

The Journal of Clinical Ethics: Tables of Contents

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The Journal of Clinical Ethics, Volume 29, Number 1, Spring 2018

At the Bedside

[Slowing Down Fast Thinking to Enhance Understanding](#)

Edmund G. Howe, *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 3-14.

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](#)

Nathan Scheiner and Joan Liaschenko, *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 15-9.

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 \(GTEx\) Project](#)

Laura A. Siminoff, Maureen Wilson-Genderson, Maghboeba Mosavel, Laura Barker, Jennifer Trgina, Heather M. Traino, Howard M. Nathan, Richard D. Hasz, and Gary Walters, *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 20-30.

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) substudy 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.

[An International Legal Review of the Relationship between Brain Death and Organ Transplantation](#)

Kiarash Aramesh, Hitoshi Arima, Dale Gardiner, and Seema K. Shah, *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 31-42.

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](#)

Maria Torroella Carney, Brian Emmert, and Brian Keefe, *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 43-51.

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](#)

Susan Sanelli-Russo, Kelly McBride Folkers, William Sakolsky, Joseph J. Fins, and Nancy Neveloff Dubler, *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 52-61.

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”](#)

Casey Jo Humbyrd, *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): 62-8.

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](#)

Jacqueline J. Glover, Deb Bennett-Woods, and Jean Abbott, *The Journal of Clinical Ethics* 29, no. 1 (Spring 2018): xx-xx.

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.

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The Journal of Clinical Ethics, Volume 28, Number 4, Winter 2017

At the Bedside

New Ways to Cut through Ethical Gordian Knots

Edmund G. Howe, The Journal of Clinical Ethics 28, no. 4 (Winter 2017): 257-68.

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

Anders Herlitz, The Journal of Clinical Ethics 28, no. 4 (Winter 2017): 269-78.

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

Karen L. Smith, Patrice Fedel, and Jay Heitman, The Journal of Clinical Ethics 28, no. 4 (Winter 2017): 279-84.

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

Alida Naudé and Juan Bornman, The Journal of Clinical Ethics 28, no. 4 (Winter 2017): 290-302.

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

James L. Benedict, *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 303-7.

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

Lisa Fuller and Margot M. Eves, *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 308-13.

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 highlights some of the ways in which a prisoner-patient's vulnerable status impacted the care he received. The article argues the following: (1) Prisoner-patients are entitled to the same quality of care as all other patients, and healthcare providers should be vigilant to ensure that the stigma of incarceration does not influence care decisions. (2) Options for treatment should reflect what is most medically appropriate in the hospital or other healthcare setting, even when not all treatments would be available in the correctional setting. (3) The presence of guards at the bedside requires that additional measures be taken to protect the privacy and confidentiality of prisoner-patients. (4) When end-of-life decisions must be made for an incapacitated patient, prison physicians are not well placed to act as surrogate decision makers, which heightens the obligations of the healthcare professionals in the hospital to ensure an ethically supportable process and outcome. Therefore, healthcare professionals should provide extra protection for those prisoner-patients who do not have decision-making capacity, by utilizing a robust process for decision making such as those used for incapacitated patients without surrogates, rather than relying solely on prison physicians as surrogates.

Clinical Ethics Consultation

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

Rebecca L. Volpe, *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 314-7.

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

Donna Messutta, *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 318-24.

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

Matthew W. McCarthy, Diego Real de Asua, and Joseph J. Fins, *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 325-32.

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?

The Journal of Clinical Ethics, Volume 28, Number 3, Fall 2017

At the Bedside

Nine Lessons from Ashley and Her Parents

Edmund G. Howe, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 177-88.

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

Jamie Lindemann Nelson, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 197-203.

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

Deb Bennett-Woods, Jean Abbott, and Jacqueline J. Glover, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 204-11.

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).¹ 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?

Armand H. Matheny Antommara, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 217-221.

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

Donna D. McKlindon, Pamela Nathanson, and Chris Feudtner, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 222-7.

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 consultations 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

Amy E. Caruso Brown, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 228-35.

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

James L. Benedict, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 236-8.

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](#)

David S. Wendler, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 239-46.

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](#)

Roger Strair, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 247-9.

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](#)

Dena S. Davis, *The Journal of Clinical Ethics* 28, no. 3 (Fall 2017): 250-4.

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.

The Journal of Clinical Ethics, Volume 28, Number 2, Summer 2017

At the Bedside

[Going from What Is, to What Should Be, to Care Better for Our Patients and Families](#)

Edmund G. Howe, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 85-96.

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](#)

Michael G. Fara, Breehan Chancellor, Aaron S. Lord, and Ariane Lewis, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 97-101.

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 (gasping 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?](#)

Alicia Pérez Blanco, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 102-16.

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 cause 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 been 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% versus 74.5 percent, $p = 0.01$). Providers were reluctant to offer families the option of being present unless they had requested it, and would only permit it under certain conditions. Having a staff member to support the family was of great value to most respondents. The author believes families have a negative right to be present during CPR and so should be invited to stay.

A Patient (Not) Alone

Lauren Sydney Flicker, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 117-21.

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

Kate Robins-Browne, Kelsey Hegarty, Marilys Guillmen, Paul Komesaroff, and Victoria Palmer, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 122-34.

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"

Jamie Lindemann Nelson, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 135-6.

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

Ellen M. Robinson, Wendy Cadge, Kimberly Erler, Sharon Brackett, Julia Bandini, Alexandra Cist, M. Cornelia Cremens, Eric L. Krakauer, and Andrew M. Courtwright, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 137-52.

We describe the structure, operation, and experience of the Massachusetts General Hospital ethics committee, formally called the Edwin H. Cassen 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

Bonnie H. Arzuaga, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 153-8.

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 bi-annual 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

Jamie Diamond, Umesh Gidwani, and Rosamond Rhodes, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 159-62.

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

Thaddeus Mason Pope, *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 163-73.

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

Edmund G. Howe, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 3-14.

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

Alisa Carse and Cynda Hylton Rushton, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 15-29.

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 ad-

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

Tessy A. Thomas and Laurence B. McCullough, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 30-2.

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

James E. Sabin, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 33-6.

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

Elizabeth G. Epstein and Ashley R. Hurst, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 37-41.

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

William J. Winslade, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 42-3.

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

Nancy S. Jecker and Arthur R. Derse, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 44-56.

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

Anna Rita Egbert, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 57-66.

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

Shahla Siddiqui, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 67-9.

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

Shenbagam Dewar and Rajan Dewar, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 70-3.

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

Thaddeus Mason Pope, *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 74-81.

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 Bourgiouse, 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 (CECSs). 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 consulta-

tion. Likewise, it can be difficult for clinical ethicists to “speak the same language” as healthcare administrators and managers, which, in turn, means that CECSs 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 CECS. Specifically, we discuss two elements that clinical ethics leaders must critically appraise and successfully argue to meet the expectations of administrators—the value of a CECS and its fit in clinical workflow.

Cases from the Cleveland Clinical Foundation

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.

Perspective

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.

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At the Bedside

Harmful Emotional Responses that Patients and Physicians May Have When their Values Conflict

Edmund G. Howe

One of the most difficult decisions a clinician may face is when, if ever, to decline what a patient wants, based on the clinician’s own moral conscience. Regardless of what the clinician decides, the outcome may be deeply emotionally painful for both parties, and the pain may last. I will discuss this pain, how it occurs, and what we can do to try to reduce it before, during, and after a conflict arises. Approaches include explaining how we are like the patient or doctor, that no one is perfect, and that what we *do* is not who we *are*.

Features

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 Antommara

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.

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.

The Journal of Clinical Ethics, Volume 27, Number 2, Summer 2016

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.

Methods: The study was a mixed methods retrospective study of consultation summaries and hospital and ethics center data on 56 age- and gender-matched Caucasian and African American Medicare patients who received ethics consultations related to issues around limiting medical treatment in the period 2011 to 2014. The average age of patients was 70.9.

Results: Consultation requests for females were made significantly earlier in their stays in the hospital (6.57 days) than were consultation requests made for males (16.07 days). For African American patients, the differences in admission-to-request intervals for female patients (5.93 days) and male patients (18.64 days) were greater than for Caucasian male and female patients. Differences in the timing of a consultation were not significantly correlated with the presence of an advance directive, the specialty of the attending physician, or the reasons for the consult request. Ethics consultants may have mitigated problems that developed during the lag in request times for African American males by spending more time, on average, on those consultations (316 minutes), especially more time, on average, than on consultations with Caucasian females (195 minutes). Most consultations (40 of 56) did result in movement toward limiting treatment, but no statistically significant differences were found among the groups studied in the movement toward limiting treatment. The average number of days from consult to discharge or death were strongly correlated with the intervals between admission to the hospital and request for an ethics consultation.

Conclusion: Our findings suggest race and gender disparities in the timing of ethics consultations that consultants may have partially mitigated.

Measuring Quality in Ethics Consultation

Sally E. Bliss, Jane E. Oppenlander, Jacob M. Dahlke, Gordon J. Meyer, Eva M. Williford, and Robert C. Macauley

For all of the emphasis on quality improvement—as well as the acknowledged overlap between assessment of the quality of healthcare services and clinical ethics—the quality of clinical ethics consultation has received scant attention, especially in terms of empirical measurement. Recognizing this need, the second edition of *Core Competencies for Health Care Ethics Consultation*¹ identified four domains of ethics quality: (1) ethicality, (2) stakeholders' satisfaction, (3) resolution of the presenting conflict/dilemma, and (4) education that translates into knowledge. This study is the first, to our knowledge, to directly measure all of these domains. Here we describe the quality improvement process undertaken at a tertiary care academic medical center, as well as the tools developed to measure the quality of ethics consultation, which include post-consultation satisfaction surveys and weekly case conferences. The information gained through these tools helps to improve not only the process of ethics consultation, but also the measurement and assurance of quality.

Defining Patient Advocacy for the Context of Clinical Ethics Consultation: A Review of the Literature and Recommendations for Consultants

Tracy Brazg, Taryn Lindhorst, Denise Dudzinski, and Benjamin Wilfond

The idea of patient advocacy as a function of clinical ethics consultation (CEC) has been debated in the bioethics literature. In particular, opinion is divided as to whether patient advocacy inherently is in conflict with the other duties of the ethics consultant, especially that of impartial mediator. The debate is complicated, however, because patient advocacy is not uniformly conceptualized. This article examines two literatures that are crucial to understanding patient advocacy in the context of bioethical deliberations: the CEC literature and the literature on advocacy in the social work profession. A review of this literature identifies four distinct approaches to patient advocacy that are relevant to CEC: (1) the best interest approach, (2) the patient rights approach, (3) the representational approach, and (4) the empowerment approach. After providing a clearer understanding of the varied meanings of patient advocacy in the context of CEC, we assert that patient advocacy is not inherently inconsistent with the function of the ethics consultant and the CEC process. Finally, we provide a framework to help consultants determine if they should adopt an advocacy role.

The Journal of Clinical Ethics, Volume 27, Number 1, Spring 2016

At the Bedside

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.

Features

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 reimplanted 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 Iirini 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](#)

Allyson L. Robichaud

Law

[Legal Briefing: Medicare Coverage of Advance Care Planning](#)

Thaddeus Mason Pope

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 DeVecchio 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 op-

erated 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 those 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).¹ 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

Nathan J. Smischney, James A. Onigkeit, Richard F. Hinds, and Wayne T. Nicholson

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 Bioethical 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

Developing and Testing a Checklist to Enhance Quality in Clinical Ethics Consultation

Lauren Sydney Flicker, Susannah L. Rose, Margot M. Eves, Anne Lederman Flamm, Ruchi Sanghani, and Martin L. Smith

Surrogate Decision Making and Intellectual Virtue

Gregory L. Bock

Identifying Challenges to Communicating with Patients about Their Imminent Death

Lena Hoff and Göran Hermerén

Medical Missions to Ghana: The Ethics of Choosing Children for Cardiac Surgery

Christine Mitchell

How Do We Choose?

Beverly M. Small, Judith Hurley, and Christine Placidi

Great Need, Scarce Resources, and Choice: Reflections on Ethical Issues Following a Medical Mission

Ravi R. Thiagarajan, Mark A. Scheurer, and Joshua W. Salvin

Ethical Aspects of Arranging Local Medical Collaboration and Care

Samuel Blay Nguah

Pediatric Heart Surgery in Ghana: Three Ethical Questions

Nir Eyal

Epilogue: Ethical Goals for the Future

Edmund G. Howe

The Journal of Clinical Ethics, Volume 25, Number 3, Fall 2014

What Should Careproviders Do When a Patient “Won’t Budge”?

Edmund G. Howe

Empirical Bioethics Research Is a Winner, But Bioethics Mission Creep Is a False Alarm

Anne Lederman Flamm and Eric Kodish

Power and Jurisdiction

John H. Evans

When Should We Not Respect a Patient’s Wish?

Stephen Napier

The Ethical and Clinical Importance of Measuring Consciousness in Continuously Sedated Patients

Kasper Raus, Martine de Laat, Eric Mortier, and Sigrid Sterckx

The Proportionate Value of Proportionality in Palliative Sedation

Jeffrey T. Berger

Family Members’ Requests to Extend Physiologic Support after Declaration of Brain Death: A Case Series Analysis and Proposed Guidelines for Clinical Management

Anne Lederman Flamm, Martin L. Smith, and Patricia A. Mayer

A Survey of Healthcare Industry Representatives’ Participation in Surgery: Some New Ethical Concerns

Jeffrey Bedard, Crystal Dea Moore, and Wayne Shelton

Legal Briefing: Brain Death and Total Brain Failure

Thaddeus Mason Pope

The Journal of Clinical Ethics, Volume 25, Number 2, Summer 2014

How to Help Patients and Families Make Better End-of-Life Decisions

Edmund G. Howe

Stumbled, Fumbled, Bumbled, Grumbled, and Humbled: Looking Back at the Future History of Clinical Ethics

Jeffrey T. Berger

A Protocol and Ethical Framework for the Distribution of Rationed Chemotherapy

Andrew Hantel

Detoxifying the Concept of Rationing

James Sabin

Uncharted Terrain: Preference Construction at the End of Life

Mary T. White

Aetna’s Compassionate Care Program and End-of-Life Decisions

Barak Krakauer, Joseph Agostini, and Randall Krakauer

Chinese Physicians’ Attitudes toward and Understanding of Medical Professionalism: Results of a National Survey

Linying Hu, Xiuyun Yin, Xiaolei Bao, and Jing-Bao Nie

Ethics Pocket Cards: An Educational Tool for Busy Clinicians

Rebecca L. Volpe, Benjamin H. Levi, George F. Blackall, and Michael J. Green

Legal Briefing: Informed Consent in the Clinical Context

Thaddeus Mason Pope and Melinda Hexum

Letter: Improving Patient-Doctor Communication about Risk and Choice in Obstetrics and Gynecology through Medical Education: A Call for Action

Macey L. Henderson, Jennifer Chevinsky, Rizwana Biviji-Sharma, and Kathryn Mills

The Journal of Clinical Ethics, Volume 25, Number 1, Spring 2014

Ethically Optimal Interventions with Impaired Patients

Edmund G. Howe

DNR and ECMO: A Paradox Worth Exploring

Ellen Cowen Meltzer, Natalia S. Ivascu, and Joseph J. Fins

Defending the Jurisdiction of the Clinical Ethicist

John H. Evans

Can the Social Sciences Save Bioethics?

Daniel Callahan

Clinical Ethicists: Consultants or Professionals?

William J. Winslade

Response to Callahan and Winslade

John H. Evans

The Desire to Die: Making Treatment Decisions for Suicidal Patients Who Have an Advance Directive

Erica K. Salter

Beyond Privacy: Benefits and Burdens of E-Health Technologies in Primary Care

Julie M. Aultman and Erin Dean

The Side-Effects of the “Facebook Effect”: Challenging Facebook’s “Organ Donor” Application

Adam M. Peña

Legal Briefing: Voluntarily Stopping Eating and Drinking

Thaddeus Mason Pope and Amanda West

2013

The Journal of Clinical Ethics, Volume 24, Number 4, Winter 2013

Families, Strangers, and Those Most Alone: Insights from Cultures, Including Our Own

Edmund G. Howe

On the Lingua Franca of Clinical Ethics

Joseph J. Fins

Surrogates and Extra-Familial Interests

Ralph Baergen and William Woodhouse

Familiar Interests and Strange Analogies: Baergen and Woodhouse on Extra-Familial Interests

James Lindemann Nelson

Challenges to Culturally Sensitive Care for Elderly Chinese Patients: A First-Generation Chinese-American Perspective

Karen C. Chan

Patients’ Experiences with Disclosure of a Large-Scale Adverse Event

Carolyn D. Prouty, Mary Beth Foglia, and Thomas H. Gallagher

Organ Donation among Undocumented Hispanic Immigrants: An Assessment of Knowledge and Attitudes

Joshua S. Baru, Brian P. Lucas, Carmen Martinez, and Daniel Brauner

Ethically Informed Pragmatic Conditions for Organ Donation after Cardiocirculatory Death: Could They Assist in Policy Development?

Jeffrey Kirby

Why We Should Continue to Worry about the Therapeutic Misconception

Larry R. Churchill, Nancy M.P. King, and Gail E. Henderson

Problems with the Consensus Definition of the Therapeutic Misconception

David S. Wendler

Modern Clinical Research: Guidelines for the Practicing Clinician or Source of Confusion?

Iliia Volkov

The Journal of Clinical Ethics, Volume 24, Number 3, Fall 2013

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

Potential Subjects’ Responses to an Ethics Questionnaire in a Phase I Study of Deep Brain Stimulation in Early Parkinson’s Disease

Stuart G. Finder, Mark J. Bliton, Chandler E. Gill, Thomas L. Davis, Peter E. Konrad, and P. David Charles

Regulatory Misconception Muddies the Ethical Waters: Challenges to a Qualitative Study

Kimberly M. Yee and Paul J. Ford

Fortitude and Community: Response to Yee and Ford

Stuart G. Finder and Mark J. Bliton

Stories and the Longitudinal Patient Relationship: What Can Clinical Ethics Consultants Learn from Palliative Care?

Wynne Morrison and Sabrina F. Derrington

The Rose of Sharon: What Is the Ideal Timing for Palliative Care Consultation versus Ethics Consultation?

Jennifer La Via and David Schiedermayer

HCEC Pearls and Pitfalls: Suggested Do’s and Don’t’s for Healthcare Ethics Consultants

Joseph A. Carrese and Members of the American Society for Bioethics and Humanities Clinical Ethics Consultation Affairs Standing Committee

Elective Delivery Before 39 Weeks’ Gestation: Reconciling Maternal, Fetal, and Family Interests in Challeng-

ing Circumstances

S. Van McCrary, Shetal I. Shah, Adriann Combs, and J. Gerald Quirk

Quality of Life and Elective C-Sections: Defining Limits to Maternal and Family Interests

Jeffrey P. Spike

Which Patient Groups Should Be Asked to Participate in First-in-Human Trials of Stem-Cell-Based Therapies?

Kristina Hug and Göran Hermerén

Time to Stop Worrying about the Therapeutic Misconception

David S. Wendler

Letter: Providing More Reasons for Individuals to Register as Organ Donors

Macey Leigh Henderson

The Journal of Clinical Ethics, Volume 23, Number 2, Summer 2012

How Should Careproviders Respond to Patients' Requests That May Be Refused?

Edmund G. Howe

Living Donation and Cosmetic Surgery: A Double Standard in Medical Ethics?

Giuliano Testa, Erica Carlisle, Mary Simmerling, and Peter Angelos

Different Standards Are Not Double Standards: All Elective Surgical Patients Are Not Alike

Lainie Friedman Ross, Walter Glannon, Lawrence J. Gottlieb, and J. Richard Thistlethwaite, Jr.

The Effect of Completing a Surrogacy Information and Decision-Making Tool upon Admission to an Intensive Care Unit on Length of Stay and Charges

Carol W. Hatler, Charlene Grove, Stephanie Strickland, Starr Barron, and Bruce D. White

Training in Clinical Ethics: Launching the Clinical Ethics Immersion Course at the Center for Ethics at the Washington Hospital Center

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

Training in Clinical Ethics Consultation: The Washington Hospital Center Course

Jeffrey P. Spike

Truly Intensive Clinical Ethics Immersion at the Washington Hospital Center

Christopher L. Church and Thalia Arawi

Credentialing the Clinical Ethics Consultant: An Academic Medical Center Affirms Professionalism and Practice

Cathleen A. Acres, Kenneth Prager, George E. Hardart, and Joseph J. Fins

Ethics Been Very Good to Us

Giles R. Scofield

Inside Baseball and Ethics Consultation: A Comment on "Ethics Been Very Good to Us"

Norman Quist

Credentialing and Certification in Ethics Consultation: Lessons from Palliative Care

David Schiedermayer and John La Puma

Always on Call: Thoughts from a Neophyte Physician

Jonathan R. Scarff and David W. Musick

Legal Briefing: The Unbefriended: Making Healthcare Decisions for Patients Without Surrogates (Part 2)

Thaddeus Mason Pope and Tanya Sellers

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

[III-Placed Democracy: Ethics Consultations and the Moral Status of Voting](#)

Autumn M. Fiester

[Commentary on Fiester's "III-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

Perspective: The Findings of the Dartmouth Atlas Project: A Challenge to Clinical and Ethical Excellence in End-of-Life Care

John J. Mitchell, Jr.

Legal Briefing: Futile or Non-Beneficial Treatment

Thaddeus Mason Pope

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 Antommara 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

Thaddeus Mason Pope and Mitchell F. Palazzo

The Journal of Clinical Ethics, Volume 21, Number 3, Fall 2010

All Careproviders Need More Opportunities to Share their Ethical Concerns with Others

Edmund G. Howe

The Rational Choice Model in Family Decision Making at the End of Life

Alison Karasz, Galit Sacajiu, Misha Kogan, and Liza Watkins

“Broken Covenant”: Healthcare Aides’ “Experience of the Ethical” in Caring for Dying Seniors in a Personal Care Home

Susan McClement, Michelle Lobchuk, Harvey Max Chochinov, and Ruth Dean

Characterizing the Risk in Pediatric Research: An Ethical Examination of the Federal Regulations

Maynard Dyson and Kayhan Parsi

Protection of Children in Research: Beyond Pediatric Risk Levels: The Emergence of the Research Subject Advocate

Tomas J. Silber

Infant Heart Transplantation after Cardiac Death: Ethical and Legal Problems

Michael Potts, Paul A. Byrne, and David W. Evans

Dying But Not Killing: Donation after Cardiac Death Donors and the Recovery of Vital Organs

Armand H. Matheny Antommara

Building *Esprit de Corps*: Learning to Better Navigate between “My” Patient and “Our” Patient

Evan G. DeRenzo and Jack Schwartz

Esprit de Corps: The Possibility for the Best Care a Hospital Can Provide

Norman Quist

Legal Briefing: Organ Donation and Allocation

Thaddeus Mason Pope

The Ambiguous Effects of Tort Law on Bioethics: The Case of Doctor-Patient Communication

Dena S. Davis

Letter: Business Interests versus Informed Consent

Duraiyah Thangathurai and Peter Roffey

The Journal of Clinical Ethics, Volume 21, Number 2, Summer 2010

Sliding “Off” the Sliding Scale: Allowing Hope, Determining Capacity, and Providing Meaning When an Illness Is Becoming Worse But a Treatment May Help

Edmund G. Howe

Deep Brain Stimulation, Ethics, and Society

Emily Bell and Eric Racine

Consent to Deep Brain Stimulation for Neurological and Psychiatric Disorders

Walter Glannon

Hope and Patients’ Expectations in Deep Brain Stimulation: Healthcare Providers’ Perspectives and Approaches

Emily Bell, Bruce Maxwell, Mary Pat McAndrews, Abbas Sadikot, and Eric Racine

Conflicts of Interest in Deep Brain Stimulation Research and the Ethics of Transparency

Joseph J. Fins and Nicholas D. Schiff

Philosophical Reflections on Narrative and Deep Brain Stimulation

Marya Schechtman

Consenting to the Ineffable: The Problem of Neuromodulation and Altered Consciousness

T. Forcht Dagi

Infants and Children with Hearing Loss Need Early Language Access

Poorna Kushalnagar, Gaurav Mathur, Christopher J. Moreland, Donna Jo Napoli, Wendy Osterling, Carol Padden, and Christian Rathmann

In Addition to Benefits and Harms: The Relevance of the Political

Barbara Russell

Language, Identity, and Belonging: Deaf Cultural and Narrative Perspectives

Rebecca Garden

Legal Briefing: Conscience Clauses and Conscientious Refusal

Thaddeus Mason Pope

The Journal of Clinical Ethics, Volume 21, Number 1, Spring 2010

“Third Generation” Ethics: What Careproviders Should Do Before They Do Ethics

Edmund G. Howe

Toward Competency-Based Certification of Clinical Ethics Consultants: A Four-Step Process

Martin L. Smith, Richard R. Sharp, Kathryn Weise, and Eric Kodish

Accounting for Vulnerability to Illness and Social Disadvantage in Pandemic Critical Care Triage

Chris Kaposy

A Physician’s Role Following a Breach of Electronic Health Information

Daniel Kim, Kristin Schleiter, Bette-Jane Crigger, John W. McMahon, Regina M. Benjamin, and Sharon P. Douglas,

for the Council on Ethical and Judicial Affairs, American Medical Association

Practicing Preventive Ethics, Protecting Patients: Challenges of the Electronic Health Record

Valerie B. Satkoske and Lisa S. Parker

Breaches of Health Information: Are Electronic Records Different from Paper Records?

Robert M. Sade

Breach Notification and the Law

Sharona Hoffman

Therapeutic Privilege

S. Van McCrary

Patients’ Expressed and Unexpressed Needs for Information for Informed Consent

Rebecca L. Volpe

Reasoning in the Capacity to Make Medical Decisions: The Consideration of Values

Michele J. Karel, Ronald J. Gurrera, Bret Hicken, and Jennifer Moyer

Legal Briefing: Informed Consent

Thaddeus Mason Pope

Legal Update

Thaddeus Mason Pope

Correspondence: Where Is the Voice of the Man the Child Will Become?

John V. Geisheker

2009

The Journal of Clinical Ethics, Volume 20, Number 4, Winter 2009

Should Careproviders Go Ethically "Off Label"?

Edmund G. Howe

The Just Distance: Narrative, Singularity, and Relationality as the Source of a New Bioethical Principle

Paul Qualtere-Burcher

Patients Don't Consider End-Stage Medical Conditions the Same as Being Permanently Unconscious When Filling Out a Living Will

Kelli M. Manippo and Jack L. DePriest

Variability in the Pediatric Intensivists' Threshold for Withdrawal/Limitation of Life Support as Perceived by Bedside Nurses

Colleen Gresiuk and Ari Joffe

Variability in the Limitation of Life Support in Pediatrics Continues

Anita J. Catlin

Moral Distress, Moral Residue, and the Crescendo Effect

Elizabeth Gingell Epstein and Ann Baile Hamric

A Quality Improvement Approach to Improving Informed Consent Practices in Pediatric Research

Mary Beth Foglia, Halle Showalter Salas, and Douglas S. Diekema

A Descriptive and Moral Evaluation of Providing Informal Medical Care to One's Own Children

Jennifer K. Walter, Elizabeth Pappano, and Lainie Friedman Ross

Legal Briefing: Advance Care Planning

Thaddeus Mason Pope

The Journal of Clinical Ethics, Volume 20, Number 3, Fall 2009

Beyond the State of the Art in Ethics Consultation

Edmund G. Howe

Physician Orders to Supplement Advance Directives: Rescuing Patient Autonomy

Ronald B. Miller

Integrating Ethics and Patient Safety: The Role of Ethics Consultants in Quality Improvement

Douglas J. Opel, Dena Brownstein, Douglas S. Diekema, Benjamin S. Wilfond, and Robert A. Pearlman

When Humor in the Hospital Is No Laughing Matter

Julie M. Aultman

Non-Adherence to Instructions to Cancel a Cycle in a Patient Overstimulated with Gonadotropins in a Planned Intrauterine Insemination Cycle

Awoniyi Olumide Awonuga, Mauro H. Schenone, Mazen E. Abdallah, Frank D. Yelian, Michael P. Diamond, and Elizabeth E. Puscheck

Preventive Ethics and Subsequent Care of Patients Self-Administering Ovarian Stimulation for the Management of Infertility

Frank A. Chervenak and Laurence B. McCullough

Boldt v. Boldt

Dena S. Davis

Where Is the Child? Circumcision and Custody in *Boldt v. Boldt*

Janet L. Dolgin

***Boldt v. Boldt*: A Pediatric Ethics Perspective**

Douglas S. Diekema

Circumcision, Conversion, and Deciding for a Minor: Some Jewish Perspectives

Noam Zohar

The Diagnosis of Dying

George F. Davis

As Prickly as a Porcupine: Reflections on a Systems-Based "Experiential Sculpting Exercise"

Thomas C. Foreman
Substituted Judgment Surrogates Have Not Been Shown to Make Inaccurate Substituted Judgments
Linus Broström and Mats Johansson
Legal Briefing: Medical Futility and Assisted Suicide
Thaddeus Mason Pope
Legal Update
Thaddeus Mason Pope

The Journal of Clinical Ethics, Volume 20, Number 2, Summer 2009

Paradigms for Choosing Paradigms

Edmund G. Howe

The 10-Year Experience of Oregon's Death with Dignity Act: 1998-2007

Katrina Hedberg, David Hopkins, Richard Leman, and Melvin Kohn

Putting Oregon's Death with Dignity Act in Perspective: Characteristics of Decedents Who Did Not Participate

Katrina Hedberg and Susan Tolle

Must Physicians Report Impaired Driving? Rethinking a Duty on a Collision Course with Itself

Jacob Appel

Is There Coercion or Undue Inducement to Participate in Health Research in Developing Countries? An Example from Rakai, Uganda

Fred Nalugoda, Jennifer Wagman, Mohammed Kiddugavu, Noah Kiwanuka, Elizabeth Garrett, Ron H. Gray, David Serwadda, Maria J. Wawer, and Ezekiel J. Emanuel

Patients' Perceptions on Healthcare Decision Making in Rural India: A Qualitative Study and Ethical Analysis

Sridevi Seetharam and Renzo Zanotti

Patients' Concerns for Family Burden: A Nonconforming Preference in Standards for Surrogate Decision Making

Jeffrey T. Berger

Berger on Burdens

James Lindemann Nelson

Commentary on "Patients' Concerns for Family Burden"

Carol Levine

Commentary on Berger's "Patients' Concerns for Family Burden"

Evan G. DeRenzo

When I Lay My Burden Down: Commentary on Berger

Arthur R. Derse

What Really Is in a Child's Best Interest? Toward a More Precise Picture of the Interests of Children

Janet Malek

Accommodating Religious and Moral Objections to Neurological Death

Robert S. Olick, Eli A. Braun, and Joel Potash

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 Degrin

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. Yeatermeyer

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

Ethical Challenges of Research on and Care for Victims of Intimate Partner Violence

Jennifer Wagman, Leilani Francisco, Nancy Glass, Phyllis W. Sharps, and Jacquelyn C. Campbell

Legal Trends in Bioethics

Sigrid Fry-Revere, Alison Mathey, Nathaniel B. Revere, Deborah Chen, and Devon Zebrovius

The Journal of Clinical Ethics, Volume 19, Number 3, Fall 2008

Three Keys to Treating Inmates and their Application in Ethics Consultation

Edmund G. Howe and Chelsea Howe

A Qualitative Report of Dual Palliative Care/Ethics Consultations: Intersecting Dilemmas and Paradigmatic Cases

Julie W. Childers, Richard Demme, Jane Greenlaw, Deborah A. King, and Timothy Quill

Dignity Matters: Advance Care Planning for People Experiencing Homelessness

Dianne M. Bartels, Nancy Ulvestad, Edward Ratner, Melanie Wall, Mari M. Uutala, and John Song

Using Family Members as Interpreters in the Clinical Setting

Anita Ho

Medical Ethics in Correctional Healthcare: An International Comparison of Guidelines

Bernice S. Elger

When Prisoners Are Patients

Sharon Douglas and Susan Dorr Goold

Commentary on Elger’s “Medical Ethics in Correctional Healthcare”

Robert W. Keisling

Commentary on Elger's "Medical Ethics in Correctional Healthcare"

Joel A. Dvoskin

Physicians, Mass Incarceration, and Medical Ethics

Scott A. Allen

Cruel and Unusual Punishment: Distinguishing Distributive and Retributive Justice

Felicia Cohn

Medical Ethics and Competence for Execution

David M. Adams

Response to Douglas and Goold

Bernice S. Elger

Legal Trends in Bioethics

Sigrid Fry-Revere, Nathaniel B. Revere, Deborah Chen, and Sheeba Koshy

Letters: Response to Stump, Klugman, and Thornton, "Last Hours of Life: Encouraging End-of-Life Conversations"

Henry S. Perkins, Josie D. Cortez, and Helen P. Hazuda

The Journal of Clinical Ethics, Volume 19, Number 2, Summer 2008

Red Towels: Maximizing the Care of Patients Who Are Dying

Edmund G. Howe

Rethinking the Ethical Framework for Surrogate Decision Making: A Qualitative Study of Physicians

Alexia M. Torke, Mary Simmerling, Mark Siegler, Danit Kaya, and G. Caleb Alexander

Deciding in the Best Interest of Clients with Dementia: The Experience of Public Guardians

Holly A. Taylor, Betty S. Black, and Peter V. Rabins

A Forced Choice: The Value of Requiring Advance Directives

Elmer D. Abbo and Angelo E. Volandes

KidneyMatch.com: The Ethics of Solicited Organ Donations

Richard H. Dees and Eric A. Singer

Last Hours of Life: Encouraging End-of-Life Conversations

Benjamin F. Stump, Craig M. Klugman, and Barbara Thornton

Spiritual Issues as an Essential Element of Quality Palliative Care: A Commentary

Christina M. Puchalski

End-of-Life Care: Conversations and Opportunities

Margaret M. Mahon

Commentary on "Last Hours of Life: Encouraging End-of-Life Conversations"

Craig D. Blinderman

Legal Trends in Bioethics

Sigrid Fry-Revere, Sheeba Koshy, Greyson C. Ruback, Rex L. Wessel, and Nathaniel B. Revere

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 Elliott 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 Elliott and Olver

Jaklin Elliott 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

Harvard Medical School Public Forum: Insuring the Uninsured: Does Massachusetts Have the Right Model? 17 May 2007

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

Julieta Bleichmar Holman and David H. Brendel

A Letter from the Children

Interview of the Children of the Patient “Margaret”

Medicating “Margaret”

Coleen Reid

Palliative Care for “Margaret”

Rosemary Ryan

“Margaret’s” Children Remember

Interview by Christine Mitchell

Attention to Caregivers and Hope: Overlooked Aspects of Ethics Consultation

Ruth B. Purtilo

Suffering and Advanced Dementia: Diagnostic and Treatment Challenges and Questions about Palliative Sedation

Jeffrey T. Berger

What Is False Hope?

Daniel K. Sokol

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”

Iliia 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 Bell-
ing

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 Defibril-
lators: 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

2005

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

Families and Futility: Forestalling Demands for Futile Treatment

John Hardwig

Practicing Physicians and the Role of Family Surrogate Decision Making

George E. Hardart and Robert D. Truog

The State of Research Ethics: A Tribute to John C. Fletcher

Franklin G. Miller and Jonathan D. Moreno

Informed Consent: An End or a Means? A Response to Miller and Moreno

Robert D. Truog

Informed Consent and the Therapeutic Misconception: Clarifying the Challenge

Gopal Sreenivasan

Response to F.G. Miller and J.D. Moreno, "The State of Research Ethics: A Tribute to John C. Fletcher"

H.M. Evans

Informed Consent and the Ethics of Clinical Research: Reply to Commentaries

Franklin G. Miller and Jonathan D. Moreno

The Journal of Clinical Ethics, Volume 16, Number 3, Fall 2005

When Should Ethics Consultants Risk Giving their Personal Views?

Edmund G. Howe

Specters, Traces, and Regret in Ethics Consultation

Paul J. Ford and Denise M. Dudzinski

"Amputate My Arm Please — I Don't Want It Anymore"

Denise M. Dudzinski

Helping Staff Help a "Hateful" Patient: The Case of TJ

Joy D. Skeel and Kristi S. Williams

Misjudging Needs: A Messy Spiral of Complexity

Paul J. Ford

The Sound of Chains: A Tragedy

Jeffrey Spike

“But How Can We Choose?”

Richard M. Zaner

Ethics First Aid: Reframing the Role of “Principlism” in Clinical Ethics Education and Practice

Daryl Pullman

Confidence and Knowledge of Medical Ethics among Interns Entering Residency in Different Specialties

Daniel P. Sulmasy, Robert E. Ferris, and Wayne A. Ury

In Defense of Tongue Splitting

Jacob M. Appel

Cochlear Implants in Children: Ethics, Informed Consent, and Parental Decision Making

Abby L. Berg, Alice Herb, and Marsha Hurst

Dying While Homeless: Is It a Concern When Life Itself Is Such a Struggle?

John Song, Edward R. Ratner, and Dianne M. Bartels

Raging Against the Night: Dying Homeless and Alone

James J. O’Connell

Ethical Issues Encountered by Clinical Researchers

Gordon DuVal, Gary Gensler, and Marion Danis

The Journal of Clinical Ethics, Volume 16, Number 2, Summer 2005

Why Are They Boxing Us in Like This?

Edmund G. Howe

Do Elderly Persons’ Concerns for Family Burden Influence their Preferences for Future Participation in Dementia Research?

Jeffrey T. Berger and S. Deborah Majerovitz

The Politics of Care: Dementia and Accounting versus Caring for Mortification

Alice Stollmeyer

Deciding for Others at the End of Life: Storytelling and Moral Agency

Mark Yarborough

Emancipation, Capacity, and the Difference Between Law and Ethics

Evan G. DeRenzo, Philip Panzarella, Steve Selinger, and Jack Schwartz

Proactive Bioethics Screening: A Prelude to Bioethics Consultation

Leon Morgenstern

Readability Level of HIPAA Notices of Privacy Practices Used by Physical Rehabilitation Centers

Steven Walfish and Sean P. Sharp

Physicians, Medical Ethics, and Capital Punishment

Timothy F. Murphy

Saying “Good-Bye”: Ethical Issues in the Stewardship of Bed Spaces

Katrina A. Bramstedt and Paul L. Schneider

A Response to Shalowitz and Emanuel

Gerrit Kimsma, Keith L. Obstein, and Tod Chambers

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

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

Cadaver Dissection and the Limits of Simulation

Bryan R. Warnick

Comment on Ganzini and Dobscha regarding Comparing Rates of Physician-Assisted Suicide in Oregon with that of Other States

Kenneth R. Stevens, Jr., and William L. Toffler

Response to Stevens and Toffler regarding Rates of Physician-Assisted Suicide in Oregon

Linda Ganzini and Steven Dobscha

The Journal of Clinical Ethics, Volume 15, Number 3, Fall 2004

Some New Paradigms for Ethics Consultants

Edmund G. Howe

Practicing Euthanasia: The Perspective of Physicians

Keith L. Obstein, Gerrit Kimsma, and Tod Chambers

Euthanasia and Physician-Assisted Suicide: Implications for Physicians

David Shalowitz and Ezekiel Emanuel

Do Potential Recipients of Cardiopulmonary Resuscitation Want their Family Members to Attend? A Survey of Public Preferences

Jeffrey T. Berger, Gerald Brody, Lawrence Eisenstein, and Simcha Pollack

Should a Loved One Be Allowed in the Resuscitation Room? The Times They Are A-Changin'

Guy Micco

Golden Rule Reasoning in Clinical Medicine: Theoretical and Empirical Aspects

James N. Kirkpatrick and Mary B. Mahowald

Geriatric Assent

Victor Molinari, Laurence B. McCollough, Richard Workman, and John Coverdale

Deciding How to Decide: What Processes Do Patients Use When Making Medical Decisions?

Maria J. Silveira, Lorna Rhodes, and Chris Feudtner

Withdrawing Ventilator Support for a Home-Based Amyotrophic Lateral Sclerosis Patient

Judith Kennedy Schwarz and Maura L. Del Bene

Baby Michael's Short Story: Infant Nutrition and Hydration Discussed with the Ethics Committee—Twice

Christine Mitchell and Robert D. Truog

Decisions for a Baby in Foster Care

Nedda Hobbs

The Experience of a Community Representative on an Ethics Consult Team

Michelle Mello

Excerpts from the Ethics Consult Report: MT

Christine Mitchell, Robert D. Truog, and the Ethics Advisory Committee at Children's Hospital Boston

Withdrawal of Medically Administered Nutrition and Hydration: The Role of Benefits and Burdens, and of Parents and Ethics Committees

Judith A. Johnson

The Journal of Clinical Ethics, Volume 15, Number 2, Summer 2004

Criteria for Deceit

Edmund G. Howe

Characteristics and Proportion of Dying Oregonians Who Personally Consider Physician-Assisted Suicide

Susan W. Tolle, Virginia P. Tilden, Linda L. Drach, Erik K. Fromme, Nancy A. Perrin, and Katrina Hedberg

Clarifying Distinctions between Contemplating and Completing Physician-Assisted Suicide

Linda Ganzini and Steven K. Dobscha

The Role of the Family in Resolving Bioethical Dilemmas: Clinical Insights from a Family Systems Perspective

David B. Seaburn, Susan H. McDaniel, Scott Kim, and Daisy Bassen

On "The Role of the Family in Resolving Bioethical Dilemmas: Clinical Insights from a Family Systems Perspective"

James Lindemann Nelson

Falling into Line: The Impact of Utilization Review Hassles on Physicians' Adherence to Insurance Contracts

Saul J. Weiner, Jonathan B. VanGeest, Matthew K. Wynia, Deborah S. Cummins, and Ira B. Wilson

Chemical Terrorism and the Ethics of Decontamination

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 Bestiality

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. Deatrack, 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. Troug, 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 13, Number 3, Fall 2002

Allowing Patients to Find Meaning Where They Can

Edmund G. Howe

A Mediation/Medical Advisory Panel Model for Resolving Disputes about End-of-Life Care

Susan Fox Buchanan, Jeanne M. Desrochers, Desmond Brian Henry, George Thomassen, and Paul H. Barrett, Jr.

Extramural Ethics Consultation: Reflections on the Mediation/Medical Advisory Panel Model and a Further Proposal

Ronald B. Miller

Perceptions of Case Managers' Professional Obligations in a Tertiary Acute Care Hospital

Anita J. Tarzian and Henry J. Silverman

Irene's Story

Christine Mitchell and Robert Truog

Irene's View

An Interview by Sigal Klipstein

Irene's Physician's View

An Interview by Sigal Klipstein

The Social Worker's View

An Interview by Stephen O'Neill

An Ethicist's View

An Interview by Lachlan Farrow

New Reproductive Options and the Incest Taboo

Sigal Klipstein

Moving from Moral Judgment to Ethical Reasoning

Lachlan Farrow

Legal Trends in Bioethics

Anne L. Flamm

The Journal of Clinical Ethics, Volume 13, Number 2, Summer 2002

Degloved Patients, Torture Victims, and "Bi-Phasic" Ethics

Edmund G. Howe

Caring for Patients within a Budget: Physicians' Tales from the Front Lines of Managed Care

Steven D. Pearson, James E. Sabin, and Tracey Hyams

The Moral Irrelevance of Proximity to Death

Lynn A. Jansen

Secrecy, Integrity, Agency: Nurses and Genetic Terminations

Catherine Swanson, Deidre Robert, and Elisabeth Boetzkes

Cases from the Harvard Ethics Consortium

Christine Mitchell and Robert Truog, Editors

Jamie's Story: The Man who Lost his Face

Pamela DiMack

Epilogue

Christine Mitchell

The Moral of the Story

Christine Mitchell

Assessing the Competence Assessment Tool

Ralph Baergen

In Response to "The Development and Piloting of a Capacity Assessment Tool"

Helen M. Sharp and Karen Mills

Legal Trends in Bioethics

Anne L. Flamm

The Journal of Clinical Ethics, Volume 13, Number 1, Spring 2002

The Paradox of Paternalism and Three Steps Careproviders Can Take to Help All Patients

Edmund G. Howe

An Assessment of Ethical Climate in Three Healthcare Organizations

Carolyn Ells, Jocelyn Downie, and Nuala Kenny

The Healthcare Organization: New Efficiency Endeavors and the Organization Ethics Program

Ann E. Mills and Edward M. Spencer

Fair Distribution and Patients Who Receive More than One Organ Transplant

Barbara J. Russell

Case Reports from the Harvard Ethics Consortium

Christine Mitchell and Robert Truog

Carl Schneider's *The Practice of Autonomy: A Précis*

James Lindemann Nelson

Patient Autonomy: Imperfect, Insufficient, but Still Quite Necessary

Lainie Friedman Ross

The Alchemy of Informed Consent

Richard T. Hull

Good-Bye to All that . . . Autonomy

Bruce Jennings

***The Practice of Autonomy* and the Practice of Bioethics**

Carl E. Schneider

Reluctant Patients: Autonomy and Delegating Medical Decisions

Jodi Halpern

Legal Trends in Bioethics

Anne L. Flamm

2001

The Journal of Clinical Ethics, Volume 12, Number 4, Winter 2001

Unicorns, Carravaggio, and Fetal Surgery

Edmund G. Howe

How Open-Uterine Fetal Repair of Spina Bifida Illuminates the Moral Complexity of Ethics Consultation and Patients' Decision Making

Mark J. Bliton

Genetic Testing for Hereditary Disease: Attending to Relational Responsibility

Michael M. Burgess

Comment on Burgess

Charles MacKay

Multi-Cultural Considerations and the American College of Physicians Ethics Manual

Jeffrey T. Berger

Moral Obligations to Families When There Is a Sudden Death

David Bishai and Andrew Siegel

An Ethical Voice in the Silence of Aphasia: Judging Understanding and Consent in People with Aphasia

A. Braunack-Mayer

Implications of Impaired Executive Control Functions for Patient Autonomy and Surrogate Decision Making

Laurence B. McCullough, Victor Molinar, and Richard H. Workman

Shared Decision Making in Dialysis: A New Clinical Practice Guideline to Assist with Dialysis-Related Ethics Consultations

Alvin H. Moss

Legal Trends in Bioethics

Anne L. Flamm

The Journal of Clinical Ethics, Volume 12, Number 3, Fall 2001

Helping Infants by Seeing the Invisible

Edmund G. Howe

Introduction to Ethics in Neonatology

Anita Catlin

From the Johns Hopkins Baby to Baby Miller: What Have We Learned from Four Decades of Reflection on Neonatal Cases?

John J. Paris, Jeffrey Ferranti, and Frank Reardon

Reflections on Neonatal Intensive Care in the U.S.: Limited Success or Success with Limits?

Brian S. Carter and Mildred Stahlman

Infertility Treatment and Neonatal Care: The Ethical Obligation to Transcend Specialty Practice in the Interest of Reducing Multiple Births

Gladys B. White and Steven R. Leuthner

Uncharted Terrain: Dilemmas Born in the NICU Grow Up in the PICU

Karen Smith and Mary Ellen Uphoff

Making Lemonade: A Parent's View of "Quality of Life" Studies

Helen Harrison

Creation and Use of *You Are Not Alone*, a Video for Parents Facing Difficult Decisions

Peter Hulac

Crisis within Crisis: Recommendations for Defining, Preventing, and Coping with Stressors in the NICU

Brad H. Reddick, Elizabeth Catlin, and Michael Jellinek

The Oregon Health Plan and the Ethics of Care for Marginally Viable Newborns

Mark J. Merkens and Michael J. Garland

For Crying Out Loud: The Ethical Treatment of Infants' Pain

Linda Franck and Linda Lefrak

International Practices in Neonatology

Edmund G. Howe

The European Union Collaborative Project on Ethical Decision Making in Neonatal Intensive Care (EURON-IC): Findings from 11 Countries

Marina Cuttini and the Euronic Study Group

Canada, the U.S., and the NICU: Cultural Differences and Ethical Consequences

Eike-Henner W. Kluge

Neonatal Issues in Hungary

Bela Blasszauer, Karoly Schultz, and Karoly Adamovich

Ethics and Neonatology in Israel

Ehud Zmora

Neonatal Medicine in Norway

Berit Støre Brinchmann

Ethical Dilemmas in Swedish Neonatal Intensive Care

Mats Eriksson and Magnus Lindroth

Neonatology and Ethics: A Word from Turkey

Hicran Cavusoglu

Creation of a Neonatal End-of-Life Palliative-Care Protocol

Anita Catlin and Brian S. Carter

Legal Trends in Bioethics

Heidi P. Forster and Seema Shah

The Journal of Clinical Ethics, Volume 12, Number 2, Summer 2001

To Teach Ethics Better—Lie

Edmund G. Howe

Medical Student Involvement in Patient Care

Karine Morin, Herbert Rakatansky, Frank A. Riddick, Jr., Leonard J. Morse, John M. O'Bannon, III, Michael S. Goldrich, Priscilla Ray, Matthew Weiss, Robert M. Sade, and Monique A. Spillman

Comment: For Healthcare Providers, Just Discerning What's Right Isn't Enough

Bruce E. Zawacki

Comment: Dealing Ethically with an Inevitable Tension

Martha Montello

Narrative, Thick Description, and Bioethics: Cases, Stories, and Simone de Beauvoir's "A Very Easy Death"

Leigh Turner

Comment: Toward Thick Reading

Tod Chambers

Informing a Recipient of Blood from a Donor Who Subsequently Developed Creutzfeldt-Jakob Disease: Characteristics of Information that Warrants Its Disclosure

David Steinberg

Comment: Dilemmas of Dementia

Roger Y. Dodd

Comment: Limiting Toxic Information

Edmund G. Howe

Disclosing the Diagnosis of HIV in Pediatrics

Erin Flanagan-Klygis, Lainie Friedman Ross, John Lantos, Joel Frader, and Ram Yogev

Comment: Disclosing a Diagnosis of HIV to Children: Providing the Best Possible Care

Steven Hirschfeld

Preliminary Study of a "Values History" Advance Directive Interview in a Pediatric HIV Clinic

Lawrence S. Wissow, Nancy Hutton, and Nancy Kass

Comment: Getting the Most Value Out of a Values History

O.J. Sahler

Legal Trends in Bioethics

Heidi P. Forster

The Journal of Clinical Ethics, Volume 12, Number 1, Spring 2001

How to Determine Competency

Edmund G. Howe

The Development and Piloting of a Capacity Assessment Tool

Maria Torroella Carney, Judith Neugroschl, R. Sean Morrison, Deborah Marin, and Albert L. Siu

Too Much Ethics, Not Enough Medicine: Clarifying the Role of Clinical Expertise for the Clinical Ethics Consultant

Clarence H. Braddock III and Mark R. Tonelli

Referral and Decision Making among Advanced Cancer Patients Participating in Phase I Trials at a Single Institution

Elisa J. Gordon and Christopher K. Daugherty

The Use of E-Mail in Clinical Ethics Case Consultation

Lisa Anderson Shaw

Active Voluntary Euthanasia, Terminal Sedation, and Assisted Suicide

Candace Cummins Gauthier

Physician-Assisted Suicide or Voluntary Euthanasia: A Meaningless Distinction for Practicing Physicians?

Harold I. Schwartz, Leslie Curry, Karen Blank, and Cindy Gruman

Telemedicine and End-of-Life Care: What's Wrong with This Picture?

Peter J. Pronovost and Michael A. Williams

Telethics and the Virtual Intensivist—A Comment on Pronovost and Williams

Tom Tomlinson

Should Ethics Consultants Use Telemedicine? A Comment on Pronovost and Williams

Edmund G. Howe

Legal Trends in Bioethics

Heidi P. Forster

2000

The Journal of Clinical Ethics, Volume 11, Number 4, Winter 2000

Improving Treatment for Patients Who Are Elderly and Have Dementia

Edmund G. Howe

Ethical Challenges Posed by Dementia and Driving

Jeffrey T. Berger and Fred Rosner

Sexuality and Intimacy in the Nursing Home: A Romantic Couple of Mixed Cognitive Capacities

Jeffrey T. Berger

Commentary on “Sexuality and Intimacy in the Nursing Home”

Stephen G. Post

The Myth of Home and the Medicalization of the Care of the Elderly

Jacqueline J. Glover and Anne Harman

Physicians’ Responses to Clinical Scenarios Involving Life-Threatening Illness Vary by Patients’ Age

Marie F. Johnson and Andrew M. Kramer

Commentary: Medical Decision Making Based on Chronological Age—Cause for Concern

Win Tadd and Antony Bayer

Actual and Perceived Stability of Preferences for Life-Sustaining Treatment

R. Mitchell Gready, Peter H. Ditto, Joseph H. Danks, Kristen M. Coppola, Lisa K. Lockhart, and William D. Smucker

Are Non-Heart-Beating Cadaver Donors Acceptable to the Public?

Deborah L. Seltzer, Robert M. Arnold, and Laura A. Siminoff

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

The Journal of Clinical Ethics, Volume 11, Number 3, Fall 2000

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

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. Boisauhin and Michele A. Carter

Death and Remembrance: Addressing the Costs of Learning Anatomy through the Memorialization of Donors

Kathleen Marie Dixon

Attitudes of Healthcare Professionals Toward Clinical Decisions in Palliative Care: A Cross-Cultural Comparison

Raymond Voltz, Akira Akabayashi, Carol Reese, Gen Ohi, and Hans-Martin Sass

Rational Suicide and Predictive Genetic Testing

Dena S. Davis

Organ Donation and the Anguish of Failure

John Portmann

The Limits of Reproductive Technology: Who Decides?

Ellen S. Agard and Edward E. Wallach

The Need for Original Ethical Analyses for Women

Edmund G. Howe

Legal Trends in Bioethics

Dena S. Davis

The Journal of Clinical Ethics, Volume 10, Number 3, Fall 1999

On Our Way to Integrated Bioethics: Clinical/Organizational/Communal

Robert Lyman Potter

The Postmodern Prescription: An Antidote to Hard Boundaries and Closed Systems in Healthcare Organizations

Robert J. Olson

Organizational Ethics: Creating Structural and Cultural Change in Healthcare Organizations

David C. Blake

Making the Most of Disequilibrium: Bridging the Gap Between Clinical and Organizational Ethics in a Newly Merged Healthcare Organization

Catherine Myser, Patricia Donehower, and Cathy Frank

Integrated Ethics: Synecdoche in Healthcare

Catherine R. Seeley and Sara L. Goldberger

All in the Family—Siblings But Not Twins: The Relationship of Clinical and Organizational Ethics Analysis

Norma J. Hirsch

Linking Professional and Economic Values in Healthcare Organizations

Leslie N. Ray, Jerry Goodstein, and Michael Garland

Actively Engaging Organizational Ethics in Healthcare: Four Essential Elements

Jerry D. Goodstein and Bridget Carney

Confidentiality as an Organizational Ethics Issue

Robert Hall

Organizational Ethics and Sentinel Events: Doing the Right Thing When the Worst Thing Happens

Kristin M. Johnson and Kathleen Roebuck-Colgan

The "Impossible" Patient: Organizational Response to a Clinical Problem

Pamela S. Harris, Martha Duermeyer, Christopher Ehly, Sonja Hartig-Toth, Sharon Hayes, Lynaia Holsapple, and Daniel Peters

Legal Trends in Bioethics

Heidi P. Forster

The Journal of Clinical Ethics, Volume 10, Number 2, Summer 1999

“Sacred” Research Practices We May Want to Change

Edmund G. Howe

Assessing Quality of Care: New Twists from Managed Care

E. Haavi Morreim

Why Should We Include Women and Minorities in Randomized Controlled Trials?

Charles Weijer and Robert A. Crouch

The Epidemiology of Bioethics

Michael D. Fetters and Howard Brody

Why Don't Physicians Use Ethics Consultation?

Louise Davies and Leonard D. Hudson

Family Decision Making for End-of-Life Treatment: The SUPPORT Nurse Narratives

Elizabeth F. Hiltunen, Cynthia Medich, Susan Chase, Lynn Peterson, and Lachlan Farrow

Community Assessment and Education in Preventive Clinical Ethics

Marc Tunzi and Mary Croughan-Minihane

A Pedophilic Physician: The Conflicting Obligations

John Song and Peter Terry

Commentary on “A Pedophilic Physician”: Should Careproviders Deceive Some Patients to Benefit Others?

Edmund G. Howe

Legal Trends in Bioethics

Heidi P. Forster

Letters

Simon Auster; Michael Kottow

The Journal of Clinical Ethics, Volume 10, Number 1, Spring 1999

An Ongoing Conversation: The Task Force Report and Bioethics Consultation

Mark P. Aulisio, Robert M. Arnold, and Stuart J. Youngner

Clinical Ethics Consultations: Some Reflections on the Report of the SHHV-SBC

Edmund D. Pellegrino

Ethics Consultants: Could They Do Better?

Edmund G. Howe

The Task Force Report: Comprehensible Forest or Unknown Beetles?

Judith Wilson Ross

Beyond Case Consultation: An Expanded Model for Organizational Ethics

Rebecca D. Pentz

The Application of the Task Force Report in Rural and Frontier Settings

Alvin H. Moss

Moving the Conversation Forward

Mark P. Aulisio, Robert M. Arnold, and Stuart J. Youngner

Brain Death, Pregnancy, and Posthumous Motherhood

Jeffrey Spike

Legal Trends in Bioethics

Heidi P. Forster

1998

The Journal of Clinical Ethics, Volume 9, Number 4, Winter 1998

Intersexuality: What Should Careproviders Do Now

Edmund G. Howe

A History of Intersexuality: From the Age of Gonads to the Age of Consent

Alice Domurat Dreger

The Hanukkah Bush: Ethical Implications in the Clinical Management of Intersex

Sherri A. Groveman

Management of Intersex: A Shifting Paradigm

Bruce E. Wilson and William G. Reiner

10 Commandments

Helena Harmon-Smith

Betwixt and Between: The Past and Future of Intersexuality

Robert A. Crouch

Surgical Progress Is Not the Answer to Intersexuality

Cheryl Chase

A Surgeon's Response to the Intersex Controversy

Justine Marut Schober

Pediatric Ethics and the Surgical Assignment of Sex

Kenneth Kipnis and Milton Diamond

For the Sake of the Children: Destigmatizing Intersexuality

Sharon E. Preves

Legal Trends in Bioethics

Heide Forster

The Journal of Clinical Ethics, Volume 9, Number 3, Fall 1998

Treating Infants Who May Die

Edmund G. Howe

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

Edmund G. Howe

Legal Trends in Bioethics

Dena S. Davis

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

Daniel Finkelstein, Albert W. Wu, Neil A. Holtzman, and Melanie K. Smith

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

Edmund G. Howe

Induction Procedures for Psychogenic Seizures: Ethical and Clinical Considerations

Martin L. Smith, Susan J. Stagno, Michelle Dolske, Joanne Kosalko, Carolyn McConnell, Larita Kasper, and Richard Lederman

Managed Care: A House of Mirrors

Nancy S. Jecker and Albert R. Jonsen

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

Neil S. Wenger, Nancy L. Greengold, Robert K. Oye, Peter Kussin, Russell S. Phillips, Norman A. Desbeins, Honghu Liu, Jonathan R. Hiatt, Joan M. Teno, and Alfred F. Connors, Jr., for the SUPPORT Investigators

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

The Journal of Clinical Ethics, Volume 8, Number 2, Summer 1997

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 Degrin

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 8, Number 1, Spring 1997

When Some Careproviders Have More Power than Others
Edmund G. Howe

Relationships, Relationships, Relationships . . .
Linda L. Emanuel and Jeremy Sugarman

John Gregory (1724-1773) and the Invention of Professional Relationships in Medicine
Laurence B. McCullough

A Manual on Manners and Courtesies for the Shared Care of Patients
John D. Stoeckle, Laurence J. Ronan, Linda L. Emanuel, and Carol M. Ehrlich

Ethical Issues and Relationships Between House Staff and Attending Physicians: A Case Study
Aaron Beckerman, Martin Doerfler, Elsbeth Couch, and Jerome Lowenstein

Who Plays What Role in Decisions about Withholding and Withdrawing Life-Sustaining Treatment?
JoAnn Bell Reckling

Thoughts about the End-of-Life Decision-Making Process
Peter B. Terry and Karen A. Korzick

Ethics Consultants and Surrogates: Can We Do Better?
John C. Fletcher

Relationships Between Primary Care Physicians and Consultants in Managed Care
Allan S. Brett

The Quality of Primary Care/Consultant Relationships in Managed Care: Have We Gone Forward or Backward?
Gail J. Povar

Communication through Interpreters in Healthcare: Ethical Dilemmas Arising from Differences in Class, Culture, Language, and Power
Joseph M. Kaufert and Robert W. Putsch

From What's Neutral to What's Meaningful: Reflections on a Study of Medical Interpreters
Mildred Z. Solomon

Physicians' Collaboration with Chaplains: Difficulties and Benefits
Mary Martha Thiel and Mary Redner Robinson

Legal Trends in Bioethics
Dena S. Davis

1996

The Journal of Clinical Ethics, Volume 7, Number 4, Winter 1996

Everyday Heroes in Bioethics: Part I
Edmund G. Howe

Where Are the Heroes of Bioethics?
Benjamin Freedman

Heroes, Martyrs, and Other Choices
John C. Fletcher and Maxwell Boverman

Perhaps We All Be Heroes
Paul J. Reitemeier

Reflections on My Father's Experience with Doctors during the *Shoah* (1939-1945)
Harold J. Bursztajn

Introduction: Feminist Approaches to Bioethics
Rosemarie Tong

She Said/He Said: Ethics Consultation and the Gendered Discourse
Susan Rubin and Laurie Zoloth-Dorfman

A Feminist Standpoint for Genetics

Mary B. Mahowald

A Model Policy Addressing Mistreatment of Medical Students

Carson Strong, Hershel P. Wall, Valerie Jameson, Howard R. Horn, Paul N. Black, Stephanie Scott, and Shannon C. Brown

Commentary on “A Model Policy Addressing Mistreatment of Medical Students”

Donald S. Kornfeld

Family Dynamics and Children in Medical Research

Valery M. Gordon and Frederick O. Bonkovsky

Audience and Authority: The Story in Front of the Story

Laurie Zoloth-Dorfman

Commentary on “Family Dynamics and Children in Medical Research”

Walter Robinson

Legal Trends in Bioethics

Dena S. Davis

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

John C. Fletcher

Conflicts of Interest, Conflicting Interests, and Interesting Conflicts, Part 3

James P. Orlowski, Janicemarie K. Vinicky, and Sue Shevlin Edwards

Legal Trends in Bioethics

Dena S. Davis

Mandatory HIV Testing in Newborns: Not Yet, Maybe Never

Dena S. Davis

Letters

Elisa J. Gordon

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

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

1995

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 Craze

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. Wicclair, 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 Bursztajn 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. Orłowski

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

The Journal of Clinical Ethics, Volume 5, Number 2, Summer 1994

Discussing Futility

Edmund G. Howe

Physicians' Quantitative Assessments of Medical Futility

S. Van McCrary, Jeffrey W. Swanson, Stuart J. Youngner, Henry S. Perkins, and William J. Winslade
Informed Consent to Amnestics, or: What Sound Does a Tree Make in the Forest When It Falls on Your Head?

Maxwell J. Mehlman, George A. Kanoti, and James P. Orłowski
Attitudes of Seriously Ill Patients toward Treatment that Involves High Costs and Burdens on Others
Lawrence J. Schneiderman, Richard Kronick, Robert M. Kaplan, John P. Anderson, and Robert D. Langer

Obligations of Physicians to Patients and Third-Party Payers
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. Orłowski

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

Book Review of *Trials, Tribulations, and Celebrations: African-American Perspectives on Health, Illness, Aging, and Loss*
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. Falloon

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

Phone Fees: A Justification of Physician Charges

Susan S. Braithwaite and Nancy O. Unferth

Requirements for Ethics, Socioeconomic, and Legal Education in Postgraduate Medical Programs

Kenneth V. Iserson and Carol Stocking

Clinical Ethics Training for Staff Physicians: Designing and Evaluating a Model Program

Bruce David White and Richard M. Zaner

Confidentiality in the Age of AIDS: A Case Study in Clinical Ethics

Martin L. Smith and Kevin P. Martin

Gathering Information and Casuistic Analysis

Athena Beldecos and Robert M. Arnold

The Legal Dilemma of Partner Notification during the HIV Epidemic

Raymond C. O'Brien

U.S. Catholic Bishops on Nutrition and Hydration: A Second Opinion

Russell B. Connors, Jr.

Clinical Ethics and Reform of Access to Health Care

Steven H. Miles

Justice and Outcomes Research: The Ethical Limits

Robert M. Veatch

Ethics, Outcomes, and Epistemology: How Should Imprecise Data Figure into Health-Policy Formulation?

Teo Forcht Dagi

Cutting to the Bone in Conflict Resolution: "Getting to Yes" with Hormonal-Replacement Therapy

Helen M. Wood

Medical Ethics Cases: Moral Conflict or Confusion?

George A. Kanoti

Telephone Fees: Are They Worth It?

Daniel J. Isaacman

Medical Ethics in Medical Education: Finding and Keeping a Place at the Table

Thomas K. McElhinney

Legal Trends in Bioethics

Dena S. Davis

The Journal of Clinical Ethics, Volume 4, Number 2, Summer 1993

On Expanding the Parameters of Assisted Suicide, Directive Counseling, and Overriding Patients' Cultural Beliefs

Edmund G. Howe

Causing, Intending, and Assisting Death

Howard Brody

Prolonged Grieving after Abortion: A Descriptive Study

Douglas Brown, Thomas E. Elkins, and David B. Larson

The Courtship of the Paying Patient

Susan S. Braithwaite

Limitation of Medical Care: An Ethnographic Analysis

William Ventres, Mark Nichter, Richard Reed, and Richard Frankel

Autopsy Decisions: The Possibility of Conflicting Cultural Attitudes

Henry S. Perkins, Josie D. Supik, and Helen P. Hazuda

The Influence of Ethnicity and Race on Attitudes toward Advance Directives, Life-Prolonging Treatments, and Euthanasia

P.V. Caralis, Bobbi Davis, Karen Wright, and Eileen Marcial

Questionable Competency of a Surrogate Decision Maker under a Durable Power of Attorney

S. Van McCrary, William L. Allen, and Clarence L. Young

Second Guessing the Patient's Trust: Facing the Challenge of the Difficult Surrogate

Gail J. Povar

Improving Advance Directives: More Dialogue, Not More Laws

Greg A. Sachs

Health-Care Agents: Decisional Capacity and Legal Compliance

Jonathan D. Moreno

Doesn't Everyone Grieve in the Abortion Choice?

Jo Ann Rosenfeld and Tom Townsend

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

Adil E. Shamoo and Dianne N. Irving

The PSDA and Geriatric Psychiatry: A Cautionary Tale

Jan Marta

The Contract Motherhood Debate: Review of *Surrogate Motherhood: Politics and Privacy*

Joan C. Callahan

Bioethics and the Liberal State: Review of *Just Doctoring: Medical Ethics in the Liberal State*

John Douard

Book Review of *Concepts and Cases in Nursing Ethics*

Joy Curtis

Book Review of *Ministry to Outpatients: A New Challenge in Pastoral Care*

J. Vincent Guss, Jr.

Book Review of *Ethics at the Bedside*

Robert Lyman Potter

Book Review of *The Shape of the Good: Christian Reflections on the Foundations of Ethics*

Harry Yeide, Jr.

Book Review of *A Time to Be Born and a Time to Die: The Ethics of Choice*

Sarah Chaffee

Book Review of *AIDS and Ethics*

Kathleen Sazama

1992

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

Edmund D. Pellegrino

Quantifying the Value of Human Life for Cost Accounting of Safeguards: Clarifying Formulas Applied to the Clozapine Controversy

L. Eugene Arnold

Some Problems with Cost-Benefit Analysis in Health Care

Alain Leplège

Can We Measure Out a Life in Coffee Spoons?

Tia Powell and Donald S. Kornfeld

Commentary on "Quantifying the Value of Human Life"

William L. Webb, Jr.

Spousal Understanding of Patient Quality of Life: Implications for Surrogate Decisions

Robert A. Pearlman, Richard F. Uhlmann, and Nancy S. Jecker

What Is the Moral Basis of the Authority of Family Members to Act as Surrogates for Incompetent Patients?

Dan W. Brock

The Development of a Clinical Ethics Consultation Service in a Community Hospital

Kenneth H. Simpson

Cultivating Ethics Consultation: Commentary on "The Development of a Clinical Ethics Consultation Service in a Community Hospital"

Daniel J. Anzia and John La Puma

Clinical Ethics Consultations: Reasons for Optimism, But Problems Exist

Henry S. Perkins

Being on Time for Appointments

Sharon Schwarze

Commentary on "Being on Time for Appointments"

Ian M. Shenk

Decision Making in the NICU: The Question of Medical Futility

Brian S. Carter and Julie Sandling

Beyond Futility

Robert D. Truog

What Should Be Done When a Proxy Is Reluctant to Carry Out the Wishes of an Incompetent Patient?

M. Rose Gasner and C. David Finley

Legal Trends in Bioethics

Suzan Onel and Sigrid Fry-Revere

Ethical Issues Described by NICU Nurses Arise from Three Areas

Joy Curtis

Letters

Mark Rosenberg

The Journal of Clinical Ethics, Volume 3, Number 1, Spring 1992

From the Editor

Edmund G. Howe

Against Caring

Hilde L. Nelson

In Defense of Caring

Nel Noddings

Caring: From Philosophical Concerns to Practice

Toni M. Vezeau

How Much of the Brain Must Die in Brain Death?

James L. Bernat

Commentary on "How Much of the Brain Must Die in Brain Death?"

Teo Forcht Dagi

Healing and Killing, Harming and Not Harming: Physician Participation in Euthanasia and Capital Punishment

Erich H. Loewy

Physician-Assisted Dying: Theory and Reality

Diane E. Meier

Imagining Ethics: Literature and the Practice of Ethics

- Charles Radey
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. Bartholme
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
 Neil A. Holtzman, Ruth R. Faden, Claire O. Leonard, Gary A. Chase, and Sharon Richmond Ulrich
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

Approximating Informed Consent and Fostering Communication: The Anatomy of an Advance Directive

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

Edmund G. Howe

The Importance of Understanding Suffering for Clinical Ethics

Eric J. Cassell

The Role of Suffering and Community in Clinical Ethics

Erich H. Loewy

Response to Erich Loewy

David C. Thomasma

Natural Resources for Morality

Friedrich Heubel

Why We Need a Theory of Suffering, and Lots of Other Theories as Well

Larry R. Churchill

Anticruelty Care

Susan S. Braithwaite

Suffering and Interpersonal Meaning

Georg Gadow

An Ethics of Suffering: Does it Solve the Problems We Want It to Solve?

Barbara Springer Edwards

High-Tech Comfort: Ethical Issues in Cancer Pain Management for the 1990s

Betty R. Ferrell and Michelle Rhiner

An Appraisal of the Ethical Issues Involved in High-Technology Cancer Pain Relief

Daniel P. Stoltzfus and John M. Stamatos

Should Newborns Receive Analgesics for Pain?

Robert D. Truog and Paul R. Hickey

Sedation Before Ventilator Withdrawal

Barbara Springer Edwards and Winston M. Ueno

Sedation Before Ventilator Withdrawal: Can It Be Justified by Double Effect and Called "Allowing a Patient to Die"?

Raymond J. Devettere

Death: The Final Stage of Confusion

Benjamin Freedman

Commentary on "Sedation Before Ventilator Withdrawal"

Tia Powell and Donald S. Kornfeld

Sedation Before Ventilator Withdrawal: Medical and Ethical Considerations

Robert D. Truog, John H. Arnold, and Mark A. Rockoff

Is It Morally Justifiable Not to Sedate This Patient Before Ventilator Withdrawal?

Lawrence J. Schneiderman

Is Active Killing of Patients Always Wrong?

Franklin G. Miller

Whisper Down the Lane: AIDS, Privacy, and the Hospital "Grapevine"

Claire C. Obade

Legal Trends in Bioethics

Sigrid Fry-Revere

The Journal of Clinical Ethics, Volume 2, Number 1, Spring 1991

From the Editor

Edmund G. Howe

Future Directions in Clinical Ethics

Edmund D. Pellegrino, Mark Siegler, and Peter A. Singer

Ethical Counseling for House Staff Considering a Strike

Bruce E. Zawacki, Richard Kravitz, and Lawrence Linn

Philosophical Methodology and Strikes

David C. Thomasma

Notes on the Morality of Strike within the Medical Profession

R. Linn and S. Linn

An Analysis of the ACOG and AAP Ethics Statements on Conflicts in Maternal-Fetal Care

Douglas Brown, H. Frank Andersen, and Thomas E. Elkins

Inadequacies with the ACOG and AAP Statements on Managing Ethical Conflict During the Intrapartum Period

Frank A. Chervenak and Laurence B. McCullough

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 D. Pellegrino
- 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**

George A. Kanoti

Air-Support Treatment: A Case Study in the Ethics of Allocating an Expensive Treatment

Benjamin Freedman, James Gilbert, and Lois A. Kaltsounakis

Pressure Sores: More Than Meets the Eye

Robert J. Moss and John La Puma

Delivery Room Decisions for Tiny Infants: An Ethical Analysis

Jeffrey R. Botkin

Caring Approaches to Clinical Decision Making: Mothering and Drugs

Toni M. Vezeau

Maternal-Fetal Conflict: A Survey of Physicians' Concerns in Court-Ordered Cesarean Section

Thomas E. Elkins, Douglas Brown, Mel Barclay, and H. Frank Anderson

The Patient Self-Determination Act: Right Church, Wrong Pew

Claire C. Obade

Legal Trends in Bioethics

Sigrid Fry Revere

Letters

Howard Morgan; Gershon Grunfeld; Franklin G. Miller; William G. Bartholome

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 Facially 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

Claire C. Obade

Lessons from Cruzan

Alan Meisel

In re A.C. Reversed: Judicial Recognition of the Rights of Pregnant Women

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 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, Marilyn 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

Steven L. Taube; Ren-Zong Qui; Paul B. Hofmann; Carl Junkerman; Reed E. Pyeritz

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 Against 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

