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INTRODUCTION

DAVID BARNARD, PH.D., J.D.
MILES J. EDWARDS CHAIR IN PROFESSIONALISM AND COMFORT CARE
CENTER FOR ETHICS IN HEALTH CARE
OREGON HEALTH & SCIENCE UNIVERSITY

The essays collected here grew from a common matrix: the “Ethics in Healthcare Organizations” course offered by the OHSU School of Medicine’s Division of Management as part of the Healthcare MBA Program. The course, taught by Drs. David Pollack, Jeanne Enders, and Ruth Ann Tsukuda, exposes the students to several frameworks for the analysis of the ethical aspects of health policy and research, organizational behavior, and clinical care. Most prominent among these frameworks are the familiar quartet of ethical principles associated most closely with the authors Tom Beauchamp and James Childress, i.e., autonomy, beneficence, non-maleficence, and justice; stakeholder analysis, or the injunction to examine carefully the interests of all parties likely to be affected by the resolution of an ethical problem or dilemma; and the criteria proposed by Norman Daniels and James Sabin to ensure that when setting limits to health care services the authorities proceed fairly, to wit, according to criteria that are relevant and accompanied by a publicly accessible rationale, opportunity for revision and appeal, and regulatory oversight.

Our authors deployed these ethical resources across a wide terrain. The result is a collection of thoughtful, imaginative treatments of both perennial and newly emerging ethical challenges in health care that are always informative and often provocative.

While moral concerns have always been present in medicine and health care, bioethics in the modern sense that we are familiar with today—the examination and explication of the bases for our moral judgments, the criteria for judging actions or policies morally right or wrong, and the application of these criteria to the actions and choices of health professionals, patients, healthcare administrators, and society as a whole—developed in the middle of the last century. The coming together of the humanities disciplines of history, philosophy, literature, religious studies, ethics, and law in close engagement with the clinical and policy aspects of healthcare was driven largely by new societal concerns

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in three areas:

- decision making with and for patients near the end of life
- the conduct of research with human subjects
- the fair allocation of limited healthcare resource

The common element underlying each of these domains is the explosion of medicine's scientific and technological prowess following World War II, and the challenges new technical abilities pose to traditional understandings of health professionals' ethical responsibilities.

These three problem areas—end-of-life care, clinical research, fair allocation of healthcare resources—are well represented in these essays. Nikhil Batra and Christina Li focus on decision making and communication near the end of life. While Batra's essay is a broad survey of ethical questions in end-of-life care, and Li's is a more narrowly targeted discussion of information disclosure to patients and families, the essays are linked by their sensitivity to the phenomena of cultural diversity and variation in people's assessments of their quality of life or the appropriate trade-offs between avoidance of suffering and the prolongation of life. Batra cautions that the frameworks and analytic tools that are available to address ethical conflict near the end of life, while frequently helpful, are not always capable of providing resolution. This is because, in a diverse society, there is no universally agreed upon hierarchy of values to which everyone can appeal when, for example, the value of prolonging biological life collides with the responsibility to use resources wisely when the benefits of medical science and technology appear to reach their limits. It is in this context that criteria of transparency, relevance, and the availability of appeal and review become especially relevant for clinical and policy choices that affect the utilization of medical resources. Li points out that the predominantly Western values of individual autonomy and the "right to know" are not shared in all cultures. This calls for caution and sometimes negotiation with family members when, as in the case Li describes, it appears that the patient herself may prefer not to be involved directly in decision making in her care, but prefers that information about her medical condition—and decision making—flow to and from her family. In this case we may *offer* truthful disclosure to the patient, but do not have the obligation to *impose* it.

In their discussion of ethics and clinical research, Tim Burdick and Rosemary Makar demonstrate how a broader organizational perspective can illuminate ethical concerns that are likely to be missed when research ethics is understood primarily in terms of the individual investigator-subject relationship. In its landmark *Belmont Report*, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research put forward three ethical principles—respect for persons, beneficence, and justice—and connected each principle to an aspect of the ethical conduct of clinical research. Respect for persons underlies the value and process of informed consent; beneficence underlies the importance of a positive ratio of potential benefits to be gained by the research relative to its potential harms to subjects. When it came to justice, the National Commission placed its greatest emphasis on the selection of research subjects, insisting that no individual or group should bear a disproportionate burden of participation in research.

While both Burdick and Makar cover a wide range of issues, they have in common a concern for the economics and society-wide consequences of research that extends the implications of the principle of justice in clinical research beyond the selection of subjects. Makar, for example, looks at the phenomenon of low-enrolling studies (studies that accrue zero to one subject over a long period of time) and asks us to reflect on the dollar costs of keeping those studies up and running, as well as the opportunity costs of potentially more promising studies. Burdick adapts the elements of the Triple Aim (improving the patient's experience of care; improving population health; and reducing costs) to the research setting. He proposes that investigators be required to provide estimates of the Quality Adjusted Life Years (QALYs) to be realized as an outcome of their research, thereby indicating the likelihood that their research will actually reduce the societal disease burden, as justification for its costs in time, money, and subjects. Reviewers of research protocols, in turn, are urged to employ cost-effectiveness analysis—looking explicitly at the efficiency of the research process itself as well as the speed with which results are made widely available—in addition to fulfilling their traditional role as protectors of research participants. These latter process aspects of research may lend themselves to much more reliable prediction than the outcomes that Burdick recommends. Moreover, it may be argued that too heavy an emphasis on actual clinical outcomes as a threshold requirement for approving research protocols could end up skewing the research enterprise too far away from studies that, while presently far removed from clear translation into practice, appear to be scientifically important nonetheless.

The principle of justice in bioethics is most often understood to refer to the fair distribution of health care resources across society. The United States has struggled for decades to ensure access to necessary medical care for all of its people—and continues to fall short. Michael Meyer and Leah Vasquez take up this problem in their essays, and both highlight the Daniels-Sabin criteria for making health care allocation decisions when they point out that "rationing"—the dread word of opponents of greater government involvement in providing universal access to care—is already a feature of the U.S. health care system, which rations care by the ability to pay. The problem, both Meyer and Vasquez assert, is the lack of transparency and public accountability for this type of rationing, which takes place indirectly through the mechanisms of poverty and socially determined barriers to services, or is obscured by complex insurance company denials of service, or by the exclusion of Medicaid beneficiaries from the rolls of medical groups and hospital systems wishing to optimize their payer mix.

Almost hidden within Vasquez's lucid application of the Daniels-Sabin framework to the workings of CareOregon, the entity through which Oregon is attempting to maximize the availability of necessary health care to the poor, is her brief but telling observation that "it is unclear if the clinicians [CareOregon partners with] engage our members in honest conversations at the individual level to clearly explain why they cannot receive a particular service if it is considered excluded." As Vasquez notes, these micro-level interactions between clinician and patient are crucial points in the overall framework of macro- and meso-level decisions and policies to allocate limited healthcare resources responsibly. Yet clinicians' reluctance to raise these issues with their patients—whether fueled by ignorance of patients' insurance coverage or by embarrassment at bringing financial considerations into the clinical encounter—may lead to frustration and disappointment for patients while doing nothing to advance transparency. It is interesting to note that the Robert Wood Johnson Foundation (www.rjf.org) has decided this problem is sufficiently important to have announced a Call for Proposals entitled "Costs of Care: Getting the Conversation Right." The program's intent is strong validation of Leah Vasquez's concern.

Michael Meyer's essay also contains a suggestive phrase, when he asks "whether or not Americans possess the generosity of spirit and moral courage necessary to ensure that every American be issued health coverage." Generosity of spirit. Moral courage. With these phrases Meyer reminds us of a tradition in ethical theory that emphasizes *virtue and character* as fundamental to moral action and judgment, more than abstract principles or rational calculations of costs and benefits. The essays by Jennifer Teeples, Jimmy Heilman, Todd Warlik, and Corey White all draw from this tradition in one way or another.

Jennifer Teeples most explicitly represents the virtue ethics tradition, titling her essay "Moral Courage." Her theme is the capacity of nurses to confront the hierarchical (read: physician-centered) culture of health care organizations in order to speak up in the face of impending medical error or substandard practice. Moral *courage*, she argues, is the positive response to moral *distress*, or the sense of frustration and anger that accompany a perception of moral wrong and the sense of powerlessness to right that wrong. Teeples acknowledges that it is unrealistic to expect nurses—or anyone, for that matter—to exhibit moral courage without some reinforcement from the institution as a whole. Barry Egener and colleagues (2012) have coined the term "organizational professionalism" for the obligation of health care organizations to create and maintain the conditions under which health professionals feel empowered to act according to their professional values.[1] Teeples' essay provides an important example of why organizational professionalism is needed.

Jimmy Heilman's critique of policies that give favorable treatment to wealthy donors and other "VIPs" in Emergency Departments (among other hospital locales) calls attention to administrative practices that have corrosive effects on the morale and professionalism of clinicians who observe such favoritism coming at the expense of patients who should have been prioritized on purely clinical grounds. The tacit acceptance of such VIP treatment for the well-off, Heilman argues, without an inclusive deliberative process and explicit policy making, is also a contradiction of the transparency and public accountability that, from an ethical perspective, ought to characterize these policies.

Todd Warlik is also concerned with employee morale in his analysis of the response of Legacy Emanuel Hospital to allegations of the sexual abuse of patients by a nurse in the Emergency Department. While acknowledging the urgency and priority of protection for the safety and dignity of patients, and emphasizing the imperative of trustworthiness of health care institutions in the eyes of the public, Warlik frames the problem for administrators as one of balancing patient protections with respect and due process for employees. It is impossible not to read Warlik's essay without being reminded of current controversies over sexual assault allegations at college campuses across the country, where the same issues of due process and protection of victims are playing out. As with many other social pathologies, e.g., structural racism, inequality, sexism, or homophobia, the problem of alleged sexual assault of patients illustrates how health care institutions often mirror their social environments rather than standing apart from them—an enduring challenge to the moral courage of administrators and health professionals alike.

The virtue of trustworthiness, and the dynamics affecting the public's trust in health care institutions, is also at the center of debates about the definition of death in the context of organ donation, the topic of Corey White's essay. White returns us to the role played by advances in medical technology in the rise of the modern field of bioethics. With mechanical ventilation and other life-supporting technologies capable of maintaining the physical body's vital functions indefinitely, more of the body's organs are viable for transplantation. The near-universal adoption of the criteria for "brain death" in the United States has facilitated organ retrieval from those bodies—a development in bioethics and law that was necessary because of the (up to now) broadly accepted "dead donor rule": that is, someone must be dead *before*, and not *as a result of*, harvesting their organs for transplantation. This rule has been deemed essential for maintaining the public's trust in the process. White observes, however, that support for the dead donor rule might be weakening, citing a survey in which approximately 70% of a sample of U.S. adults said they approved of a hypothetical example of lethal organ donation, and 67% would agree to donate organs themselves if they were in an irreversible coma but still biologically alive.[2]

The authors of the survey cited by White speculate that in light of their results the dead donor rule may not be necessary to maintain public trust in the process of organ donation after all. This presents an occasion for a comment on the importance of one's ethical theory for one's evaluation of alternative social policies, in particular, the distinction between consequentialist and non-consequentialist or deontological theories of what makes actions or policies morally right or wrong. According to a theory in which actions and policies are morally right or wrong depending on their consequences, we should evaluate the dead donor rule by comparing the consequences for organ transplantation of abandoning the rule to the consequences of keeping the rule. If the overall number of organs for transplantation could plausibly go down if the public lost trust in the process of organ donation, and the dead donor rule is necessary to maintain public trust, then we should keep the dead donor rule, even if in particular circumstances we might miss the opportunity to harvest some organs. On the other hand, if, as the data cited by White suggests, the public's trust in organ donation is *not* dependent on the dead donor rule and if abandoning the rule might allow us to retrieve organs that we would otherwise miss, then it seems as though the overall number of organs for transplantation would likely increase, and therefore we should abandon the rule. According to at least some versions of consequentialist ethics, then, lethal organ donation should be legally permitted, if not encouraged.

If, on the other hand, we hold to an ethical theory in which the consequences of an action or policy are not the only considerations in its moral evaluation, we may evaluate the dead donor rule differently. We might hold to a theory that requires us to ask whether an action or policy is related to moral duties that we have in relation to other humans or to society as a whole, such as the duty not to kill, or not to take advantage of another human's weakness or vulnerability in order to achieve someone else's good ends. On this type of theory (often referred to as a non-consequentialist or *deontological* theory—for the Greek root *deon*, "duty") the fact that we could maintain the public's trust and increase the number of organs for transplant, while relevant to our evaluation, could not be decisive. We would have to take equally or more seriously (depending on the particulars of our version of non-consequentialist ethics) our duties to refrain from killing or from taking advantage of the weak and vulnerable, and this may well lead us to continue to defend the dead donor rule, the survey results notwithstanding.

Ethical theory figures also in the last essay in our group, where Paul Wilkens considers the potential utility of artificial intelligence in clinical medicine. Put simply (though Wilkens's elegant essay is anything but simple), how could or should computers be programmed to provide physicians and other clinical decision makers with information to guide their diagnostic or therapeutic options with patients? Wilkins concisely inventories some of the ethical theories that might underlie particular programming choices (affecting the order and content of information presented in response to particular clinical inputs)—consequentialism, Kantian ethics, Rawlsian ethics—and points out shortcomings or impracticalities of each when it comes to translating their imperatives into computer algorithms. Machines are coming, however, and their algorithms are influencing our choices and actions in the service of Evidence-Based Medicine. It is just here, Wilkens argues, that the values of transparency and public accountability rise to the fore, prompting us to ask whether the data presented by the machines, and the actions they recommend, match our considered professional and personal moral judgments. Wilkens underscores the importance of human deliberation, sensitivity to context, and emotional intelligence—not data alone—in the clinical encounter. Reading his essay, we may be tempted to coin a new phrase—Evidence-and-Empathy-Based Medicine—to describe the optimal practice of the contemporary clinician.

These brief introductory comments are by no means complete summaries of the essays that follow. In attempting to pick out a few of their common themes and overlapping concerns I have necessarily omitted many interesting points and challenging arguments. There is only one way to savor in full the contributions our authors have made to current bioethical debate: Read their essays yourself!

References:

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