

# 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).<sup>1</sup> 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,<sup>1</sup> 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.

## 2016

### The Journal of Clinical Ethics, Volume 27, Number 4, Winter 2016

#### 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.

## The Journal of Clinical Ethics, Volume 27, Number 3, Fall 2016

### 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.<sup>1</sup> 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*<sup>1</sup> 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

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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

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**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).<sup>1</sup> 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).”<sup>1</sup> Broadly related articles have been published in previous issues of JCE.<sup>2</sup> 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.

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