



## *Included in this issue...*

Click on the highlighted title to go directly to the article.

- 1** **Welcome: Framing the Day**  
Kate Scannell, MD, FACP
- 2** **Keynote Address: Ethics and Epigenetics**  
R. Alta Charo, JD
- 2** **Morning Plenary: Caring for Patients with Disabilities**  
Elizabeth Pendo, JD, BA

### WORKSHOPS

- 4** **Teaching Bioethics: The Constitutional Framework of Physician Assisted Death**  
Elizabeth Pendo, Kelly Dineen, and Jennifer S. Bard
- 4** **Ethics and Communication of Medical Error Disclosure**  
Kayte Fulton, BA
- 5** **Operationalizing Justice: From Clinical to Organizational Ethics**  
Kate Michi Ettinger, JD
- 6** **Mandatory Immunization of Healthcare Workers: Patient or Employee Right?**  
Howard Slyter, MD
- 8** **Conflict of Interest in Research**  
Jeffrey P. Braff, DrPH, MBA, CP

### AFTERNOON PLENARIES

- 9** **Provider Moral Disengagement: Another Clue to the Problem of Neglected Pain**  
Kelly Dineen, JD, RN
- 10** **Legal and Ethical Issues in Medical Futility**  
Jennifer S. Bard, JD

## HEALTH LAW IN THE DOMAIN OF HEALTH CARE ETHICS

The 19<sup>th</sup> Annual Ethics Symposium  
presented by  
Northern California KP TPMG  
Department of Medical Ethics

## WELCOME

### Framing the Day

Kate Scannell, MD  
Director, Department of Medical Ethics, KP NCAL

This year's symposium focused on relationships between medical and legal ethics within the domain of health care. Our esteemed keynote speaker, R. Alta Charo, JD, energized the audience with her robust analytical appraisal of ethical issues raised by the emerging field of epigenetics. Subsequent plenary sessions addressed an overview of American bioethical issues featured the prior year in public media, disability issues, moral disengagement in pain control, and "futility." Concurrent workshop leaders explored organizational ethics, mandatory vaccination of health care providers, research ethics, error disclosure, and physician assisted suicide.

It was a rich symposium fostering moral community, and we thank our speakers and attendees for making it so. We are also grateful to the many volunteers and KP colleagues who worked behind the curtain to make it all work out. I especially want to thank Kathleen Martin who has masterfully

## Save the Date! Saturday, March 5, 2011

20<sup>th</sup> Anniversary Ethics Symposium: Reflecting Forward, Minding the Past

Keynote Speaker: Sandra H. Johnson, Professor Emerita of Law and Health Care Ethics, St. Louis University School of Law

San Ramon Valley Conference Center, CA

TPMG Department of Medical Ethics • Kaiser Permanente Northern California



managed our last five symposia and who now looks forward to a well-earned retirement and new life journeys.

Next year — on Saturday, March 5, 2011 — we will celebrate our 20th annual symposium. On this special anniversary, we're going to take a "past and present tense" look at ethical issues that have continued to hold our attention over the last two decades. We hope you will join us.

---

## KEYNOTE ADDRESS

### ETHICS AND EPIGENETICS

R. Alta Charo, Knowles Professor of Law & Bioethics, University of Wisconsin Law School

In recent years there has been an explosion of interest and research in epigenetics, which involves changes in gene function and, it is suspected, heritable changes in phenotype — all without changes in DNA. This research suggests a multitude of ways in which environment, diet and other factors can have lifelong or even transgenerational effects, ranging from a tendency to obesity to life threatening illnesses. Doing the research necessary to tease out these relationships has ethical challenges, given the number of subjects and level of intrusion necessary to account for so many variables over such long timeframes.

The conclusions may well affect how we think about our collective obligation to each other and to future generations, with implications for the limits we place on workplace and environmental exposures, the ways we explore new reproductive technologies, and the techniques we use for genetic counseling. While few of these are new topics, the addition of epigenetics to the discussion adds a new level of complexity and urgency to the debates.

---

## MORNING PLENARY

### CARING FOR PATIENTS WITH DISABILITIES: Removing Barriers to Health and Health Care

Elizabeth Pendo, JD. Professor of Law, Saint Louis University School of Law, Center for Health Law Studies; Adjunct Professor, Albert Gnaegi Center for Health Care Ethics, Saint Louis University

The health status of people with disabilities is finally receiving national attention. Unfortunately, not all of the news is good. A growing body of literature reveals that people with disabilities experience significant health care disparities and multiple barriers to health care. Briefly, I would like to outline the key health disparities and barriers, uncover the legal and ethical issues raised by such inequalities for health care professionals, and share some recommendations to improve the health and health care of patients with disabilities.

According to the US Census, about one in five people in the United States — 54.4 million of us — reported some level of disability in 2005. Of those, 35 million, or 12 percent of the population, were classified as having a severe disability. In addition, both the number and percentage of people with disabilities is expected to grow as our population ages. People with disabilities are a diverse group, as disabilities may be physical (the most common type of disability), mental, sensory, developmental, intellectual, episodic, hidden, or a combination of these. People with disabilities do share some commonalities. According to a 2003 study by the Kaiser Family Foundation, they have lower average incomes, are more likely to be older, more likely to be female, are much less likely to be employed, and are in poorer health.

People with disabilities are also more likely to have health care needs, so access to health care is especially important. We know that people with disabilities are more likely to go without needed care, experience more preventable emergency room



visits and hospitalizations, face a significantly higher prevalence of secondary conditions, receive less preventative care, and experience poorer overall health outcomes as compared with non-disabled people. We also know that people with disabilities experience multiple barriers to health and health care, including issues with health insurance, communication barriers and lack of accommodations, architectural barriers in offices and facilities, lack of accessible medical equipment and stereotypes about disability. As a result, patients with disabilities may receive unequal care, suffer worse outcomes, and face a sense of frustration, fatigue and exclusion. The National Council on Disability (NCD) recently reaffirmed some of these findings, and also noted the absence of training in disability competence issues for health care practitioners, and that people with disabilities are not included in the federally funded health disparities research.

This is puzzling for many reasons, including the fact that there are legal protections in place. The Rehabilitation Act of 1973 requires that hospitals, clinics, and other health care agencies that accept Medicaid funds, Medicare funds, or any other form of federal funding, ensure equal access to programs and services. The Americans with Disabilities Act of 1990 extends this requirement to all public entities, including state and local public health programs, services, and activities, as well as private offices and hospitals. By way or example, my current research focuses on inaccessible medical equipment and its effect on the delivery of women's health care to women with mobility disabilities. As an example here, nearly 20 years after the passage of the ADA, people with mobility impairments cannot get on examination tables or chairs, cannot be weighed, and cannot use x-ray equipment. This pervasive and unequal treatment has serious consequences for the health and well-being of millions of people.

Framing the problem simply as a lack of equipment suggests a straightforward solution—simply get accessible tables, scales, and machines into doctors' offices. The problem is serious, there are legal requirements regarding accessible equipment, and equipment meeting those standards is affordable and available. So why hasn't this been done? Perhaps the problem needs to be framed more broadly, starting with the failure to recognize the need for accessible equipment. The continuing *invisibility* of the problem suggests that it needs to be put into a broader context. Women with disabilities may not be seen as sexually active or as mothers, and the specific context of sexual and reproductive care for women with mobility disabilities has the potential to intensify negative attitudes. The stigmatization of disability—and the stigmatization of sexuality, reproduction, and parenting by women with disabilities in particular—is a deep-rooted problem that impacts all aspects of our society, including the delivery of health care.

In light of the legal and ethical issues noted above, what can be done to improve the health and health care of patients with disabilities? Seeing the issue in terms of equality is key, as is improved awareness of and compliance with the legal requirements of the ADA. Developing specific standards for accessible equipment, as required by the Patient Protection and Affordable Care Act of 2010 (PPACA), will also be helpful. Although the ADA requires equal access to health care in public and private health care settings, it does not require health care institutions or private providers to have any specific equipment. The PPACA seeks to remedy this gap, and calls for the development of detailed standards for all new medical and diagnostic equipment. Finally, improved research, as well as provider training and education on disability issues, is needed.



---

## WORKSHOP

# TEACHING BIOETHICS: The Constitutional Framework of Physician Assisted Death

Elizabeth Pendo, Kelly Dineen, Jennifer Bard

This workshop presented a series of fundamental legal points drawn from a reading of the major cases in the area of physician assisted death (PAD). The speakers offered a series of statements as a starting point for discussion, with a focus on understanding what the law is before talking about what it should or could be.

### TRUE OR FALSE?

1. Anyone with decisional capacity can refuse medical treatment, even life saving treatment.
2. Anyone with decisional capacity can refuse medical treatment, even life saving treatment, unless is it for the purpose of suicide.
3. A doctor can prescribe a pain medication for a terminally ill patient at doses sufficient to relieve his or her pain, but may not prescribe a lethal dose.
4. The United States Supreme Court decided that competent terminally ill patients have a constitutionally protected liberty to make end-of-life decisions free of undue government interference.
5. The United States Supreme Court decided that the due process clause of the Constitution includes a right to commit suicide with another's assistance.
6. A state may claim an interest in preserving the ethics of the medical profession as one of the reasons for instituting a ban on physician assisted death.
7. Congress could (but has chosen not to) make it illegal for a state to allow physician assisted

death (because they have the power to control prescription drugs).

8. A state can forbid health care providers from assisting a competent, terminally ill patient to commit suicide.
9. A state can pass a statute that permits physician assisted death.
10. "Mercy killing" is a defense to homicide.

The goals were: (1) to provide an understanding of the legal framework of PAD, (2) to illustrate the types of insights and distinctions that we ask law students to grasp as a foundation for class discussion, and (3) to compare the law school teaching style with teaching styles for medical students, nurses, and other health care professionals.

---

## WORKSHOP

# ETHICS AND COMMUNICATION OF MEDICAL ERROR DISCLOSURE

Kayte Fulton, BA –Education and Development Specialist, Colorado Permanente Medical Group, P.C.

The workshop was created to help participants do the following:

- ▶ Understand the ethical and moral dimensions of disclosure of medical error and unanticipated adverse outcomes; apology; and forgiveness.
- ▶ Appreciate the differences and commonalities between medical error and unanticipated adverse outcomes from the perspectives of ethics, communication, and reparation.
- ▶ Learn approaches and techniques for communicating instances of medical error and unanticipated adverse outcomes to patients and family.
  - Use of The Four Habits
    - Invest in the Beginning



- Elicit the Patient's Perspective
  - Demonstrate Empathy
  - Invest in the End
- ▶ Practice these techniques in small groups using patient scenarios.

---

## WORKSHOP

### OPERATIONAL JUSTICE: From Clinical to Organizational Ethics

Kate Michi Ettinger, JD -The Mural Institute

The workshop will begin by explaining key differences between clinical ethics and organizational ethics. Clinical ethics deals with issues raised in the care of an individual patient while organizational ethics deals with care of patients in general, and not the particular patient. Thus, organizational issues such as resource allocation should not be part of an individual patient's ethical analysis.

An ethics committee can support its institution in implementing organizational ethics. The principle of justice, which calls for treating similarly situated patients similarly, is appropriately applied at the organizational level. In the analyses of organizational actions, we must consider whether these actions will be applied fairly and equally to all patients who are in a similar situation. Additionally, promoting transparency in decisions that impact patient care is necessary; the distribution of burdens and benefits stemming from these institutional actions must be clearly justified. Thus, the ethics committee supports the institution to operationalize the justice principle.

A key part of the workshop is sharing our experiences with institutional ethics issues. The workshop reviews three institutions' pioneering approaches to organizational ethics issues; an integrated care delivery system, a charitable (non-profit) hospital, and a safety net hospital. We will

open the discussion to participants and their experiences with organizational issues including their successes and barriers. These experiences will highlight the types of issues that might be addressed, will identify diverse methods employed, and will examine organizational ethics principles that have been applied.

Organizational ethics can be applied at the department or institutional level. An ethics committee might bring its expertise in ethical analysis to promote justice by advocating for a systematic approach to frequently arising patient care issues, (e.g. decisions for the incapacitated patient alone), consistency in practice (e.g. disclosure of medical errors), and transparency in decision making (e.g. interdepartmental transfers).

We need to consider an expanding role for ethics committees in the area of organizational ethics. They could help in developing a policy that promotes consistency for a recurring clinical ethics issue, in advising a department in developing a protocol for allocation of its resources, and in facilitating the development of an ethically justified approach to an issue with clinical and administrative elements. Thus, the ethics committee can serve as a vital resource in supporting the institution's mission.

The workshop will conclude with the presentation of a proposed framework to approach an organizational issue. Participants will apply the framework to a hypothetical case.

#### SUGGESTED FRAMEWORK FOR ADDRESSING AN ORGANIZATIONAL ETHICS ISSUE

- ▶ Understand the issue/problem
  - Identify the issue/problem's causes/considerations



- Understand data relevant to the problem
  - Scientific/Clinical
  - Business
  - Legal
  - Ethical
  - Peer practice
- Consider strategies to address the issue
- ▶ Talk to stakeholders
  - Identify all relevant stakeholders
  - Understand stakeholder interests
  - Develop plan to integrate stakeholders into process
- ▶ Options: Brainstorm possibilities
  - Identify options
  - Understand the feasibility of each option
    - Clinical implications
    - Business implications
    - Legal considerations
    - Understand the ethical dimension of options
      - Determine what principles apply
      - Analyze ethical considerations
      - Provide ethical justification
  - Develop stakeholder analysis
- ▶ Propose: Integrated solution
  - Identify a “proposed” solution
  - Understand ethical implications
  - Understand barriers for stakeholders
  - Develop implementation plan
    - Revise proposal based upon feedback
    - Addressing implementation concerns in plan
- ▶ Implement
  - Implement the plan
    - Provide transparent reasoning for plan
    - Explain implications
  - Provide procedures to ensure consistent implementation

- Develop outcome measures to ensure effectiveness

▶ Assess Impact

- Evaluate outcomes
- Integrate solution into ongoing QI

---

## WORKSHOP

# MANDATORY IMMUNIZATION OF HEALTHCARE WORKERS: Patient or Employee Right?

Howard Slyter, MD, KP Sacramento Medical Center

When a novel strain of the H1N1 influenza virus (dubbed ‘swine flu’) first surfaced in Mexico in early 2009, there were widely-publicized fears of an influenza pandemic. In short order, thousands of people had been infected, and by the end of April nearly 100 were reported dead. Unexpectedly, this new virus was disproportionately killing the young and the pregnant. Public Health leaders needed to quickly assess the situation and devise a plan that would assure optimal public safety without causing undue panic, unwarranted costs, or an overreaction that would further undermine public trust of the healthcare system. What should be their historical model, and what should they advise?

Consider: Following World War I, more than 50,000,000 people died in the Spanish Flu epidemic. No one wanted that. On the other hand, in 1976 the Ford administration tried to immunize the entire nation against a different H1N1 virus – for an epidemic that never materialized. Unfortunately, the vaccine itself became associated with an increased rate of Guillain-Barre Syndrome, a serious and sometimes fatal paralyzing disease. No one wanted that.

Between these two extremes, we have had much experience with garden-variety seasonal influenza. Annual deaths number about 35,000, primarily among the elderly, the already-compromised, and



very young children. Every year it kills about as many people as breast cancer and three times as many as HIV/AIDS. Hundreds of thousands of non-fatal hospitalizations can be traced to the virus. The estimated annual direct cost of influenza infection in the US is between 3 and 5 billion dollars. Epidemiologic studies have identified specific hospital wards and long-term care hospitals with fatal influenza outbreaks that are associated with low immunization rates of employees.

Historically, fewer than 50% of healthcare workers have gotten flu vaccination. Surveys have shown many reasons – fear of adverse effects, the misconception that “vaccination can cause influenza”, feeling not-at-risk, doubts about the seriousness of the disease or the effectiveness of the vaccine, and fear of shots. Yet influenza has proven quite prevalent among healthcare workers: up to 25% of the non-immunized develop clinical influenza every winter, and many more are asymptomatic carriers. Given that there is an asymptomatic incubation period of 2 days, and many workers stay on the job even when they are sick, there can be no question that healthcare workers expose their patients (the most vulnerable and at-risk population) to the virus.

Education and exhortation have led to improved vaccination rates approaching 80% in some systems. But mandatory vaccination has achieved a spectacular 98% rate in one Seattle hospital and in a large healthcare system in the Midwest.

Given this thumbnail sketch of the matter, what should be done?

Many believe that better education and easier access to vaccine is the answer. And studies suggest that these will improve vaccination rates. But they by no means accomplish universal protection.

Others insist that the only effective approach is to mandate vaccination. Accordingly, in 2009, the UC System required that all Health System employees and students get seasonal and H1N1 vaccines or wear face masks throughout the flu season. In the state of New York, all health employees were required to get both vaccines. With this, four nurses threatened to sue the state, claiming that their civil rights and freedom, not to mention their health and their jobs, were threatened by such a requirement.

Battle lines had been drawn.

On one side are advocates of universal mandatory healthcare worker immunization. They see immunization as beneficial for both the immunized workers and for the patients they care for. They claim that the vaccines this year are no different in any meaningful way from vaccines given the prior years. The science, technology, and production processes are identical, if not improved. Evidence shows that the flu virus is quite contagious and the vaccine historically quite effective. Immunized healthcare workers protect their vulnerable patients from preventable exposure to a potentially deadly virus. Recall, very few families oppose mandatory immunization of their children against a multitude of previously-deadly diseases (polio, diphtheria, measles, etc.), and many workers already acquiesce to requirements for TB testing, rubella and hepatitis immunity. We all accept the need to wash our hands, every patient, every time. There is no rational argument for treating these vaccines, this year, any differently.

Those who oppose mandatory immunization have not published their views widely in the medical literature, but the lay press and the internet are good sources of articles about “the swine flu scare” and about resistance to authority – be it the State of New York or the World Health Organization. The swine flu threat is characterized as “hyped (and) non-existent” and the vaccine as “inadequately tested (and) potentially dangerous.” For years the



press has carried stories connecting childhood immunizations with autism and other dread conditions. Now governmental agencies and international organizations, possibly plotting with Big Pharma, are seen as striking at citizens' most fundamental rights and freedoms by trying to impose mandatory immunization first on healthcare workers, and next on everyone. While some of these alarms may seem exaggerated, if not crack-pot, there is plausible skepticism about the scope of the threat and the motives of some who are promoting it. There are reasonable fears of a replay of 1976, and there are fundamental issues of personal freedom from external coercion.

The Kaiser organization has chosen to not mandate flu immunization. Given who we are and what we do, is this an ethical position?

---

## WORKSHOP

# CONFLICT OF INTEREST IN RESEARCH

Jeffrey P. Braff, DrPH, MBA, CIP, Director, Human Subjects Protections (HRPPP), Kaiser Foundation Research Institute

The subject of researcher conflict of interest (COI) has received considerable attention recently in both the national popular press and professional journals. This is due in large part to significant undisclosed conflicts by researchers at academic medical centers being discovered and reported in US Senate investigations.

In addition, the growing importance and visibility of research to Kaiser Permanente has prompted national leaders at Health Plan/Hospitals and The Permanente Federation to direct that all KP researchers (investigators and co-investigators) identify, on an annual basis, investments, relationships, and other situations which might reasonably present or appear to present possible COI with their accountabilities at KFHP/H, the Permanente Medical Groups, and any other KP

entity. This process—a Conflict of Interest Questionnaire for Researchers—was piloted across the Program for the first time in 2009, and has now become an annual requirement.

The session defined just what COI is, explored the history of COI in research generally, detailed what is required by the Federal Government regulations with respect to COI in research, and looked at the ethical and practical challenges of dealing with researcher COI or the appearance of COI at Kaiser Permanente, where our organizational structure allows for differing policies among various KP entities.

The principal lessons learned were:

- ▶ Application of the federal regulations dealing with COI is subject to considerable leeway due to both the regulation's general nature and to the fact that not all situations that can occur are envisaged by them—the research world is a complex place, where nuanced interpretation can lead to what some might regard as unethical decision-making. Frequently, the answers to the ethical questions may not be obvious – subject to scrutiny through the lens of how a situation appears, rather than what it really might be.
- ▶ Because of the possibility of harm to research subjects, as well as reputational damage to the institution, KP policies attempt to minimize, if not eliminate, the possibility of nuance by establishing a “bright line” with respect to what is permissible and what is not, but some may view it as problematic that different KP entities have different policies with respect to COI. The general trend externally seems to be moving to “zero COI.”
- ▶ In an effort to assure ethical conduct on the part of researchers, KP has increased its scrutiny of researcher COI through the introduction and management of a Program-wide annual



researcher attestation program requiring the self-identification of COI, or the appearance of COI.

- ▶ Due to their concern about the advent of restrictive federal reporting requirements, external sponsors of research, such as pharmaceutical companies, find themselves in a position where they are “forced” to be ethical, by “voluntarily” publishing lists of payments made to researchers and consultants. KP is exploring how to incorporate these data into our COI compliance process.
- ▶ Oversight of COI and scrutiny of researchers, both internally and externally, will only increase.
- ▶ The results of the scenario-based interactive session, in which participants were asked to determine whether situations presented actually do represent conflicts – and, if so, why – bore out the fact that there are shades of gray, and much is subject to interpretation.

---

## AFTERNOON PLENARIES

### **PROVIDER MORAL DISENGAGEMENT: Another Clue to the Problem of Neglected Treatable Pain?**

Kelly K. Dineen, Assistant Dean for Academic Affairs and Instructor of Health Law in the Center for Health Law Studies, Saint Louis University School of Law.

Pain may be the only patient complaint that every provider has also experienced. At the same time, no provider has experienced her patients’ pain and must rely on the patient to explain. Yet, evidence that providers do not rely on their patients’ reports and generally under-treat pain is widespread. Treatable pain is too often neglected despite expansive educational efforts, extensive multi-disciplinary research, federal and state policy reform and organizational level efforts.

While barriers to the adequate treatment of pain are multifaceted, one source of under-treated pain arises from provider decision-making and behavior. Most providers can recall more than a few instances when they were less than fully present, engaged and empathetic with the patients in their charge. Of course, providers generally do not intend to cause patient suffering. Instead, there are usually subtle influences on provider decisions that range from under-estimating pain levels to concerns about addiction.

Why providers sometimes fail to treat patients’ pain and suffering eludes any one answer. One possible mechanism among many factors may be the pervasive and subtle moral disengagement of providers. Moral disengagement is the social cognitive processes that allow individuals to behave inconsistently with their internal moral framework. Moral disengagement may operate in synergy with other biases and barriers that lead providers to inadequately treat pain. The theory of moral disengagement has been applied to settings ranging from capital punishment to business misconduct but to date, not to the health care setting.

Moral disengagement is self-regulatory. It allows individuals to reconcile harmful conduct and their own self-image as a moral person and to justify their otherwise harmful acts. Moral disengagement also frees the actor from associated guilt or self-sanctions. The three primary mechanisms of moral disengagement include: 1) cognitive reconstruction; 2) minimizing of the actor’s role in the harm; and, 3) focusing on the target of the act as unfavorable or deserving.

1. Cognitive reconstruction or sanitizing the act is the process of reframing the behavior as moral. This is achieved through a) moral justification, b) euphemistic labeling and c) advantageous comparison. Moral justification focuses on the use of moral, social or economic rationale to sanctify the behavior. One example in the



context of pain is a provider who prematurely takes patients in pain off of opioids and justifies it as better than allowing the patients to develop tolerance or addiction. Euphemistic labeling uses sanitized or passive language to cloak immoral acts. An example of passive language comes from *Inside Chronic Pain* by Lous Heshusius in which the author described a physician's reaction after he caused her serious pain with a rough examination. The physician's passive apology was "sorry I had to hurt you." Advantageous comparison uses a more egregious example to sanitize the act. For example, the physician in the previous scenario might say "at least I didn't cause you any permanent damage like Dr. X did."

2. Minimizing the actor's role in the harm or sanitizing the actor is accomplished by: (a) displacing or diffusing responsibility for the act/s, and, (b) disregarding or distorting the consequences of the act/s. Whenever acts are characterized as "necessary" because of organizational or regulatory requirements, responsibility is displaced. For example, physicians who refuse to provide effective opioid therapy may displace responsibility to the DEA or state licensing boards. Nurses may displace responsibility for under-treating pain to the patient's physician's lack of adequate orders or may blame hospital policy for arbitrary adherence to administration of pain medication. Similarly, a nurse may diffuse responsibility by saying they are too busy to provide timely pain medication. Disregard for the extent of the harm of under-treating pain is well illustrated in literature on the discord between patient and provider pain level assessments and disbelief of patient reports.
3. Finally, characterizing the victim as unfavorable or sullyng the victim is achieved by a) disparaging or denigrating the patient and b)

attributing blame to the patient because of her behavior, psychosocial or biological differences. Nearly every provider has heard patients asking for better pain treatment being called names such as "babies," "whiners," and "drug addicts." Disparities in pain treatment based on gender, sex, age, socioeconomic status, race and ethnicity are well established. Patients in pain often tell stories about suspicious or accusatory providers, and many providers dread caring for patients in chronic pain.

This plenary explores moral disengagement as just one possible explanation for the disconnect between the obligation to alleviate pain and the evidence that clinical practices often perpetuate the inadequate treatment of pain. This may be a first step in examining the role that moral disengagement may play in the day-to-day ethical lapses that negatively impact patient care.

---

## AFTERNOON PLENARIES

### LEGAL AND ETHICAL ISSUES IN MEDICAL FUTILITY

Jennifer S. Bard, JD, MPH, Alvin R. Allison Professor of Law, Texas Tech University School of Law, Associate Professor (adjunct) Texas Tech University School of Medicine

The civil rights movement of the late 1960s and early 1970s brought with it recognition that patients, as a group, lacked the power to direct their own health care. This drive towards patient self-determination or autonomy coincided with significant advances in medical technology which made it possible to reliably restart beating hearts as well as indefinitely extend the lives of people in permanent vegetative states who lacked consciousness and would never leave their beds. The issue was brought to the public's attention with the dramatic case of Karen Quinlan in 1976 in which a family sought and, against the state's objections, was allowed to remove their daughter's breathing tube. [*Matter of Quinlan*, 70 N.J. 10, 355



A.2d 647 (N.J. 1976)] The 15 years after the Quinlan decision saw a substantial but uneasy compromise emerge in most states as supporters of patient autonomy advocated that people fill out “living wills” stating their wishes should they find themselves in a state like Ms. Quinlan’s and, increasingly, these documents – often now called **advance directives** – were honored.

The disputes which arose after that only strengthened the principle that any competent individual had the right to refuse life sustaining medical treatment and a doctor who honored that request would not be legally or ethically responsible for the patient’s death. The Supreme Court has made clear that in evaluating disputes over withdrawal of life sustaining medical treatment it would “assum[e]...that the United States Constitution would grant a competent person a constitutionally protected right to refuse [any medical] lifesaving [intervention including] hydration and nutrition.” [*Washington v. Glucksberg*, 521 U.S. 702,723 (1997)]

The issue of a doctor’s or hospital’s legal authority to withhold life sustaining treatment against the wishes of a patient or her surrogate which is in front of us today rests on this legal and ethical foundation in a way that it would have been difficult to anticipate in 1976 or even 1996. The complaint now is not that doctors are providing too much care at the end of life but, rather, too little.

Doctors have no legal obligation to provide health care they believe is medically unnecessary, but outside of Texas there is no established procedure which can provide comprehensive protection from civil or criminal liability for a doctor or hospital who withdraws treatment in the face of a patient’s objection. Texas Health & Safety Code §166.046, et seq. – which took effect in 2001 – does have that protection and although not perfect, it works. [*Hudson v. Texas Children’s Hosp.*, 177 S.W.3d 232 (Tex. Ct. App. 2005)] Hospitals in Texas that have

followed the procedures set out in the act, which the law describes as “refusing to follow” an Advanced Directive, have avoided legal liability. [Fine RL and Mayo TW. Resolution of futility by due process: early experience with the Texas Advanced Directives Act. *Annals of Internal Medicine* (2003) 128: 743-746.]

The workings of the Texas Law are quite straightforward. The legislature has created a process that starts with a doctor or hospital being required to give the patient 48-hour notice that the decision to terminate will be reviewed by a statutorily undefined entity called an “Ethics Committee.” If the Ethics Committee agrees that further care is inappropriate, the patient must be given ten days to find another doctor or hospital willing to undertake the life sustaining treatment. After that, the hospital may terminate treatment. To promote quick resolution, the statute has a very unusual feature: the family cannot challenge the decision of the Ethics Committee in court. [Miller, Geoffrey, *Futility by Any Other Name. The Texas 10 Day Rule*, *Bioethical Inquiry* (2008) 5:265-270.]

California and several other states have a statute which recognizes a doctor’s or hospital’s right to withdraw treatment in the face of a patient’s objection. Calif. Probate Code provides that “[F]or reasons of conscience” or because the instruction is “contrary to a policy of the institution that is expressly based on reasons of conscience” or “requires medically ineffective health care or health care contrary to generally accepted health care standards.” But neither California, nor any other State, provides specific procedures which, if followed, can offer comprehensive protection.

It is therefore not surprising that doctors and hospitals in California are reluctant to proceed in the face of strong family opposition and that these decisions when made are often the subject of debate and concern within the medical facility. While no legal innovation is going to make the decision to withhold life sustaining treatment in the



face of a patient or his family’s objection easy, a law like the one in Texas which provides a procedure for the hospital to follow would provide a predictable and reliable method for making those decisions.



**Seattle Children’s Hospital**  
**6<sup>th</sup> Annual Pediatric Bioethics Conference**  
*Tiny Babies, Large Questions: Ethical Issues in Prenatal and Neonatal Care*  
July 23–24, 2010  
Bell Harbor International Conference Center  
Seattle, CA  
Registration and Information:  
<http://bioethics.seattlechildrens.org/>

**23<sup>rd</sup> Annual Summer Seminar in Health Care Ethics**  
**University of Washington School of Medicine**  
August 2 – 6, 2010  
University of Washington Campus  
<http://depts.washington.edu/cme/live/pdf/MJ1101.pdf>

**12<sup>th</sup> Annual Meeting**  
**American Society for Bioethics and Humanities (ASBH)**  
October 21–24, 2010  
Hilton San Diego Bayfront Hotel  
<http://www.asbh.org/meetings/annual/>

**Save the Date!**  
**20<sup>th</sup> Anniversary Ethics Symposium**  
**Reflecting Forward, Minding the Past**  
Keynote Speaker: Sandra H. Johnson, Professor Emerita of Law and Health Care Ethics, St. Louis University School of Law  
TPMG Dept of Medical Ethics  
Kaiser Permanente Northern California  
Saturday, March 5, 2011

## ETHICS ROUNDS

### Editor

Kate Scannell, MD

### Editorial Advisory Board

Leslea Brickner, MD  
Robert Klein, MD  
Leslie Lopato, MD  
Howard Slyter, MD  
Stanley Watson, JD

### Copyeditor

Christopher P. Kelly

### Layout Editor

Sharon Olsen

Published for Kaiser Permanente Northern California for Kaiser Permanente Medical Ethics Committee members and interested staff.

© 2010, Kaiser Foundation Health Plan, Inc. and The Permanente Medical Group, Inc. No portion may be reproduced in any manner without prior written consent of the Permanente Medical Group, Inc. For permission to reprint, call Kate Scannell, MD (510) 625-6829 or send fax to (510) 625-3096.

For concerns related to the distribution or subscription list, please contact Willette Nacnac at (510) 625-3452.

The opinions and views expressed in Ethics Rounds are solely those of the authors and do not necessarily represent the views of the Editor, the Editorial Board, the Kaiser Permanente (KP) Medical Groups, KP Foundation and Hospitals, or the KP Health Plan.