

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Summer 2008

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
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“The Ethics of Health Care Reform” was a one-day conference that MHECN sponsored on April 7, 2008. In this issue of the Newsletter, we include a series of articles based on presentations made by several of the conference speakers. We welcome your feedback and comments on this topic, perhaps for inclusion in a future Newsletter. Please send them to MHECN@law.umaryland.edu.

MORAL ASSUMPTIONS OF HEALTH CARE REFORM PROPOSALS

Many of us have heard or voiced statements of criticism or outrage about the U.S. health care system being inherently “unjust.” Political rhetoric surrounding the Democratic and Republican parties’ positions on health care reform rarely addresses ethics head on. Nevertheless, the underlying moral assumptions of each party’s approach to health care reform can better inform a discussion about the ethics of health care reform.

Ruth Faden, the Philip Franklin Wagley Professor of Biomedical Ethics and Executive Director of The Johns Hopkins Berman Institute of Bioethics, addressed this topic at “The Ethics of Health Care Reform,” a conference co-sponsored by MHECN and the Law & Health Care Program at the University of Maryland School of Law on April 7, 2008. Faden discussed the differing interpretations of “social justice” that inform Republican and Democratic approaches to health care reform. For example, both Democratic and Republican supporters might agree that a socially just society ensures universal and continuous access to a reasonably

comprehensive level of care for its citizens. However, how universality and access are achieved, and what counts as a “reasonably comprehensive level of care” is interpreted differently.

Faden identified the following underlying moral assumptions driving Republican health care policy proposals:

- Individuals are morally responsible for their own health and their children’s health;
- Individuals have the right to decide for themselves how to obtain and secure their own health care;
- Government is morally obligated to subsidize health care for some but not all of its citizens;
- A compassionate, affluent society should assist those who cannot afford health care or health insurance.

Faden contrasted these moral assumptions of U.S. health care policy with those of Democrats, which include:

- The growing numbers of uninsured citizens in the U.S. is “unfair” because these individuals experience profound disadvan-

The Mid-Atlantic Ethics Committee Newsletter is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law’s Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities. Each issue includes a feature article, “Regional News,” a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing and related disciplines.

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Editor

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CURING AMERICA'S AILING HEALTH CARE SYSTEM—ONE PROPOSAL

Most Americans think the U.S. health care system functions poorly. Yet, most are personally happy with the health care services we receive. This makes reforming the U.S. health care system a challenge, to say the least. Dr. Ezekiel Emanuel, Chair of the Department of Bioethics at the Clinical Center, National Institutes of Health, outlined elements of the “Perfect Storm” conditions of our current health care system in his plenary talk at the April 7 conference.

Currently 47 million Americans lack health care coverage, including 9 million children. This does not include “under-insured” Americans. In 2006, the U.S. spent \$2.1 trillion (\$1 out of every \$6 dollars) on health care. This comprises 16% of the GDP. If the spending rate continues, by 2050, Medicare and Medicaid will consume all federal taxes. The problem is two-fold: our health care financing system is “inefficient, inequitable, and fiscally unsustainable,” and the delivery system is fragmented, not designed to care for chronic diseases; promotes haphazard and poor quality care; and over-uses unproven and marginal therapies. To properly fix the system, we need to fix both the financing and the delivery systems. However, most proposals for health care reform focus on financing (e.g., health insurance and coverage), ignoring the needed delivery system reforms and need for cost control.

Current health care is fragmented, with the typical Medicare beneficiary seeing seven physicians (including five specialists) in one year. In Switzerland and France, a requirement that all patients see a primary care physician gatekeeper has reduced such fragmentation. Despite the amount of money spent on health care, many Americans do not get effective, proven therapies. Lacking comprehensive outcome data, the system reimburses expensive, unproven interventions. For example, Medicare

reimburses treatments for early prostate cancer that range from \$11,000 to \$115,000, with no added benefit demonstrated for the higher-cost treatment.

Emanuel proposes what he calls the “Guaranteed Healthcare Access Plan,” features of which include:

- Every American receives a certificate to choose a qualified standard benefits package through an insurance company or health plan. The certificate is funded by a dedicated value added tax. Administration and oversight is provided by a National Health Board and 12 Regional Health Boards modeled on the Federal Reserve System.

- Medicare, Medicaid, SCHIP and other government programs are phased out.

- An Institute for Technology and Outcomes Assessment evaluates new interventions and collects and disseminates patient outcomes in health plans.

- A Center for Dispute Resolution and Patient Safety adjudicates claims of patient injury and promotes proven patient safety measures. Quick payment is provided to people who are harmed.

Emanuel addresses several important ethical challenges, which include the use of cost as one criterion for determining what health services to provide, the unavoidability of health benefit tiering (i.e., allowing the rich to buy more services), and challenges in holding individuals responsible for their health behaviors.

Barriers to implementing such widespread change include the “rule of satisfaction” (i.e., 85% of Americans have health insurance and most claim they are satisfied), the “James Madison Rule of Government” (i.e., American government was designed with many places for special interests to kill legislation, and our health care system has developed many special interests), and the “rule of second best” (i.e., a majority

of Americans favor health care reform, but are divided among many different plans; after their preferred reform, their second choice is the status quo). Emanuel quotes Machiavelli's Rule of Reform, "There is nothing more difficult to carry out, nor more doubtful of success, nor more dangerous to handle, than to initiate a new order of things. For the reformer has enemies in all those who profit by the old order, and only lukewarm defenders in all those who would profit by the new order."

Emanuel identifies the following prerequisites for reforming our health care system:

- The problem must attract widespread public and political attention.

- The proposal to solve the problem must be agreed on by the major actors.

- A major actor or set of actors must vigorously champion the policy proposal.

- A transforming political event is needed to create an open policy window to enact the agreed upon proposal.

There is a growing recognition that we have a serious a problem that must be addressed. Congress could do more to show how bad the health care system really is. But the system will eventually implode, and when it does, we must be ready when the policy window opens.

You can read more about the "Guaranteed Healthcare Access Plan" in Emanuel's new book, *Healthcare Guaranteed: A Simple, Secure Solution for America*. More information is also available at www.healthcarevouchers.org, and www.FRESH-Thinking.org.

THE ETHICS OF THE INDIVIDUAL MANDATE

Professor Diane Hoffmann, Director of the Law & Health Care Program and the Maryland Healthcare Ethics Committee Network at the University of Maryland School of Law, spoke about the ethics of the individual mandate as a vehicle for achieving universal health insurance coverage. In terms of ethical principles, the principle of autonomy would appear to undermine an individual mandate. But, there is also the countervailing principle of justice. Under some conceptualizations of the principle, we might conclude that the current system, in which individuals who can otherwise afford health insurance but fail to buy it and, when they get sick, put the burden on others to pay for it, is unjust. The issues of distributive justice raised by an individual mandate are complex, i.e., how do we expand access to health care to everyone and fairly distribute the burdens associated with paying for health care for people who need it?

Philosophers have come up with several theories to determine appropriate distribution of such rights and responsibilities across society. Libertarian theories are generally grounded in rights to social and economic liberty. Libertarians support a market model and ability to pay as the basis to distribute goods and services. Hanson (2007) asserts that

libertarians may object to an individual mandate (and the subsidies likely to accompany them) on two grounds:

1. They impose a government mandate on persons to purchase insurance when they might not want to; and
2. They constitute a "coercive and unjust redistribution of funds from one group of persons to another" by using public funds to subsidize the purchase of health insurance by the less well off.

Both are violations of individual freedom. One forces people to do something against their will; the other takes money from individuals without their consent. This is objectionable to the libertarian. According to a strict libertarian, "the right to have one's self and one's property left alone cannot be overridden even to produce a great social good – or even to create a social good that will benefit the persons whose rights were violated."

In contrast to the libertarian view, adherents of an egalitarian or communitarian ethic would more readily support an individual mandate. From an egalitarian perspective, mandates would make free riders pay their fair share. So, in that sense it is fairer than the current system. However, the cost of the mandate raises other issues from an egalitarian perspective, specifically,

what should individuals be required to pay? What is a fair allocation of burden? We don't have consensus on what is a reasonable percentage of one's income that one should have to devote to health insurance coverage. Determining what levels of subsidies would be fair is thus debatable.

From a communitarian or caring perspective, an individual mandate would also be supportable as it underscores the notions that this is a communal problem, not one that should be left to individual choice because the health of each of us affects others in a number of ways. It embodies the concept of shared responsibility between individuals, government and employers. It is similar to the approach that is entrenched in many European countries – the concept of solidarity – that is, we are all in this together—everyone is covered in the same pool and shares the burden equally.

One of the most challenging questions is how an individual mandate fares from a utilitarian perspective, that is, will the approach lead to the greatest good for the greatest number? Will the benefits it is able to achieve outweigh the costs? This is dependent on a number of assumptions about its effectiveness and the

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weight one places on various benefits and costs. Most agree that with the appropriate subsidies, it will take us a long way toward universal coverage. This will likely lead to benefits of being part of a more caring society, where individuals feel more secure and less anxious about paying for health care costs. But, will it improve health outcomes? Will it lead to increased productivity from

individuals who can work because they are able to get health care treatment when they were not able to before? In the end, will it cost more or less? And what role should cost play? The answer to that question, Hoffmann concluded, lies in how we answer the larger question raised at the beginning of the conference: Should we think about health care as a good or service that is bought and sold in the marketplace, subject to individual choice and willingness/ability

to pay? Or should it be treated more as a public or communal good or service, like education, available to all and with a requirement that all contribute toward paying for it?

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INCENTIVIZING WELLNESS

Many have looked to promoting healthy behaviors as a way of addressing the health care crisis. Proponents argue that such an approach would allow for a more equitable distribution of health care resources by avoiding preventable disability and disease, which is expensive and resource-intensive to treat. Promoting healthy behaviors sounds uncontroversial. What could be wrong with increasing rates of immunization, well-child care, tobacco cessation, weight management, and improved disease management? Judith Solomon, Senior Fellow for the Center on Budget and Policy Priorities, described different states' Medicaid wellness incentive programs, why they were implemented, results thus far, and what concerns have been raised about these programs.

Florida's "Enhanced Benefit Accounts" program is one example. Covered individuals received credits for any of 19 healthy behaviors, such as health check-ups, screenings, immunizations, etc. The

credits could be used for certain non-covered pharmacy products. The problem? Only 4% of the almost \$6 million earned in credits has been redeemed by Florida's Medicaid enrollees to date, pointing to dubious return on investment (administrative costs for the program ran over one million dollars). A similar program instituted for Medicaid participants in Idaho attracted few participants.

West Virginia's Medicaid redesign provides another example. Medicaid enrollees were offered the option of enrolling in a basic or an enhanced benefit plan. The enhanced plan was conditioned on signing and complying with a member agreement—for example, to bring children in for well-child visits, to avoid unnecessary emergency room visits, etc. If an enrollee was non-compliant with the agreement, (s)he would be reverted to the basic plan, which had limited coverage for pharmacy prescriptions and mental health services, among other things. The first problem with this program was low uptake—only 15% of Medicaid participants enrolled

in it. This was partly due to many not having access to a health care provider in the first place. A second problem was that physicians refused to report patients who were non-compliant with the Enhanced plan agreement. Many providers saw the program as unfairly geared toward children. Mental health providers reported significant numbers of patients without coverage for needed services.

Solomon pointed to naïve and uninformed legislators who propose such programs as one cause for failures. In West Virginia, for example, little attention was given to education about the program, and to health education within the program. For example, there is evidence to show that educating parents about unnecessary use of the emergency room reduces this misuse. Such a focus on education would likely have produced better outcomes than relying on penalties alone to change behavior.

The questions remain: what is the best way to control rising health care costs, and what role might wellness incentives play, if any?

SOARING HEALTH COVERAGE COSTS—WHAT'S AN EMPLOYER TO DO?

Some employers have attempted to rein in rising health care costs by raising employee health insurance premiums or conditioning employment on health outcomes, such as normal weight, blood pressure, and cholesterol levels, non-smoking status, and controlled blood sugar. A case study of such a proposed program formed the basis of a mock ethics committee discussion at the April 7 conference. Attendees generally found the proposed program to be unethical based on lack of equity. There are many unhealthy conditions that could lead to poor health outcomes and high health care expenditure. Picking a few (e.g., high blood pressure, elevated blood cholesterol, obesity) is arbitrary, and assumes that behavior change alone is sufficient to achieve targeted health outcomes.

E-MEDICINE & PRIVACY

Many have pointed to a universal electronic billing and medical record system as a key component of health care reform. This could reduce the current high administrative costs of managing the complex billing procedures that vary among third party payers, and help avoid medical service duplication that contributes to inefficiencies in health care delivery. Related to this issue is the topic of “E-medicine.”

Keith Bauer, PhD, Associate Professor of Philosophy at Marquette University, defines “e-medicine” as “a networked health information environment” that includes online support services, e-mail, electronic medical records, and telemedicine. This offers the promise of improving the quality, delivery, and cost-effectiveness of healthcare services. However, it also has the potential to exacerbate privacy intrusions and violations. Surveys show that a majority of Americans are concerned that too many people have access to their medical records, and may share their health information without their consent.

What constitutes a privacy violation? First, privacy and confidentiality are not synonymous. In general, privacy refers to people, whereas confidentiality refers to data. Patients give up privacy when they disclose health-related information to their healthcare providers. Disclosure can take the form of a verbal discussion, a medical history, or a physical examination. In both cases, patients reveal private information about themselves for the purpose of medical treatment. The healthcare provider promises to maintain the patient’s confidence by not disclosing this information to unauthorized persons (i.e., to protect the patient’s

confidentiality). Without confidentiality protections, patients are less likely to trust their physicians and, subsequently, less likely to share important information with them. This would jeopardize the physician’s ability to correctly diagnose and provide his or her patients with appropriate treatments. Physicians and healthcare institutions that fail to protect patient privacy and confidentiality violate a basic ethical principle of medicine: *Primum non nocere* or “first of all, do no harm.”

Threats to health privacy are not new. What has changed with the rise of E-medicine is the scope of potential violations. E-medicine facilitates the illicit acquisition and dissemination of data. This is in large part due to the digitalization of information, which is easier to collect, store, replicate, transmit, and steal. Also, the traditional definition of privacy has focused on informational privacy. E-medicine however, has implications for physical privacy, as well. For example, a patient’s private medical information can be extracted from medical devices such as implantable cardiac defibrillators and pacemakers equipped with wireless technology to allow for remote device checks, sometimes without the patient’s authorization or knowledge.

The following are types of potential privacy violations:

Commercial—Information compiled by data aggregators, who repackage and sell the data without the knowledge or consent of the original information owner.

Governmental—Surveillance activities performed in the name of national security.

Criminal—Stealing another person’s bank account information, credit card number, social security number, or other identification for the purpose of financial fraud (i.e., identify theft).

Security Breach—Unauthorized persons gaining access to restricted information (e.g., by hacking into a hospital’s electronic patient database or email accounts).

Among these, the last is of greatest concern to the future of e-medicine, as socially stigmatizing information that gets into the wrong hands can create very real social costs for individuals.

Legislation and technology can do much to minimize the risks of security breaches, but it is the human factor that is most important. If health care professionals are poorly trained in the use of electronic patient information and do not know the ethical and social implications of its misuse, the medical privacy of patients will not remain protected for very long. While the privacy and security rules of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 have increased awareness of health information protection, HIPAA compliance does not guarantee that a provider is securely protecting patient information that is sent or stored electronically. Perhaps time will tell as we learn from pioneers in this arena. France, Germany, and Taiwan have all instituted national smart cards that store patient data and allow for automated health services billing. It will be interesting to see how these systems perform in regards to protecting patients’ privacy.

CASE PRESENTATION

The following case and commentaries are reprinted from the Winter 1993 issue of the Mid-Atlantic Ethics Committee Newsletter. Do you think positions on this case would be different today? Please send your comments on this case analysis to MHECN@law.umaryland.edu.

CASE STUDY FROM A MARYLAND HOSPITAL

A 58 year old woman, with a history of chronic alcohol abuse, was admitted to the hospital on August 20 with upper gastrointestinal bleeding and liver failure. She bled severely and continued to bleed until she was taken to surgery on August 22. A total gastrectomy and pyloroplasty was performed.

Following surgery, the patient developed Adult Respiratory Distress Syndrome (ARDS) and Disseminated Intravascular Coagulation (DIC). She was mechanically ventilated for six weeks before weaning occurred. During this time, she was treated for almost continuous bleeding problems requiring 196 units of blood products including 50 units platelets, 50 units packed cells and other products. In addition, treatment continued for sepsis, respiratory failure and liver failure. The patient had been on TPN (total parenteral nutrition) since surgery and on a Clinitron bed for five weeks.

The patient had altered mental status and seemed childlike most of the time. She seemed to recognize her husband who visited her daily. She followed some simple commands. She did not speak or write although many attempts were made to teach her to talk with her endotracheal tube.

The family refused to discuss a NO CPR order and wanted everything done for the patient. The family was made aware of the severe drain on community blood supply the patient had caused. The patient required ICU care since

regular medical and surgical floors could not handle rapid blood replacement. The patient was resuscitated numerous times.

The attending physician requested an ethics committee consult six weeks after the patient was admitted to the hospital to determine whether the patient should continue to be treated aggressively. He was concerned about the rapid use of blood product and the drain on the local community's supply of blood. The continued request for blood was depleting the institution's supply as well as that of the local Red Cross. The physician also stated to the patient's family that because the patient was on medical assistance, her continued treatment was costing society significant amounts of money for what in his view was little or no benefit.

The ethics committee basically agreed with the attending physician that continued treatment of the patient was of little or no benefit to her. However, because the physician had raised the issue of the patient's receiving medical assistance to the family, the committee feared that the decision to stop treatment might be construed by the family as one based solely on that factor rather than on the medical facts of the case. As a result the committee recommended that treatment not be stopped.

COMMENTS FROM A HOSPITAL CHAPLAIN

I am in agreement with the decision of the Ethics Committee: to recommend that treatment of the patient with upper gastrointestinal bleeding and liver failure not be stopped at this time. However, before wholeheartedly endorsing this decision, there are a number of questions that need to be addressed which were not presented in the case study. For example, what does the family mean by wanting "everything to be done"? Was "everything that could be done" fully, understandably, and clearly communicated to the family? Did the patient herself indicate any advanced directives or even any suggestion about what she might want in terms of ag-

gressive treatment should she ever find herself in such a situation? What are her cultural, philosophical, religious values? What were the specific treatment goals held by the physicians and how do they compare to specific treatment goals currently envisioned by the family? What was the process by which the Ethics Committee came to its decision?

Further, I qualify my agreement with the decision to recommend continued treatment by opposing the stated reason given justifying that recommendation: the physician bringing up the issue of the patient's receiving medical assistance. I strongly agree that it was highly inappropriate, unprofessional, and even ethically questionable for the physician to bring this matter up with the family in the midst of the ongoing crisis. However, for the ethics committee to react out of fear of what might be perceived from a public relations point of view rather than act on behalf of the best interest of the family is not an effective use of an ethics committee. Its deliberations need to be based on careful reflection of the various values, conflicting opinions, dialogue and concerns brought forth by the family and professional caregivers within the context of bioethical principles.

It is ethically appropriate to consider the "cost to society" in treating a patient with marginal chances for recovery. Clearly, valuable and scarce resources were being utilized in this case with little chance of return of health for the patient as a result of that investment of resources. The mortality rate from ARDS and DIC, especially after 196 units of blood expended, additional blood products, and after six weeks of acute treatment is very high. Nevertheless, while local ethics committees need to be mindful and aware of such enormous costs to society's scarce resources, I believe it is beyond their purview to act on the principle of "distributive justice" when faced with the urgency, emotions, and personal concerns of an individual case. Decisions regarding the allocation of resources in such situations need to be made at the policy making level of society— nationally or

regionally or even within health care systems. Local ethics committees have the responsibility to educate their own institutions, communities, and political decision makers regarding allocation of resources.

On the other hand, if there were an emergency need for the blood and other resources utilized for this patient with marginal chances for recovery, then the Ethics Committee might have an appropriate role to act on the principle of triage: allocating the resource to those who can best benefit and who need it most urgently. The value of providing the greatest good for the greatest number of persons becomes operative. How to determine what potential emergency needs might be and who can best benefit could be a complicated matter. Blood and blood products are a replenishable resource, but they are not always immediately available when needed.

A physician should not be required to provide futile treatment. However, who determines what "futility" is? If a certain quality of life is acceptable to an individual, even if it would appear to be a low quality of life to most others, then, if the resources are not immediately needed by someone else, and in the absence of a clear social policy governing the allocation of resources, then that quality, whatever it is, should be maintained. It is not immediately clear whether the patient herself would find such a quality of life acceptable for an indefinite period. However, apparently, her surrogate decision makers are satisfied. They are vested with the authority and right to speak for the patient. Yet, there is a need to regularly communicate with this family to search out what their treatment goals are, and whether current treatment can attain those goals. At the point treatment cannot attain those goals, then there is no ethical responsibility to treat. The risk of harm to the patient and the possible benefit of better health or life has to be constantly weighed by both the caregivers and the family. Perhaps the place to start is to return to the issue of discussing "no-CPR" in light of the harm and possible pain it could bring the patient versus the benefit of continued life without much hope of recovery. The family does not have

the right to halt discussion about any medical matter as the patient's condition changes since the family is insisting on continued treatment.

This process of continually weighing the risk/benefit ratio can be very painful for both the family and caregivers. Those supporting the family, such as hospital chaplains, social workers, or counselors, as well as the nurses and physicians need to be aware of the special needs of the family at such a time and can play a significant role in helping to define their own values as well as get in touch with what the patient would want in such a situation. Persons who lack economic resources often have a distrustful attitude toward established institutions, including the healthcare delivery system. It is important to construct rapport within which the true best interest of the patient can be discerned by both the family and the caregivers. While autonomy of the patient, expressed through surrogate decision makers, may trump what others determine to be the best interest of the patient and society, there is a cost to exercising that autonomy. Establishing an atmosphere of trust and rapport within which solid ethical reflection and dialogue can occur, inviting the participation of family and professionals can minimize that cost and best meet the needs of the patient.

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COMMENTS FROM A HEALTH LAW PROFESSOR

This case raises the interesting question of whether resource allocation issues should ever enter into the decision-making of a physician or ethics committee, and the potential confusion between futility and rationing. In this case, it appears that the physician and the committee were in agreement that continued treatment of the patient was of no "medical benefit." Some have referred to such treatment as futile. Futility may, in the view of some practitioners, involve a kind of cost effectiveness analysis or

weighing of the benefits and burdens of a proposed treatment. But, in my view, such an analysis is most appropriate under a best interest test. Futility must be limited to actual cases of no medical benefit, or of medical benefit below some predetermined threshold. To expand it to include a consideration of cost is to let the physician make a decision about the value of life (in terms of real resources) to a particular patient. This is a dangerous area for physicians to tread—it raises the specter of bedside rationing.

Jecker and Schneiderman have written an article on "Futility and Rationing" that is of direct relevance to this case. They point out that different writers have defined futility and rationing somewhat differently. Definitions of futility have included an unacceptable likelihood of achieving: (1) life prolongation; (2) the patient's goals; (3) a physiological effect on the body; or (4) a therapeutic benefit or a minimum quality of life for the patient. Definitions of "rationing" have included: (1) limiting expectations of health care, even where health care is beneficial; (2) denying health care treatments, even where treatments are life-extending; (3) sharing of health care resources, even by those in need; (4) apportioning medical resources equitably based on need; or (5) distributing resources unequally. Futility and rationing come close together when rationing is based "on either the quality or likelihood of medical benefit." They may overlap when rationing is based on assigning the lowest priority of receipt of resources to those who have the "poorest quality of medical outcome." In these cases, withholding treatment might also be decided on the basis of futility.

However, even in these cases, the rationale for arriving at a decision based on rationing or one based on futility will differ. Futility, as pointed out by Jecker and Schneiderman, has no distributive aspect, it is based on a cause and effect relationship of the effect of a medical intervention on a single patient and takes no consideration of scarcity of resources. Rationing, on the other hand, always includes a distributive choice and takes place in an environment of scarcity.

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VALUE-DRIVEN MEDICINE

A discussion of the ethics of health care delivery and reform often starts with the assumption that health care access is a basic right that a just society owes to its citizens. Ensuing questions include, what constitutes “access,” what specific health care services should all citizens should have access to, and how much should we pay for them?

In response to the “bang” for our health care “buck,” we are left with little boasting rights. The U.S. health care system delivers “Yugo quality at Cadillac prices,” contends Dennis White, Senior Vice President of Value-Based Purchasing at the National Business Coalition on Health. Health outcomes are poor in comparison to other industrialized countries, and waste is rampant, with 30% of employer-based health care resources wasted due to overuse, underuse and misuse. We are to blame, White concludes, for endorsing a payment structure that has not held providers accountable for health outcomes, that has rewarded acute care over prevention, and that allows for an increasing number of medical errors. Compounding

this quality crisis is third party payment for health care services, which insulates “consumers” from cost sensitivity. Reimbursement structures have added to the problem, with fee-for-service systems encouraging over use of health care services, and capitated systems (like HMO’s) encouraging under use of health care services.

Value-driven medicine is one approach to redressing the inequities in our current health care system by promoting quality and efficiency of health care services. This is accomplished by tying reimbursement to provider performance and health outcomes. Pay-for-performance programs reward providers who document compliance with specified performance standards. Examples include the Bridges to Excellence program for physicians, and the Leapfrog Hospital Rewards Program for hospitals. In addition, these programs provide consumer access to provider performance data to allow individuals to choose providers based on quality. Value-driven medicine also relies on outcomes-based research to evaluate health care inter-

ventions and to contrast, compare, and evaluate new technology and services.

Value-based medicine has its roots in the formation of the Agency for Health Care Policy and Research in 1989 (now the Agency for Healthcare Research and Quality, AHRQ). AHRQ develops, disseminates, and evaluates clinical practice guidelines and conducts outcome research by which to evaluate health services for cost-effectiveness. The thought was that health care providers should be held to uniform standards, and that health care consumers should be better educated and empowered to judge quality based on outcomes. According to criteria identified by the Commonwealth Fund as indicators of a top-performing health care system, the U.S. consistently performed poorly in comparison to other industrialized countries (see Box). The goal of a values-driven approach is to get more value for dollars spent, and to advance evidence concerning the manner in which diseases, disorders and other health conditions can best be prevented, diagnosed, treated and managed.

RANKING OF 6 COUNTRIES, ACCORDING TO KEY PERFORMANCE INDICATORS.*

	Australia	Canada	Germany	NZ	UK	US
Overall ranking	3.5	5	2	3.5	1	6
Quality care	4	6	2.5	2.5	1	5
Right care	5	6	3	4	2	1
Safe care	4	5	1	3	2	6
Coordinated care	3	6	4	2	1	5
Patient-centered care	3	6	2	1	4	5
Access	3	5	1	2	4	6
Efficiency	4	5	3	2	1	6
Equity	2	5	4	3	1	6
'03 per capita expenditure	\$2,876	\$3,165	\$3,005	\$2,083	\$2,546	\$6,102

*1=best, 6=worst

ACP (2008). Achieving a High-Performance Health Care System with Universal Access: What the United States Can Learn from Other Countries. *Annals of Internal Medicine*, 148(1), 1, 55-75, adapted from Figure 5 on p. 65.

CONSUMER-DRIVEN HEALTH CARE

While values-driven medicine strives to empower consumers by making health provider quality data more accessible, the “consumer-driven” health care model goes even further in giving individuals control over their health care choices. Not surprisingly, this approach to health care reform is popular among Republicans, who favor minimizing government involvement and maximizing individual citizens’ responsibility and control of their own and their family’s health.

Marshall Kapp, the Garwin Distinguished Professor of Law & Medicine at Southern Illinois University School of Law and School of Medicine and Co-Director of the School of Law’s Center for Health Law and Policy, describes the traditional consumer-driven model. In it, consumers rely on a high deductible health insurance product to cover catastrophic health expenditures, and individually-managed, tax-exempt, interest-bearing Health Savings Accounts to pay for day-to-day health services. This approach is rooted in the ethical principle of individual autonomy. It assumes that the individual whose health is in the balance is the best risk manager, which is in stark contrast to the paternalistic

model, which argues that there is too much knowledge and power differential between patients and physicians for patients to make the right health care choices.

Proponents of consumer-driven health care believe that health care costs will never be controlled until patients are invested (literally and figuratively) in decisions about what health care interventions to spend money on. Kapp recognizes that consumer-driven health care has its faults, but believes it is better able to create a society in which “health care is treated as the precious resource that it is, rather than a costless entitlement; where nationwide competition pushes down the price of catastrophic care and consumers focus their attention and budgets on what’s really crucial to their health” (Tully, 2008). The criticism that consumer-driven health care would disadvantage the poor and uneducated members of society is countered with evidence that patronizing and infantilizing the poor also disadvantages them.

Kapp recognizes the moral hazards of the consumer-driven model, and acknowledges that it would require consumer protection and regulation to make

the marketplace work fairly. He sees consumer protection as including protection of choice, and cautions against ideological close-mindedness. For example, a consumer-driven approach that protects consumer choice could also promote solidarity through consumer empowerment. “I’ve come to realize,” Kapp recounts George McGovern’s summation, “that protecting freedom of choice in our everyday lives is essential to maintaining a healthy civil society. Why do we think we are helping adult consumers by taking away their options? ... The nature of freedom of choice is that some people will misuse their responsibility and hurt themselves in the process. We should do our best to educate them, but without diminishing choice for everyone else” (McGovern, 2008).

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Tully, S. (March 17, 2008). *Fortune*, 143, 146.

BEYOND HEALTH INSURANCE

The ultimate goal of health care reform is to better distribute health care resources to improve the health of the population and to minimize suffering. What if we could accomplish the latter by interventions outside of the health care delivery system? For example, over the last decade in the U.S., we have seen a disturbing increase in extreme poverty, homelessness, and unemployment, which have more direct correlations with poor health outcomes than lack of health care access alone.

Marion Danis, Head of the Section on Ethics and Health Policy in the Department of Clinical Bioethics at the National Institutes of Health, brought conference attendees’ focus aptly to the issue of

socio-economic influences on health and health disparities. For example, general practitioners in Blackpool, England, observed that deteriorating local economic conditions caused sleeplessness, depression, and substance abuse among their patients. This was often linked to the patients’ worries about indebtedness and other socioeconomic concerns. Universal health insurance alone did not address these health disparities; interventions from outside of the health sector were required.

Causal theories for these health disparities include the the psychosocial model (i.e., racial and class discrimination causes stress and neuro-endocrine responses that lead to poor health outcomes), the social production theory

(i.e., Capitalist priorities for accumulating wealth are achieved at the cost of the disadvantaged) and the eco-social theory (i.e., social and physical environments interact with biology to cause disease).

The WHO Commission on Social Determinants of Health proposes ways to address these disparities, including upstream interventions (e.g., reducing poverty) and downstream interventions (e.g., mitigating the effects of socio-economic factors). Policy solutions involve many sectors beyond health, such as education, physical education, health education, labor, employment, housing, transportation, and urban planning (e.g., public transit, side walks, trails, parks,

Cont. on page 10

*Moral Assumptions of Health Care Reform
Cont. from page 1*

tages—not just health disadvantages but disadvantages to their whole way of life;

- Access to health care is too morally important to be dependent on individual good luck or judgment;
- Individual health and well-being is best achieved if all Americans have health insurance.
- Individual citizens have a moral obligation to have health insurance—it is unfair to impose the risks and burdens of one's ill health on others.

Most likely, identifying which approach is “more just” is a losing proposition. When core values defining one's concept of social justice are in conflict (e.g., individual autonomy and beneficence as they relate to the individual insurance mandate), what results is an ethics show-down. Can only one side “win” the ethics argument? Faden hinted at possible bipartisan reform solutions, with the ultimate ethical justification for superiority resting not only in ideology but in outcomes. Which approach best achieves universal access to comprehensive medical care? Which approach will be most likely to reduce the most egregious injustices? But ultimately, Faden pointed out, we cannot answer the priority-setting question without first getting clear on what the ultimate goal is.

*Case Study
Cont. from page 7*

In the case under discussion, the concepts become somewhat murky because we are talking about a resource that may at times be in scarce supply—blood or blood products. The situation is not the same as allocation of organ transplants where the demand consistently outstrips supply and there is almost never an equilibrium. In the case of blood, at times there may be excess and at times there may be insufficient amounts. With blood there is a greater ability to replenish a supply or to shift resources, although at times the emergent nature of the need for blood may not allow such replenishment or transfer of existing supplies. In those cases, however, which

must be truly rare, where an institution has only a limited supply of blood and cannot obtain additional supplies in the time they are needed, and more than one patient needs the blood, a decision based on who can best benefit from that blood may need to be made. That would be a rationing decision. In all other cases, it would seem inappropriate for a physician to make a decision not to provide blood to someone who may benefit from it, even if the physician believes someone else might benefit from it more. A physician treating an individual patient cannot know what the other needs for blood are in the system or how quickly a regional blood bank can replenish its supplies.

In this case, the issue of whether or not to provide additional treatment to the patient should have been made simply on whether the treatment could be of any benefit to the patient. The issue of the impact on the blood supply and the fact that the patient was a Medicaid patient were wholly irrelevant to that determination. I believe it is the role of the physician, rather than the family, to decide when treatment is futile or of no medical benefit. Although this line of futility can be a difficult one to draw, there has to be space for such a decision by a physician. If we don't allow for it, physicians will be forced to provide care that is of no benefit — except perhaps emotional benefit to the patient's family. More work clearly needs to be done on defining “futility,” and an effort on the part of physicians to come to a consensus on such a definition in certain cases would be a significant step forward in resolving these cases.

As regards the physician's remark to the patient's family about the patient's Medicaid status, the remark was insensitive and inappropriate. This is what makes most of us cringe at the thought of providers using cost or ability to pay as a basis for health care decision-making. Our health care system is already biased at least as regards access to those who do not have medical private health care insurance. To allow ability to pay or source of payment to become a factor in receipt of medical treatment would further divide our system of health care

for the haves and have nots.

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*Beyond Health Insurance
Cont. from page 9*

etc.). Individuals are helped to take personal responsibility for their health by addressing upstream needs, such as pre-school education or day care for working parents, after school programs, community college enrollment, English language training, and job training programs. Health service access barriers not typically considered are addressed, such as pre-natal and post-natal home visits, reduced co-payments for non-smokers, housing supplements for home ownership and housing repair, neighborhood policing, and reduced fares on public transportation.

In some low income neighborhoods, incentive programs have improved access to grocery stores with healthy food choices, nutrition at school community centers, programs to reduce violence, to promote exercise and other healthy behaviors, and to deliver cognitive behavioral therapy in community settings. Considering the costs to society of preventable deaths, illness, lost labor and productivity, redressing these health disparities is not only an ethical obligation, but stands to offer a substantial return on investment. Danis points to historic American precedents: the GI bill, and the Serviceman's Readjustment Act of 1944, with an estimated seven-fold return on investment in the form of taxable income from beneficiaries of these programs.

In summary, health care reform is necessary but not sufficient to reduce health disparities. Substantial human and economic costs will continue to accrue if we ignore this reality.

CALENDAR OF EVENTS

APRIL

- 24 Practical Clinical Ethics. Sponsored by Harbor Hospital's Ethics Committee. Harbor Hospital's Baum Auditorium at 3001 South Hanover Street, Baltimore, MD. For more information, contact Sally Lewis at 410-350-8218.
- 29 Ethical Dilemmas in Research Involving Children: Damned whether you do or you don't. SUNY Downstate Medical Center, Brooklyn, NY. For more information, call Alice Herb at (718) 270-2752 or e-mail aherb@downstate.edu.

MAY

- 6-7 The Patient Alone: Making Health Care Choices For Patients Without Surrogates. Sponsored by American Health Decisions. John Hancock Hotel & Conference Center, Boston, Massachusetts. For more information, visit <http://www.ahd.org/conference.html>.
- 8-9 Ethical Challenges in Surgical Innovation. Sponsored by the Cleveland Clinic. InterContinental Hotel, Cleveland, OH. For more information, call (216) 932 3448, or visit <http://www.clevelandclinicmeded.com/live/courses/2008/ethicalsurgery08/faculty.htm>.
- 13-14 Seeing Making Healing: Art, the Arts, and Creativity in Medicine and the Medical Humanities: The Sixth Annual Meeting of the Pennsylvania Medical Humanities Consortium. Carnegie Museum of Art, Pittsburgh, PA. For more information, call (412) 647-5700.
- 14 More is Not Always Better: Seeking Value in End-of-Life Care. Sponsored by the West Virginia Network of Ethics Committees. 2008 Stonewall Resort, Morgantown, VA. MHECN members receive a 20% registration discount. For more information, call (877) 209-8086 or e-mail cjamison@hsc.wvu.edu.

JUNE

- 2-6 The Future of Bioethics—How It Began. Where It's Going. The Kennedy Institute of Ethics Intensive Bioethics Course. For more information, visit <http://kennedyinstitute.georgetown.edu/courses/ibc/ibc2008.htm>.
- 14 How Do I Determine if My Patient has Capacity to Make Medical Decisions? Assessing Decision Making Capacity. Fromm Institute for Lifelong Learning, University of San Francisco. San Francisco, CA. For more information, visit <http://www.cpmc.org/services/ethics/seminar.html>.

JULY

- 17-19 Nursing Ethics Health Care Policy: Bridging Local, National & International Perspectives. Yale University School of Nursing, 100 Church St. South, New Haven, CT. For more information, visit <http://nursing.yale.edu/Centers/International/EthicsConference/>.
- 14-17 Building clinical ethics capacity, bettering patient care. Clinical Ethics Summer Institute, Hamilton Health Sciences. Hamilton, ON (Canada). For more information, visit <http://www.clinicalethics.ca>, or e-mail info_clinicalethics@hhsc.ca.

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