnold</td>
</tr>
<tr>
<td><strong>The Legal Dilemma of Partner Notification during the HIV Epidemic</strong></td>
<td>Raymond C. O'Brien</td>
</tr>
<tr>
<td><strong>Clinical Ethics and Reform of Access to Health Care</strong></td>
<td>Steven H. Miles</td>
</tr>
<tr>
<td><strong>Justice and Outcomes Research: The Ethical Limits</strong></td>
<td>Robert M. Veatch</td>
</tr>
<tr>
<td><strong>Ethics, Outcomes, and Epistemology: How Should Imprecise Data Figure into Health-Policy Formulation?</strong></td>
<td>Teo Forcht Dagi</td>
</tr>
<tr>
<td><strong>Cutting to the Bone in Conflict Resolution: “Getting to Yes” with Hormonal-Replacement Therapy</strong></td>
<td>Helen M. Wood</td>
</tr>
<tr>
<td><strong>Medical Ethics Cases: Moral Conflict or Confusion?</strong></td>
<td>George A. Kanoti</td>
</tr>
<tr>
<td><strong>Telephone Fees: Are They Worth It?</strong></td>
<td>Daniel J. Isaacman</td>
</tr>
<tr>
<td><strong>Medical Ethics in Medical Education: Finding and Keeping a Place at the Table</strong></td>
<td>Thomas K. McElhinney</td>
</tr>
<tr>
<td><strong>Legal Trends in Bioethics</strong></td>
<td>Dena S. Davis</td>
</tr>
<tr>
<td><strong>The Journal of Clinical Ethics, Volume 4, Number 2, Summer 1993</strong></td>
<td></td>
</tr>
<tr>
<td><strong>On Expanding the Parameters of Assisted Suicide, Directive Counseling, and Overriding Patients’ Cultural Beliefs</strong></td>
<td>Edmund G. Howe</td>
</tr>
<tr>
<td><strong>Causing, Intending, and Assisting Death</strong></td>
<td>Howard Brody</td>
</tr>
<tr>
<td><strong>Prolonged Grieving after Abortion: A Descriptive Study</strong></td>
<td>Douglas Brown, Thomas E. Elkins, and David B. Larson</td>
</tr>
<tr>
<td><strong>The Courtship of the Paying Patient</strong></td>
<td>Susan S. Braithwaite</td>
</tr>
<tr>
<td><strong>Limitation of Medical Care: An Ethnographic Analysis</strong></td>
<td>William Ventres, Mark Nichter, Richard Reed, and Richard Frankel</td>
</tr>
<tr>
<td><strong>Autopsy Decisions: The Possibility of Conflicting Cultural Attitudes</strong></td>
<td>Henry S. Perkins, Josie D. Supik, and Helen P. Hazuda</td>
</tr>
<tr>
<td><strong>The Influence of Ethnicity and Race on Attitudes toward Advance Directives, Life-Prolonging Treatments, and Euthanasia</strong></td>
<td>P.V. Caralis, Bobbi Davis, Karen Wright, and Eileen Marcial</td>
</tr>
<tr>
<td><strong>Questionable Competency of a Surrogate Decision Maker under a Durable Power of Attorney</strong></td>
<td>S. Van McCrary, William L. Allen, and Clarence L. Young</td>
</tr>
<tr>
<td><strong>Second Guessing the Patient’s Trust: Facing the Challenge of the Difficult Surrogate</strong></td>
<td>Gail J. Povar</td>
</tr>
<tr>
<td><strong>Improving Advance Directives: More Dialogue, Not More Laws</strong></td>
<td>Greg A. Sachs</td>
</tr>
<tr>
<td><strong>Health-Care Agents: Decisional Capacity and Legal Compliance</strong></td>
<td>Jonathan D. Moreno</td>
</tr>
<tr>
<td><strong>Doesn’t Everyone Grieve in the Abortion Choice?</strong></td>
<td>Jo Ann Rosenfeld and Tom Townsend</td>
</tr>
</tbody>
</table>
Realistic Reflections on an Emotional Subject
   Nada L. Stotland

Some Real Issues Surrounding Abortion, or, the Current Practice of Abortion is Unscientific
   Philip G. Ney

Discussing Resuscitation Status with Patients and Families
   Alvin H. Moss

Should Medical Encounters Be Studied Using Ethnographic Techniques?
   Cynthia J. Stolman

Balancing Communication Skills and Clinical Assessment
   Marian Gray Secundy

Getting the CPR You Want: DNR and Alice’s Restaurant
   Paul P. Chiang and David Schiedermayer

Interpreting Cultural Differences in Medical Intervention: The Use of Wittgenstein’s “Forms of Life”
   Carol Nash

The Influence of Culture in the Authorization of an Autopsy
   Clicerio González-Villalpando

Conflicting Cultural Attitudes about Autopsies
   James P. Orlowski and Janicemarie K. Vinicky

An Important Beginning
   Marian Gray Secundy

Letters
   Howard Brody; David J. Doukas; Shimon Glick

The Journal of Clinical Ethics, Volume 4, Number 1, Spring 1993

   The Vagaries of Patients’ and Families’ Discussing Advance Directives
      Edmund G. Howe

Advance Directives: What Have We Learned So Far?
   Linda Emanuel

Being a Burden on Others
   Nancy S. Jecker

The Problem of Proxies with Interests of Their Own: Toward a Better Theory of Proxy Decisions
   John Hardwig

Do Physicians’ Own Preferences for Life-Sustaining Treatment Influence Their Perceptions of Patients’ Preferences?
   Lawrence J. Schneiderman, Robert M. Kaplan, Robert A. Pearlman, and Holly Teetzel

Insights Pertaining to Patient Assessments of States Worse than Death
   Robert A. Pearlman, Kevin C. Cain, Donald L. Patrick, Malka Appelbaum-Maizel, Helene E. Starks, Nancy S. Jecker, and Richard F. Uhlmann

Analyzing the Values History: An Evaluation of Patient Medical Values and Advance Directives
   David John Doukas and Daniel W. Gorenflo

Is the Patient Self-Determination Act Appropriate for Elderly Persons Hospitalized for Depression?
   Linda Ganzini, Melinda A. Lee, Ronald T. Heintz, and Joseph D. Bloom

Establishing Advance Medical Directives with Demented Patients: A Pilot Study
   Thomas E. Finucane, Brock A. Beamer, Robert P. Roca, and Claudia H. Kawas

Decision Making in an Incapacitated Patient
   Jack P. Freer

Authenticity, Autonomy, and Mental Disorders
   Linda Ganzini and Melinda A. Lee

Meaning What You Say
   Carl Elliott

Patients Should Not Always Come First in Treatment Decisions
   Carson Strong

Hardwig on Proxy Decision Making
   Baruch A. Brody

Justice within Intimate Spheres
   Alisa L. Carse

From PSDA to PTSD: The Patient Self-Determination Act and Post-Traumatic Stress Disorder
   Harold J. Bursztajn

The PSDA and the Depressed Elderly: “Intermittent Competency” Revisited
The Journal of Clinical Ethics, Volume 3, Number 4, Winter 1992

Caveats Regarding Slippery Slopes and Physicians' Moral Conscience
Edmund G. Howe

The Slippery-Slope Argument
Wibren van der Burg

The Many Faces of Autonomy
Harry Yeide, Jr.

The Seductive Beauty of Physiology
Jeffrey R. Botkin

The Institutional Review Board: An Evolving Ethics Committee
Stuart E. Lind

Providing and Forgoing Resuscitative Therapy for Babies of Very Low Birth Weight
John D. Lantos, William Meadow, Steven H. Miles, Edem Ekwo, John Paton, Joseph R. Hageman, and Mark Siegler

Learning the Patient’s Narrative to Determine Decision-Making Capacity: The Role of Ethics Consultation
Kristina A. Maciunas and Alvin H. Moss

Ethics Committees, Decision-Making Quality Assurance, and Conflict Resolution
Edward E. Waldron

Mediation and Communication Techniques in Ethics Consultation
Mary Beth West

The Slippery-Slope Argument Reconstructed: Response to van der Burg
Benjamin Freedman

Slippery Slopes and Moral Reasoning
Raymond J. Devettere

The Characteristics of a Valid “Empirical” Slippery-Slope Argument
David Ozar

Surrogate Decision Makers and Respect: Commentary on “The Many Faces of Autonomy”
Murray M. Pollack

Rogue Approaches in Medical Education
Lois LaCivita Nixon and Delese Wear

Knowing Souls
Charles Radey

Researcher as Witness
Troyen A. Brennan

An Ethics Issue for Cadaver Renal Transplantation
John B. Dossetor
The Need for Consistency in NICUs
Robert F. Weir

Can Empirical Data Establish Futility?
Robert D. Truog

Legal Trends in Bioethics
Suzan Onel and Sigrid Fry-Revere

The Journal of Clinical Ethics, Volume 3, Number 3, Fall 1992

Attributing Preferences and Violating Neutrality
Edmund G. Howe

The Boundaries of the Persistent Vegetative State
James L. Bernat

Brain Death and Slippery Slopes
Robert M. Veatch

Obtaining Consent from the Family: A Horizon for Clinical Ethics
Sandro Spinsanti

Ethical Difficulties with Randomized Clinical Trials Involving Cancer Patients: Examples from the Field of Gynecologic Oncology
Maurie Markman

A Perinatal Ethics Committee on Abortion: Process and Outcome in Thirty-One Cases
John La Puma, Cheryl M. Darling, Carol B. Stocking, and Katy Schiller

Awakening: Bad News and Good News
Robert D. Orr

Permanently Locked-In Syndrome in the Neurologically Impaired Neonate: Report of a Case of Werdnig-Hoffmann Disease
Robert J. Echenberg

Locked-In Syndrome and Ethics Committee Deliberation
Robert D. Truog

Abating Treatment in the NICU
Robert F. Weir

Compassion, Consensus, and Conflict: Should Caregivers’ Needs Influence the Ethical Dialectic?
Teo Forcht Dagi

The Physician, the Family, and the Truth
Paolo Cattorini and Massimo Reichlin

On Grinding Axes and Examining Practices
John C. Fletcher

Consent, Ethics, and Community
Erich H. Loewy

Ignorance and Altruism
Richard M. Royall

A Response to a Purported Ethical Difficulty with Randomized Clinical Trials Involving Cancer Patients
Benjamin Freedman

The Microethics and Macroethics of Hospital Abortion Committees
Hyman Rodman

Abortion: Doomed Only to an Immoderate Response?
James F. Drane

Commentary on “A Perinatal Ethics Committee on Abortion”
Jerry Edelwich

Legal Trends in Bioethics
Suzan Onel and Sigrid Fry-Revere

“Cost Accounting of Safeguards in Life Equivalents” Is a Better Title
L. Eugene Arnold

Euthanasia: Still Open for Debate
Franklin G. Miller

The Journal of Clinical Ethics, Volume 3, Number 2, Summer 1992

From the Editor
Edmund G. Howe

Doctors Must Not Kill
A Libertarian Critique of H. Tristram Engelhardt, Jr.’s *The Foundations of Bioethics*
Sigrid Fry-Revere

**The Social Individual in Clinical Ethics**
Jonathan D. Moreno

**Perinatal Technology: Answers and Questions**
Alfred N. Krauss, Valerie Miké, and Gail S. Ross

**Ethics and Evidence**
Jeffrey R. Botkin

**The “Ethics of Evidence” and Randomized Controlled Trials**
Robert D. Truog and John H. Arnold

**Sedating Women with Mental Retardation for Routine Gynecologic Examination: An Ethical Analysis**
Douglas Brown, David Rosen, and Thomas E. Elkins

**The Autonomy of Adult Women Should Be Paramount, Not the Exam**
Dohn Hoyle

**Family Refusal to Accept Brain Death and Termination of Life Support: To Whom Is the Physician Responsible?**
Lisa L. Kirkland

**Discussion of Brain-Death Case**
Jack P. Freer

**It Is Reasonable to Reject the Diagnosis of Brain Death**
Robert D. Truog and James C. Fackler

**Discussion of Brain-Death Case**
William G. Bartholome

**Discussion of Brain-Death Case**
Howard Morgan

**Legal Trends in Bioethics**
Suzan Onel and Sigrid Fry-Revere

**Letter**
Dan W. Brock

1991

**The Journal of Clinical Ethics, Volume 2, Number 4, Winter 1991**

**From the Editor**
Edmund G. Howe

**The Ethical Justification for Minimal Paternalism in the Use of the Predictive Test for Huntington’s Disease**
David DeGrazia

**The Physician as Fortune Teller: A Commentary on “The Ethical Justification for Minimal Paternalism”**
Charles R. MacKay

**Predictive Testing for HD: Maximizing Patient Autonomy**
Kimberly A. Quaid

**The Interpretation of Laboratory Results: The Paradoxical Effect of Medical Training**
Neil A. Holtzman

**The Effect of Education on Physicians’ Knowledge of a Laboratory Test: The Case of Maternal Serum Alpha-Fetoprotein Screening**

**The Effects of Uncertainty on the Physician-Patient Relationship in Predictive Genetic Testing**
Charles R. MacKay

**Screening for Tay-Sachs Disease: A Note of Caution**
Fred Rosner

**Ethical Issues Described by NICU Nurses**
Pamela A. Miya, Karen K. Boardman, Kathleen L. Harr, and Annabelle Keene

**Introduction: Genetics Research and Social Roles: On a Collision Course?**
David J. Doukas

**Medical and Ethical Consequences of the Human Genome Project**
Francis S. Collins

**Ethical Issues in Human Gene Therapy**
LeRoy Walters
The History of Eugenics and the Future of Gene Therapy
Joel D. Howell

Ethics, Technology, and the Human Genome Project
Howard Brody

The Next Wanglie Case: The Problems of Litigating Medical Ethics
Douglas B. Mishkin

Legal Procedures in Wanglie: A Two-Step, Not a Sidestep
Steven H. Miles

Legal Trends in Bioethics
Suzan Onel and Sigrid Fry-Revere

Letter
Franklin G. Miller

The Journal of Clinical Ethics, Volume 2, Number 3, Fall 1991

From the Editor
Edmund G. Howe

Autonomy and Beneficence in the Family: Describing the Family Covenant
David J. Doukas

A Breakdown in the Family Unit
Fred Rosner

Families, Communities, and Making Medical Decisions
Erich H. Loewy

Chronic Illness: A Problem of Passive Injustice
John Douard

The Injustice of It All: Caring for the Chronically Ill
Richard M. Zaner and Mark J. Bliton

Chronic Illness: Not-So-Passive Injustice?
Norman Daniels

Ethics Education for Psychiatry
H. Steven Moffic, John Coverdale, and Timothy Bayer

Ethics Education or Moral Persuasion?
Robert Michels

Competence as Accountability
Carol Elliott

Family Refusal to Accept Brain Death and Termination of Life Support: To Whom Is the Physician Responsible?
Lisa L. Kirkland

Hopes for PSDA
Elizabeth Leibold McCloskey

The PSDA: A Logical Next Step
M. Rose Gasner

Getting Ready for the PSDA: What Are Hospitals and Nursing Homes Doing?
Rebecca Jackson and Andrea Carlos

Robert S. Olick

The PSDA: A Long-Term Care View
Suzanne M. Weiss

Implementing the PSDA for Psychiatric Patients: A Common Sense Approach
Karen N. Swisher

The PSDA of 1991: What Does It Mean for Health-Care Organizations?
Alexandra Gekas

Legal Trends in Bioethics
Sigrid Fry-Revere

Letters
Dena S. Davis; Fred Rosner

The Journal of Clinical Ethics, Volume 2, Number 2, Summer 1991

From the Editor
Confidentiality: A Survey in a Research Hospital
Christine Grady, Joan Jacob, and Carol Romano

Ethics Is Everybody's Business, Especially in Regard to Confidentiality
John C. Fletcher

Validity Concerns: Commentary in Response to “Confidentiality”
Sandra Graham McClowry

Guarding Secrets and Keeping Counsel in the Computer Age
David L. Schiedermayer

Patients as “Subjects” or “Objects” in Residency Education?
Janicemarie K. Vinicky, Russell B. Connors, Jr., Richard Leader, and John D. Nash

Commentary on "Patients as 'Subjects' or 'Objects'"
W. Sterling Edwards

Is Health-Care Delivery by Partially Trained Professionals Ever Morally Justified?
Sara T. Fry

In Whose Voice? Composing a Lifesong Collaboratively
Gretchen M.-E. Aumann and Thomas R. Cole

Commentary on “In Whose Voice?”
Joanne Lynn

Medical Treatment after Brain Death: A Case Report and Ethical Analysis
Felicia Miedema

Treating the Brain Dead for the Benefit of the Family
John Hardwig

Personal Choices: Communication Between Physicians and Patients When Confronting Critical Illness
Robert L. Fine

Confidentiality in Cases of Rape: A Concept Reconsidered
Margaret Marx Aiken and Patricia M. Speck

Confidentiality and the Rape Victim: Ethical Intent Versus Political Reality
Deanna Nass

Legal Trends in Bioethics
Sigrid Fry-Revere

Letters
Ross Kessel; John La Puma

1990

The Journal of Clinical Ethics, Volume 1, Number 4, Winter 1990

From the Editor
Edmund G. Howe

Ethics Committees and Consultants
Peter A. Singer, Edmund D. Pellegrino, and Mark Siegler

The Imprecise Language of Euthanasia and Causing Death
Raymond J. Devettere

Titration of Death: A New Sin
Benjamin Freedman

Ethical Aspects of Research Involving Elderly Subjects: Are We Doing More than We Say?
Laura Weiss Lane, Christine K. Cassel, and Woodward Bennett

Ethical Aspects of Research Involving Elderly Subjects
John C. Fletcher

The Hippocratic Oath and Clinical Ethics
H. Steven Moffic, John Coverdale, and Timothy Bayer

The Question Is: What Is Medicine Supposed To Be All About?
Linda Emanuel

The Hippocratic Oath
Edmund G. Howe

Should We Study the Hippocratic Oath?
Robert M. Veatch

The Value of an Oath of Professional Conduct: Process, Content, or Both?
Robert Allan Pearlman

Ethics and Medical Humanities Education
The Journal of Clinical Ethics, Volume 1, Number 3, Fall 1990

From the Editor
Edmund G. Howe

Teaching Clinical Ethics
Edmund D. Pellegrino, Mark Siegler, and Peter A. Singer

Pregnancy Reduction in Jewish Law
Fred Rosner

Practical Reasoning in Medicine and the Rise of Clinical Ethics
Jane Kelley Rodeheffer

Right Action: Commentary on “Practical Reasoning in Medicine”
Daniel J. Anzia and John La Puma

Computer Searches of the Medical Ethics Literature
Peter A. Singer, Steven H. Miles, and Mark Siegler

Commentary: Computer Searches of the Medical Ethics Literature
Tamar Joy Kahn and Mary Carrington Coutts

The Ethical Dilemma of Permitting the Teaching and Perfecting of Resuscitation Techniques on Recently Expired Patients
James P. Orlowsky, George A. Kanoti, and Maxwell J. Mehlman

Truth Telling in the Case of an Infant with Multiple Congenital Anomalies
Kathleen Stevens

Medical Ethics and Medical Injuries: Taking Our Duties Seriously
Lynn M. Peterson and Troyen Brennan

The Quasimodo Complex: Deformity Reconsidered
Jonathan Sinclair Carey

Self-Help for the Facialy Disfigured: Commentary on “The Quasimodo Complex”
Elisabeth A. Bednar

A Brief Response to “The Quasimodo Complex”
Harry Yeide, Jr.

A Response to “The Quasimodo Complex”
Frances Cooke MacGregor

Commentary on “The Quasimodo Complex”
Arlette Lefebvre

Literature as a Clinical Capacity: Commentary on “The Quasimodo Complex”
Joanne Trautmann Banks

Quasimodo and Medicine: What Role for the Clinician in Treating Deformity?
Ronald P. Strauss

Deformity and the Humane Ideal of Medicine
Robert M. Goldwyn

Cruzan: It’s Not Over, Nancy?
Evelyn Shuster

Cruzan and Its Sequelae: The Supreme Court Decides Its First “Right-to-Die” Case
The Journal of Clinical Ethics, Volume 1, Number 2, Summer 1990

From the Editor
Edmund G. Howe

Research in Clinical Ethics
Peter A. Singer, Mark Siegler, and Edmund D. Pellegrino

Conceiving a Child to Save a Child: Reproductive and Filial Ethics
Nancy S. Jecker

To What Extent Should We Think of Our Intimates as Persons? Commentary on “Conceiving a Child”
Virginia A. Sharpe

Advance-Treatment Planning Discussions with Nursing Home Residents: Pilot Experience with Simulated Interviews
Steven H. Miles, Susan Bannick-Mohrland, and Nicole Lurie

Active Euthanasia
John Lachs

The Ethics of Surreptitious Diagnostics for Factitious Hypoglycemia
Susan S. Braithwaite, Jan Eatherton, William Ellos, Mary Ann Emanuele, Marilynn Morrissey, and Glen W. Sizemore

Commentary on “The Ethics of Surreptitious Diagnostics”
Michael G. Wise

An Ethical Dilemma in Clinical Practice: Termination versus Continuation of Life-Sustaining Treatment
Patricia Ann Cady

Another Ethics Consultant Looks at Mr. B’s Case: Commentary on “An Ethical Dilemma”
Henry S. Perkins

Clinical and Ethical Dilemmas in the Elderly: Commentary on “An Ethical Dilemma”
Nancy Boucot Cummings

Birth Penalty: Societal Responses to Perinatal Chemical Dependence
Sandra Anderson Garcia

Jennifer Johnson’s Sentence: Commentary on “Birth Penalty”
Wendy Chavkin

Beyond Schizophrenia: Commentary on “Birth Penalty”
Marian G. Secundy

House of Cards: Commentary on “Birth Penalty”
Robert E. Fullilove and Mindy Thompson Fullilove

Perinatal Drug Use—A Different Perspective: Commentary on “Birth Penalty”
Toni M. Vezeau

Sex, Drugs, and Pregnant Addicts: An Ethical and Legal Critique of Societal Responses to Pregnant Addicts
Michelle Oberman

Expanding the Role of Physicians in Drug Abuse Treatment: Problems and Perspectives
Carol Levine and David M. Novick

Genetic Counseling for Addicted Obstetric Patients
Judith Benkendorf and Kevin FitzGerald

Preventive Ethics Strategies for Drug Abuse During Pregnancy
Frank A. Chervenak and Laurence B. McCullough

A “Right to Die” Case in Practical Perspective
Claire C. Obade

Legal Trends in Bioethics
Sigrid Frye-Revere

Letters
Donald T. Ridley; Teo Forcht Dagi
The Journal of Clinical Ethics, Volume 1, Number 1, Spring 1990

The Journal of Clinical Ethics: Genesis, Purposes, and Scope
Edmund G. Howe

Clinical Medical Ethics
Mark Siegler, Edmund D. Pellegrino, and Peter A. Singer

Living Wills: Past, Present, and Future
Ezekiel J. Emanuel and Linda Emanuel

Is There a Right to Futile Treatment? The Case of a Dying Patient with AIDS
Jay Alexander Gold, Daniel F. Jablonski, Paul J. Christensen, Robyn S. Shapiro, and David L. Schiedermayer

Medical Ethics and Personal Doctors: Conflicts Between What We Teach and What We Want
Robert J. Levine

Case Study: Conjoined Twins and Anencephaly
Roger A. Williamson, Robert T. Soper, John A. Widness, and Robert F. Weir

Commentary: The Moral Status of Patients Who Are Not Strict Persons
Nancy S. Jecker

What Means This Consensus? Ethics Committees and Philosophic Tradition
Jonathan D. Moreno

Commentary: Consensus—Real or Imaginary
Dorothy Rasinski Gregory

Commentary: A Response to Jonathan Moreno
Ian Shenk

An Analysis of Some Social Issues Related to HIV Disease from the Perspective of Jewish Law and Values
Benjamin Freedman

Withdrawing and Withholding Therapy: Putting Ethics into Practice
Gail Povar

Must the Ethics Consultant See the Patient?
John La Puma and David L. Schiedermayer

The Story of Mr. and Mrs. Doe: “You can’t tell my husband he’s dying; it will kill him.”
Margot L. White and John C. Fletcher

Case Analysis in Clinical Ethics
Albert R. Jonsen

The Jehovah’s Witness and Blood: New Perspectives on an Old Dilemma
Janicemarie K. Vinicky, Martin L. Smith, Russell B. Connors, Jr., and Walter E. Kozachuk

Commentary: Jehovah’s Witnesses and Blood
Albert R. Jonsen

Commentary: Response from Jehovah’s Witnesses
Nathanael Reed

Withdrawal of Life Support Aganist Family Wishes: Is It Justified?
Barbara Springer Edwards

Role Responsibilities in Clinical Bioethics: The Dialectic of Consultation: Comments on the Case Presented by Barbara Edwards
T. Forcht Dagi

Missing the Point: Comments on the Case Presented by Barbara Edwards
Laurence J. O’Connell

Commentary: The Many Styles of Clinical Ethics
Harry Yeide, Jr.

Compelling Treatment of the Mother to Protect the Fetus: The Limits of Personal Privacy and Paternalism
Claire C. Obade

Legal Trends in Bioethics
Sigrid Fry-Revere