Special Issue on Medicine, Law, and Bioethics

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**The Art of Making Canoes**

The art of making canoes involved much ritual and ceremony and was the exclusive domain of men.

It was, however, the goddess Hina who presided over the ritual of selecting a proper tree and laying out the vessel.

When Hina assisted canoe makers she took the name Lea and assumed the form of an elepaio bird. This bird has a voracious appetite for tree-boring insects and flies. If the bird pecked on a tree, canoe makers would know it to be fouled by insects or worms; they would not cut such a tree.

The positioning of the bow and stern of a canoe would also be determined by the habits of the bird. Where the elepaio first landed on the felled tree was to be the bow. Where the bird walked thereafter would be the stern.
In Memoriam— J.I. Frederick Reppun MD

On March 15, 1995, Destiny dealt a fatal stroke by snatching from us our dear colleague, a compassionate physician, and a pillar of our community.

J.I. Frederick Reppun, 81, a physician who practiced medicine for more than half a century, continued to treat patients until March 10, 1995, and made his patients feel special. And yes, even on March 10, 1995, his patients found comfort and hope in his caring.

Truly a family physician he was! He ministered to children, adolescents, adults, elderly and even delivered babies. While practicing on Molokai, he once delivered twins whose combined weight was 19 pounds!

Dr Reppun was a pioneer in patient care for Windward Oahu. He was one of the founding members and fund-raisers for Castle Medical Center in Kailua where he served as chief of staff.

A man of principles he made a statement when he refused to carry professional liability insurance required as a condition for medical staff privileges at Castle Medical Center, although he continued to see patients in his office.

Our colleague gave his utmost energy to the medical profession. He gave countless hours to the Hawaii Medical Association and worked diligently as the editor of the Hawaii Medical Journal. He earned the well-deserved 1974 HMA Physician of the Year award.

Fred’s horizons were not limited to medical practice. He had vision for the safety of future generations—he had seen two world wars. He provided the much needed leadership to the Hawaii chapter of Physicians for Social Responsibility to prevent nuclear war. He collaborated with physicians in the United States and other countries and invited physicians from Russia to give lectures on the effects of nuclear disasters.

Fred was a family man: A dear father of seven children—Martha, Charlie, Tom, Paul, John, David, and Josh—and a loving grandfather to nine. For many summers, he took some of the children and grandchildren on vacation to Kailihawai Beach on Kauai where he provided a true sense of family to the children and grandchildren.

Fred was a community man. He gave his time to young children interested in a medical career and encouraged them by sharing his personal experiences and the valuable insights of his life. His son John derived inspiration from his community work and assumed a leadership position to save Heeia meadowlands in Kaneohe. Sons Charlie and Paul joined John to keep Waiahole Valley water on the Windward side and not diverted to the Ewa Plain.

What a profile in courage! He recently had back surgery to repair a long-term injury from a fall from a ladder. Wow! Within four days, he left the hospital to return to his home and continue his daily activities, including consulting some patients, and yes, he did walk on March 14, 1995.

Fred had fulfilled his purpose of life. It was a stroke of Destiny that took his wife Jean from him in 1981, exactly 15 years to the month prior to his own death, and now another stroke of destiny took him away at 81 years of age.

Oh dear colleague—painfully, we miss you. Affectionately, we remember you. Fondly, we will continue to be inspired by your deeds.

Krishna Kumar MD

Fred Reppun MD is Gone

The Hawaii Medical Journal has lost its past editor (1985 to 1993) and a good friend and supporter of the Journal for many years.

When I assumed the editorship of the Journal, Fred warned me “it would be a lot of work” and he was right. But he encouraged and supported me and our staff “to keep the Journal going,” and we are—thank you, Fred.

We are not able to publish Fred’s last commentary in this issue of the Journal, “The Physician as Patient: The Thallium Treadmill Stress Test” will appear in a future issue. Fred sent it to me one week before he died—in his sleep at his home—as he wanted.

Mahalo nui loa and aloha, Fred.

Norman Goldstein, Editor
The earliest reference to a code of ethics for Hawaii physicians was reported by Dr Harry Arnold in the Hawaii Medical Journal (1956:15). In 1895 the Medical Society of Hawaii reactivated and adopted the Principles of Medical Ethics of the AMA. It is unknown whether the Society that was founded in 1856 ever had a formal code of ethics. The Hawaii Medical Association has traditionally adopted the American Medical Association’s Principles of Medical Ethics as the code for Hawaii.

The Role of Ethics and Law in Medical Education

S.Y. Tan MD, JD
Professor of Medicine and Adjunct Professor of Law
John A. Burns School of Medicine
University of Hawaii

The new intern approached the bedside of his assigned patient, an 85 year old in the intensive care unit. The senior resident barked “…keep her alive, no case is ever hopeless. That’s what the attending and the family want.” What faced the intern was a limp, frail woman with multi-organ failure, paralyzed by the hemorrhagic stroke that brought her to the hospital three weeks before. He quietly counted the tubes attached to her body: A nematode-like plastic leading to the respirator, three intravenous lines, a foley catheter, an arterial line, a naso-gastric tube.

And now she needs a chest tube; a pneumothorax had developed overnight, presumably from the increasing PEEP her ventilator was calibrated to deliver. The intern wondered who would sign the consent form, then quickly dismissed the thought since he knew she would surely die without it. None of the doctors had tried to find out what the patient’s preferences were.

The above scenario plays out daily across the nation’s ICUs. Physicians, many still in training, are called on to make decisions with grave ethical and legal implications. Who gives consent for a medical procedure when the patient is unable to communicate? When can treatment be stopped in order to allow a peaceful death? Is letting go the same as physician-assisted suicide, or active euthanasia, and what does the law have to say about this? Is there a duty to perform CPR in the event of a cardiac arrest?

These are relevant and serious questions that touch on life-and-death as much as a decision regarding surgery or blood transfusions. Doctors face other equally important ethical questions that speak to competence, credibility, and integrity, in short, professionalism. Examples are the physicians’ ethics in dealing with the pharmaceutical industry, their conduct in scientific research, their approach to impaired colleagues, and their resolution of conflicts of interest in the course of practice.

Ethics ought to be therefore an integral part of the curriculum in medical schools and in postgraduate residency programs. Medical students and young doctors need to learn how to recognize and competently analyze ethical problems, and when to ask for consultative assistance. Many bioethical issues are of

Editorial

Words of Wisdom
April 1995

This issue of the Hawaii Medical Journal has many words of wisdom. Words from the best minds in the medical and legal professions in Hawaii. Words from physicians who practice medicine, words from physicians who are lawyers and practice medicine, and attorneys who advise, consent and, at times, defend physicians. We also have excellent manuscripts by philosophers and theologians. The manuscripts by George Burnell MD and S.Y. Tan MD, guest editor for the special issue, are especially poignant.

Many thanks to the authors, their secretaries, the Hawaii Medical Library, and the Richardson Law Library staffs.

My deepest appreciation to S.Y. Tan. This special issue will serve as required reading for our medical students and our law students. Mahalo nui loa, S.Y.

Norman Goldstein MD, Editor

Historical Notes

John A. Breinich
Executive Director
Hawaii Medical Library

Medical ethics codes have a very long history dating back about 2000 years to the Babylonians and the Code of Hammurabi, the earliest written code of ethics. This was a code of conduct for physicians dealing with surgical procedures and with details of the penalties for various offenses.

Hippocrates was born in 460 BC on the Greek island of Cos. The oath bearing his name was probably not written by him, but rather by the Pythagoreans, a philosophical sect started in the latter part of the fourth century BC. A Christian version of the Oath was written in the tenth or eleventh century AD to eliminate references to pagan gods. Today, the English version of the original Oath is most frequently used and quoted.

Many codes have been written over the centuries, but the contribution of Thomas Percival (1740-1804) is perhaps the most significant. He was an English physician, sociologist, and philosopher whose 1803 treatise was a prototype for various codes of ethics, and particularly influenced the code created at the first official meeting of the American Medical Association in 1847. The AMA code has changed over the years to reflect changes in language and ideas with major revisions in 1903, 1912, and 1947, but the basic structure and philosophy were still based on Percival’s Code. In June 1957 a major revision of the Principles was adopted consisting of 10 short sections with a preamble, significantly changing the format of Percival. In 1980, the AMA adopted a revised Principles of Medical Ethics to update language, remove references to gender, and seek to balance professional and legal standards.

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These are relevant and serious questions that touch on life-and-death as much as a decision regarding surgery or blood transfusions. Doctors face other equally important ethical questions that speak to competence, credibility, and integrity, in short, professionalism. Examples are the physicians’ ethics in dealing with the pharmaceutical industry, their conduct in scientific research, their approach to impaired colleagues, and their resolution of conflicts of interest in the course of practice.

Ethics ought to be therefore an integral part of the curriculum in medical schools and in postgraduate residency programs. Medical students and young doctors need to learn how to recognize and competently analyze ethical problems, and when to ask for consultative assistance. Many bioethical issues are of
recent vintage, a result of our new technology that keeps patients
alive, though not necessarily well. Sometimes the ethical dilem­
mas are not easily solved, but the need to address the issues
remains. At a minimum, this will lead to better and open
communication. Doctors-to-be must be equipped with analyti­
cal tools to tackle new ethical issues. Already, questions of
confidentiality, privacy, and choice surrounding informatics,
the new genetics and managed care increasingly confront us.
Some of these issues will tear at the ethical fabric of the
physician-patient relationship, pitting duty to patient against
responsibility to society and third-party payers.

Physicians should also be aware of the positive role that the
law plays in medicine—that of ensuring quality and affordability
of care, access, and patient autonomy. Because of the ever-present
threat of a malpractice lawsuit, beleaguered doctors understand­
ably view the law more as a hindrance than a help. Health law
covers more than just malpractice litigation; it also addresses
antitrust, statutory regulations such as those governing patient
transfers, access, and HIV-infections, peer review and creden­
tialing activities. Hospital law is another specialized area. Fi­
nally, it is American law, more so than medicine, philosophy or
theology, that drives American bioethics. It can be reasonably
concluded that a case-oriented course in legal medicine will be both attractive
and useful to all students.

At the University of Hawaii John A. Burns School of Medicine, the
problem-based learning (PBL) curriculum readily admits the discussion of ethi­
cal issues within the medical problems
that students are required to work through. Such issues are introduced into case dis­
cussions. Junior and senior students also
employ problem-based learning modules
during their clinical rotations. There, stu­
dents debate real-life ethical issues under
the guidance and facilitation of a faculty
member. Residents and students also part­
cipate in lectures, seminars, case discus­
sions, and bedside rounds that regularly
feature bioethical and legal questions.
Finally, trainees are encouraged to access
hospital ethics committees that convene
to resolve difficult treatment decisions.

There is more to be done. For ex­
ample, a center or department of ethics
and health law could be established. Such
a structure will better coordinate, review
and expand the ongoing educational ac­
tivities. It can pool and focus community
resources to foster academic growth, in­
cluding research. It can tap the faculty in
the academic community such as law,
nursing, the humanities, and public health.
Such integration augurs well for a disci­
pline that transcends traditional pedagogi­
ical lines, with promise of academic rich­
ness and rigor. The patients will be the
ultimate beneficiaries when the school of
medicine and its teaching hospitals work
together to bring clinical ethics to the
bedside.

Multiethnic Hawaii serves as an ideal
research laboratory for the study of trans-cultural bioethics and law. This
should attract visiting bioethicists from
around the world to conduct collabora­
tive studies at our medical centers, thus
enhancing our own research and develop­
ment.
HMA Alliance

Legislative Watch
Scott Carrothers
Legislative Chair, Hawaii County Medical Society

Health care reform is not dead! Nineteen ninety-five is going to be an interesting year to say the least. The mad rush is on to submit bills and changes that will affect important aspects of health care and physicians, most notably in the areas of QUEST and workers comp reform.

There have been more than 25 bills introduced this session regarding workers comp, some with just a few sentences, others with stacks of pages. The general trend is to look at ways of “managing the medical costs” as they are among the highest. On Saturday, February 4, there was a public meeting on workers comp reform. Naturally the unions, insurance companies, and the Chamber of Commerce were all well represented and expressing their views. At this time I don’t have any information about who was representing physicians or HMA, nor what was voiced.

QUEST membership continues to grow beyond the original projections. There are now more than 120,000 covered by QUEST as compared to the original estimated 110,000. There continues to be approximately 2,000 applicants per month with only approximately 1,000 applications being processed creating quite a backlog. Funding will be a problem as enrollment continues to grow above projections, especially in light of the existing budget constraints. Consequently, the next phase of QUEST to include the aged, blind and disabled (originally estimated at approximately 30,000) which was supposed to occur in 1996 has been shifted to 1997.

Another bill in the works but not yet submitted proposes to change the pharmacy laws regarding prescription-dispensing authority. This is a revised strategy from last session’s failed attempt to authorize nurses’ prescription authority, but may open a Pandora’s box in several areas, not just with nurses.

There is also a bill awaiting submission requiring an annual audit of HMSA, which is sure to provide interesting debate.

Senator Andy Levin introduced Senate Bill 1674, an Omnibus Bill, relating to community hospitals’ autonomous operation. The HMA and HCMSA have voiced their support of this bill to provide more autonomy for Hilo Medical Center.

On February 7, members of the legislature met to address some of our concerns. It’s obvious, though, that there are many possible changes coming down the road, and not all of them good for physicians or their patients. The better informed, better organized, and better prepared we are, the better our chances are of protecting our own interests and the interests, health and welfare of those we are pledged to serve—our patients. It will happen only if we get involved!

The AMA Alliance Confluence: 1995
Verna Lau, President-elect

The AMA Alliance Confluence was held on January 27 to 31 in Chicago. Medical Alliance representatives from the county and state levels were able to meet one another and national represen-
tatives. This meeting proved to be four days of opportunity for state and county medical alliance members to share their ideas and feelings regarding legislative issues, health projects, and membership dilemmas. Confluence representatives were showered with kindness and generosity from the national board members and Alliance staff members. This was a great way for local and state members to gain exposure to the hardworking and influential organization.

Both state and county Alliance members were assigned to workshops on managerial and health-related issues. These included parliamentary procedure, domestic violence, time management, creating healthy educational programs, legislative updates, speech preparation, AMA-ERF updates, and the latest news from the strategic task force.

The highlight of the Confluence was probably the exhibit fair. Each state had the opportunity to share its special health project and/or Alliance-related activities. A great deal of pride was generated by these Alliance members as they shared their ideas with other state Alliance representatives. There was an overabundance of positive energy that filled the atmosphere during the course of the Confluence. It’s probably comparable to having a battery charge. This motivated the local and state representatives to take back to their respective committees a bit of the positive energy and a lot of ideas.

Book Review

Legal, Ethical, and Political Issues in Nursing

Legal, Ethical, and Political Issues in Nursing is a well-written book that could serve either as a text for the classroom or a reference book destined to be dog-eared and often borrowed. It is well researched with many contributors from nursing and law, balanced with nursing educators and administrators as consultants.

The book presents a basic description of the law and details those aspects of the judicial system with which many health care providers will become all too familiar. The author’s intent is to educate students and practicing nurses with legal, ethical, and political issues that affect their practice and profession.

Each chapter is illustrated with case examples, practice tips, and highlighted boxes of important information. A summary, study questions, and points to remember follow. The chapter concludes with “Ethics in Practice,” a four or five-paragraph ethical situation the reader is to work through using ethical decision-making concepts. The problems presented are those a nurse might confront in everyday work life.

In addition to a specific chapter on the law and ethics, the book devotes chapters to such topics as: Standards of Care, The Nurse and the Lawsuit, Informed Consent, Common Causes of Negligence and Liability, International Torts, Professional Liability Insurance, Liability of Nursing Supervisors, Hospital Liability and Employment Issues, Contracts, and Documentation. The
Appendices provide a good treatment of Lobbying, the Americans with Disabilities Act, and Harassment and Discrimination. An instructor's manual is available with case examples and charts for classroom discussion, examples of legal pleadings, and test questions for each chapter.

*Legal, Ethical, and Political Issues in Nursing* is a book that I recommend for use in nursing education programs as well as for purchase by health care professionals looking for a good resource.

Reviewed by Rene McWade RN, MEd, JD

Rene Y. McWade is an attorney and a registered professional nurse. A graduate of the University of Hawaii William S. Richardson School of Law, she received her BSN degree from the University of Hawaii School of Nursing, and obtained her master's degree in education in health, physical education and recreation from Colorado State University. She is currently Administration Risk Manager for the Division of Community Hospitals, Department of Health, State of Hawaii.—ED

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**HMA President’s Message**

**Frederick C. Holschuh MD**

Although I have not read the articles, I have looked over the titles of the presentations for the special issue of our *Hawaii Medical Journal* on medicine, law and bioethics with guest editor S.Y. Tan MD. It appears to be an impressive collection of articles. We are faced with decisions daily regarding the end-of-life process. We, as the leaders in the health care team, need to make decisions for families easier by participating with them in an honest and involved manner. We can’t put the burden of end-of-life decisions solely on loved ones by saying, “What do you want us to do?”

In my 24 years of emergency medicine practice, I have been saddened by our inability as physicians, the leaders in health care expertise, to effectively deal with the dying process. Over the past seven or eight years, I have developed a system that works well for me regarding continuing resuscitation or code status. As soon as the rescue unit arrives with a futile code, after a quick look, I talk with the family to prepare them for the potential of death. I then continue the attempt at resuscitation as medically indicated. When it is time to stop the resuscitation efforts, the family has been prepared and we can make a sensible, joint decision.

It is critical for doctors not to ask, “Do you want us to ‘Do everything’ for your dad?” No family can say no. We can very honestly and effectively assist them by explaining to them what the do-everything approach really means in a futile code. We should also give compassionate advice on the decision and not expect them to make it alone.

Over a number of years I have also asked family members if they wish to be with their loved one when we stop resuscitation. If they choose to do so, we will cease CPR and turn off the monitor in their presence. This has been a very uplifting experience for families, and I must admit an emotional one for the emergency department team and for me.

I had a very interesting experience a year or so ago where the MICTs brought in an elderly, chronically ill woman with full CPR in progress. When the daughter and others arrived (the primary caregiver had not been home), they presented her living will stating *No CPR* and a durable power of attorney. Her request was to die in her home. We stopped everything, pulled all the tubes, and she went home in a private car and died peacefully. I pronounced her dead about three hours later when she was returned, and the family was very grateful that her wishes had been honored.

I recently mailed out the AMA Council on Ethical and Judicial Affairs report regarding ethics and managed care. I hope everyone will pay close attention to these principles as changes in health delivery occur.

In this regard, my old friend and former Queen’s house officer, Dr Robin Cook wrote a book on managed care entitled *Fatal Cure*. Although a bit sensational, it is interesting reading and raises some very provocative questions. One quote from the book: “I’m afraid the major concern is the bottom line on the balance sheet, not patient care.”

Let’s make sure in all of these discussions that the overriding concern of all of us is the best care for our patients. Thanks again to Dr Tan and the other authors on behalf of all of us in HMA.

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**Military Medicine**

**Benjamin W. Berg MD**

Department of Medicine
Tripler Army Medical Center

Widespread right sizing of governmental organizations has begun to take effect within military medicine. The Department of Defense will respond to congressional mandates over the next few years to streamline medical services with a variety of strategies. Current mandates are to provide care to active duty troops during times of both conflict and peace, for the families of the active duty troops, and for the retired soldiers who served in military careers. To accomplish this mission there is a network of facilities from small clinics to large tertiary care hospitals throughout the world. In the Pacific theater there are facilities in Japan, Korea, Thailand, Okinawa, Guam, and Hawaii, with Hawaii facilities serving as a referral center for this network. There undoubtedly will be a significant change in the medical capabilities in concert with the rest of the defense structure of our nation. We have embarked on a project of enrolling Champus-eligible dependents in Triicare, a managed care system of cost sharing and cost shifting in which primary care will be provided by a network of civilian providers. Spe-
cialty and subspecialty referrals will be made to civilian providers when services are not available within military health care facilities. These providers will be our colleagues in the community, with whom military physicians will develop close working relationships.

Another strategy that will permit downsizing of the military medical capability includes reduction in the number of graduate medical education programs, which have been a source of career officers for many years. Graduate medical education in the U.S. Army has been shrinking for the past few years and many fellowship and residency programs have closed. All fellowship programs will be relocated to Washington DC or San Antonio, Texas within the next few years. Tripler Army Medical Center has been fortunate to retain its full compliment of medical, pediatric, family practice, surgical, obstetric/gynecology, radiology, and psychiatric training programs. The pathology residency at TAMC will not be enrolling new residents this year, our only casualty.

As we enter this new era of military medicine, it is likely there will be consolidation of services across services. Tripler has been a test-bed of cooperative efforts in this arena. Navy and Air Force physicians are assigned to TAMC in the departments of surgery and psychiatry. This trend is likely to continue, with increasing numbers of the Army Medical Center’s physicians emanating from other services. Likewise, the Army has begun assigning physicians to Air Force and Navy facilities in an effort to most efficiently utilize the resources of the combined medical corps.

In Hawaii we look forward to the growing professional relationships that will undoubtedly result from the Tricare initiative. We will share in the care of patients and develop closer relationships with our civilian colleagues.

Food for Thought
“Commonly physicians, like beer, are best when they are old; and lawyers, like bread, when they are young and new.”

Thomas Fuller (1608-1661)
HMA Council Highlights

March 3, 1995
Roger T. Kimura MD, Secretary

The HMA Council meeting was called to order at 5:42 pm by Dr Frederick C. Holschuh, President.


Guests were Messrs Marvin Hall, Robert Hiam and Bernard Ho of HMSA and Ms Susan Johnson, a private consultant for Queen’s and Kuakini Medical Centers.

Staff members present were J. Won, B. Kendro, L. Tong, J. Asato, J. Estioko, P. Kawamoto, and Recording Secretary A. Rogness.

Dr Holschuh reported he is paying his own way to Ponape to represent the HMA at a conference. Many years ago, Mr Won and a few physicians were invited to Ponape to help establish the Micronesian Medical Society based on the HMA Charter and Bylaws. Over the years the Micronesian Society dwindled and the documents were lost. Dr Holschuh was invited to Ponape and will take another copy of the HMA Charter and Bylaws to help reactivate the society.

Actions

1. A motion was passed by Council that the HMA take a grassroots approach and send a brief informational generic letter on workers compensation to members and nonmembers to use to send to legislators.

2. Council approved the Legislative Committee’s recommendation to submit the following statement if the issue of the Health Council is heard at the Legislature: The Hawaii Medical Association: 1) wholeheartedly supports the concept of and diligent work of the Vision 2000 program; 2) urges continued efforts to move forward the proposed federal bill; 3) supports the formation of a Health Care Council under private auspices.

3. Council approved Dr Don’s motion, as chair of the IPN Steering Committee, that the HMA Council approve the concept of the joint venture between the HMA and PMAG to establish a statewide IPN and to continue negotiations to finalize the joint venture to be presented to Council for final approval. The written IPN/PMAG joint venture proposal will be sent to Council members prior to the Council meeting to allow for their review. Written material for any important Council agenda items will be mailed in the same way.

4. HMA has been asked by Dr Robert Whang, Assistant Dean for VA Affairs of the John A. Burns School of Medicine to co-sponsor in name only a seminar on alternative medicine to be held in the fall. An agenda/proposal will be presented to Council before any decision is made whether to support such a seminar. A motion was passed by Council that the alternative medicine seminar consider including some time for opposing viewpoints.

5. Council approved the HMA Annual Meeting and Arrangements Committee’s recommendations: 1) 1995 annual meeting fees and the proposed budget. (Same fees as 1994; cost of exhibitor booth space will increase from $900 to $950 because of less exhibitor booth space); 2) the 1996 annual meeting is to be held at the Kauai Marriott and Beach Villas (formerly The Westin Kauai), October 17 to 20, 1996. This date will not conflict with other specialty society meetings.

Component Society Reports

Honolulu.—Dr Howard reported 1) the HCMS is working on a universal generic medical ID card designed to be accepted by all hospitals. The HCMS will make and provide the cards as a service; 2) the HCMS is proposing that the HMA and the HCMS combine their efforts and publish one bulletin instead of a separate HMA Newsletter and HCMS Bulletin. It was pointed out this would save on duplication of information and be cost-effective. There were a number of concerns raised by Council. The issue was referred to the HMA Publications Committee.

Hawaii.—Dr Kadooka reported a membership meeting was held where Dr David John spoke on arthritis at the Hilo Yacht Club.

Maui.—Dr Joshi reported that Dr Schlesinger, co-chair of the Committee on Physicians’ Health, will be speaking at the county meeting in March, a cardiologist will be speaking in April, and a talk on new advances in plastic surgery in May.

For Information

HMSA old/new.—Mr Marvin Hall is retiring from HMSA in April and he thanked HMA for the good working relationship between the two organizations. He also introduced Mr Robert Hiam who will be filling his position.

Credential Verification Service (CVS).—Ms Susan Johnson, a private consultant for the Queen’s and Kuakini joint venture, gave a presentation on the CVS the two hospitals wish to organize. Her research indicates the feasibility of this service is good. The CVS organization does not exist now and HMA is invited to work with the CVS to work out the details. The HMA will be given a voting seat on the board (no funding required). The intended benefits of this service to practitioners are time saving and convenience. It will be a for-profit service and will be funded by the hospitals and the managed care programs. The organization will not assess physicians any fees. The CVS will not be intended to be a reporting or disciplinary body. The purpose of the service is to eliminate the amount of paperwork. A generic standardized application and a single reappointment date for each practitioner will be developed. Dr Holschuh will have discussions with Queen’s and Kuakini and get back to Council.

QUEST.—Dr Jim Budde and HMA staff worked on the QUEST survey sent to HMA members. An immediate response has been requested.

Public Relations Committee.—Dr Lehman informed Council 1) that the Distinguished Medical Reporting Awards Banquet will be held on Saturday, April 29 at the Hilton Hawaiian Village, Tapa Ballrooms 1 and 2. Billy Sage will be the master of ceremonies and Marvin Hall of HMSA will be roasted. The tickets are $100 per person or $1,000 per table. 2) The Great Aloha Health and Fitness Expo held mid-February was a success. The Girl Scouts from Kaimuki Christian Church covered the anti-smoking booth and did an excellent job. Another booth presented height and weight. A third booth demonstrated in-line skating safety and HMA raised enough money to buy three sets of protective gear. HMA Drs Carl Lehman, Amy Ebisutani, Roger Kimura, Ron Peroff, and HMA staff donated their time during that busy weekend.

RBRVS.—Dr Kunimoto reported that this is the year for the five-year RBRVS review and AMA is asking for input from medical and specialty societies. The first meeting with specialty societies was on March 3 and the next RBRVS meeting will be held mid-April. The AMA deadline is September when it will deliberate and prepare a report to Congress.
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Bioethics and the New Medicine: An Overview

S.Y. Tan MD, JD

The term New Medicine describes our new age of health-care reform and biotechnological discoveries. While offering hope for a healthier and more productive nation, New Medicine challenges us to come to terms with the cost, the complex social issues resulting from medical breakthroughs, and the limits to autonomy. A simplified ABC overview of some of the many bioethical dilemmas that now confront us are offered in this article.

A is for Affordability
America spends nearly 14% of its GDP on health care, about twice as much as other industrialized countries. Despite expenditures of nearly $1 trillion, some 37 million Americans are without health coverage. Even those who have health insurance are aghast at the high cost of becoming ill.

Medical expenditures continue to mount because of: 1) our aging population, 2) the increasing prevalence of chronic diseases, 3) new expensive medical technology, 4) a demanding citizenry, 5) physicians’ practice of defensive medicine, and 6) no personal incentive to minimize expenses. Managed care has been touted as an effective means to contain costs. Capitation will replace fee-for-service. Increased reliance on gatekeeping primary care providers is expected to curtail the overutilization of specialists and expensive testing. Because the incentive is to do less, not more, it is expected that managed care will reduce costs in the short term. What is of concern, however, is whether managed care will reduce the high quality of care that Americans expect and demand.

If we accept that our resources are finite, and medical costs will not abate, then we must accept that we cannot afford all the health care we desire. In order to assure universal access should we resort to rationing? One proposal is to offer a basic package to all Americans irrespective of their ability to pay. Those who want more will bear the added costs themselves. This approach pits the wealthy against the poor, and arguably violates the bioethical principle of distributive justice. On the other hand, if the basic health-benefit package is carefully defined, all patients should enjoy excellent medical care, forgoing only treatment that is experimental, unproven, desperate, futile, or prohibitively expensive.

B is for Breakthroughs
Medical discoveries are accelerating at a breakneck pace, due largely to breakthroughs in cracking the genetic code. We can isolate and clone genetic material that directs the production of vital body chemicals such as enzymes, hormones, and proteins. The National Institutes of Health are well into their multicenter Human Genome Project; scientists are expected to complete this task by the year 2010. The project maps the entire genetic structure and function of human cells, which will unlock secrets of cellular physiology and pathology. Treatment for once-incurable conditions will swiftly follow by replacing the missing or defective genes.

Gene drugs have apparently cured two young girls with severe combined immunodeficiency and are being used in experimental trials to treat such disparate diseases as cancer, hemophilia, hypercholesterolemia, and cystic fibrosis. In the near future, they will be standard fare in the fight against many other diseases including diabetes and hypertension. A brave new world of medical triumphs will mark the turn of the millennium. But these breakthrough technologies are likely to be expensive, threatening to stretch and strain our finite health care budget. And genetic engineering is likely to create new ethical dangers.

Understanding the genetic code allows us to control not only diseases, but also such things as eye color, height, and intelligence, since these attributes, like all cellular functions and products, are under direct genetic DNA control. Bioethicists are rightly nervous and suspicious about this new power to tinker with nature.

Take height as an example. We would surely welcome a genetic cure for a child stunted by growth hormone deficiency. Currently these children are treated with injections of human growth hormone, with only partial success. It is quite another matter, however, to select out tall progenies by genetic manipulation of otherwise perfectly normal individuals. Tallness is socially advantageous. Sports value it, the sexes crave it, and businesses reward it (six-foot graduates command a starting salary 12.4% more than their shorter classmates). Height even wins presidencies; the taller candidate was victorious in 80% of all presidential elections in this century. Once the height gene is cloned and clinically available, should parents be allowed to opt for taller offspring?

The new genetics will also identify aberrant gene markers that can predict a disease state long before it becomes clinically manifest. Such knowledge is likely to invite discriminatory practices in insurance underwriting and in employment. Genetic
testing additionally raises ethical and legal issues of consent and privacy.

Breaking the genetic code breaks the taboo against eugenics, that notorious science of improving the hereditary qualities of the human race. Prudence and history remind us that selfish tampering with nature frequently leads to unintended and undesirable outcomes. What moral code do we adopt to constrain the new genetics? Are we apt to repeat those Nazi experiments in eugenics to produce a superior race? Ethical guidelines lag far behind scientific strides, yet the genetic genie is virtually out of the bottle. Will the glare of its potential for good blind us to the evil it can unleash?

Another technological breakthrough of the New Medicine is the marvelous electronic communication systems that instantly record, collect, store, and transmit information. Medical charts will become obsolete. Poor communication, illegible record keeping, and misplaced prescriptions will thankfully disappear. Patient records will be instantly retrievable, as will the latest in medical research. Patient care will be dramatically more efficient.

But we risk losing the privacy and confidentiality of our medical lives by getting on this electronic information superhighway. The health care system is no longer just doctors, nurses and patients. It is now populated by assorted faceless health plan administrators, third-party payers, governmental agents, and purveyors of medical products. Protecting the confidentiality of these electronic records will require much care, foresight and sensitivity. Irrespective of the safeguards employed, one thing is clear: In the New Medicine, like it or not, many more in the system will know and share our medical profiles.

One other concern. Medical informatics threatens the doctor-patient relationship with its offer to take histories by computer, and physical examination and surgery by programmed robots. Meaningful personal contact with a health care provider, who may not even be a doctor, is likely to be brief. Advocates of computer medicine believe in its superiority, because the methodology employs outcomes-determined algorithms with proven cost-effectiveness. Others wisely ask whether high tech can ever supplant the high touch of the doctor’s hand, her placebos, and her humanity.

C is for Choice

Patient autonomy is a bioethical principle of recent vintage, an outgrowth of American laws governing privacy and liberty rights. Autonomy underpins many widely accepted western medical practices such as informed consent, living wills, and do-not-resuscitate orders. It properly empowers the patient with the control of her body, even for decisions that run counter to the doctor’s advice. But patient choice, like free speech, has its limits. Testing these limits of autonomy is at the heart of the current heated debate on two bioethical issues: Futile treatment and euthanasia.

Futile treatment can be defined as that which neither cures nor palliates. Examples of medical futility include treating patients in a persistently vegetative state, or condemning a patient to an irreversible permanent dependence on intrusive life support in an intensive care unit. Families are sometimes known to demand such non-beneficial treatment. Unfortunately, recent case-law appears to favor such family requests for continued expensive futile treatment. Should this trend continue, autonomy’s triumph over paternalism will wastefully bloat our health care budget deficit.

A final ethical dilemma: Euthanasia. Supporters of euthanasia assert that the right to die is the logical and ultimate expression of self-determination. Opponents, on the other hand, question the existence of such an absolute right, pointing to the sanctity of life and the dangers of abuse should mercy-killing be legalized.

Such abuse concerns led to the narrow 54 to 46 rejection of aid-in-dying initiatives in Washington and California in 1992 and 1993. However, this past November 8, voters in Oregon approved Measure 16, which sanctions any terminally ill patient’s request for drugs to end life. Around the same time, the Michigan court absolved Dr. Kevorkian of wrongdoing. Kevorkian is the pathologist who assisted in the suicidal death of 21 patients. It is easy to predict that legalizing euthanasia will rank as the premier ethical issue as we enter the era of the New Medicine.

Conclusions

The modern doctor faces a bewildering array of ethical dilemmas in the practice of her profession. The selection seems endless. In addition to those discussed earlier, we have test-tube babies and surrogate motherhood, life support for very low birth-weight infants and organ transplantation, to name just a few. Observers of America’s health scene lament that physicians are not very good at identifying or solving bioethical issues. Pertinently, one might ask whether and how our medical schools and teaching hospitals are preparing future generations of doctors to meet ethical challenges—those recognized and those yet undefined. Never before in the history of medicine has its art been more dangerously asynchronous with, and outpaced by, its science.
Entering the Age of the New Genetics with Eyes Wide Open

Sharon S. Ayabe, S.Y. Tan MD, JD

A concerted international effort currently is being made to localize human genes and to identify their role in specific diseases. This will enable physicians to test for a broader range of genetic characteristics and to manipulate human somatic and germ-line cells. With this new age of genetics comes a host of ethical issues and questions.

Introduction
Richard is 2 years old and his uncle just died from Huntington’s disease. His parents read in Reader’s Digest that a simple blood test could determine if he, too, will develop Huntington’s disease.

Malia, 35, is 10 weeks pregnant. She is requesting “genetic testing” on her fetus because she and her husband want to have “the perfect family.”

Susie is 21 and from Cleveland; she has been dating your patient Kimo. They recently visited her family on the Mainland, including a few cousins with cystic fibrosis and now Kimo is concerned that Susie may be a carrier. Today she presents at your office asking to be screened for the cystic fibrosis gene.

Any one of these patients may present at the physician’s office with questions concerning medical genetics. Questions which hitherto had been prefaced with if and when have now burst forth as the issues for the here and now. Ready or not, primary care physicians will move to the frontlines of this genetic revolution as they manage their patients’ requests and needs for genetic services.

Genetic Testing
Genetic screening is generally used in two arenas: 1) testing of presymptomatic individuals for medical treatment, and 2) testing of couples for reproductive decision making. Ideally, in the former case, people learn they have a genetic disorder and then receive effective treatment through conventional medical or genetic therapy. And in the latter, couples can decide whether they will risk conception, terminate a pregnancy, or prepare for the birth of an affected child.

Why Test if There is No Cure?
Almost everyone agrees that presymptomatic testing is appropriate when an intervention is efficacious when started before symptoms appear. But is testing beneficial when no cure for the disease is available?

For example, Huntington’s chorea is an autosomal-dominant disease that usually cannot be clinically diagnosed until the fourth or fifth decade of life. But it can be genetically diagnosed in an asymptomatic individual. Unfortunately, no cure exists for this mentally and physically debilitating condition yet. Individuals have approached their physicians requesting testing for themselves or their offspring hoping that they are not at risk. Usually they are unaware of the emotional and social harm stemming from a positive test result.

Some studies suggest that as many as one in 10 patients who test positive for the Huntington’s disease mutation never make a full emotional recovery. Even with professional counseling, a few have had to be hospitalized for severe depression and some have even committed suicide.

Individuals who test positive may be stigmatized. In the past, large screening efforts were made for sickle cell traits, Tay-Sachs disease, and Alpha-1-antitrypsin deficiency which led to adverse psychological consequences for parents of affected children. They felt afraid, worried, and anxious. Carriers of the sickle cell trait were stigmatized as being undesirable marriage partners and were socially ostracized. Additionally, children who test positive may become scapegoats who are abused because they remind their parents of their own unacceptable traits.

Similarly, Dr Bruce Ponder, who has been seeking the genetic marker for breast cancer at Cambridge University, worries that patients who test positive for cancer might actually increase their cancer mortality. Positive test results, by triggering depression, may actually worsen a patient’s chances of survival. Emotional stress, disturbed sleep patterns, and decreased appetite may all contribute to a diminished immune response and hasten disease progression.

On the other hand, a large study conducted in Canada suggested that knowledge of disease status can actually improve the quality of life. After they requested testing for Huntington’s disease and learned of their risk, many patients reported improved well-being, less anxiety, less depression, and general improvement in their psychological status than when they were living with uncertainty.

Clearly, for some people living with ambiguity is worse than bad news. For these individuals a case can be made for testing even if there is no cure. For others, ignorance is preferable to knowledge of impending disease. Those who request testing will need counseling and education regarding how the test result might affect them.

Primary care physicians are familiar with patients requesting a variety of diagnostic tests and medical therapies. They know
their patients well, and they are skilled at helping them understand the risks and benefits of medical services. When necessary, they do not hesitate to discourage certain patient requests believing that more harm than good would result. These patient-care skills, coupled with an understanding of the new genetics, will allow the primary care physician to assume the lead advisory role with regard to genetic testing.

Will Genetic Testing Enforce Fatalistic Attitudes?

Some critics have condemned the overemphasis, particularly in the media, on genetic causes of behavior and disease. They speak of the *geneiticization of society* and argue that over-expenditure of resources on genetic research will be at the expense of basic social needs, such as food, shelter, and routine prenatal care. "*Over-geneticization* can adversely affect individuals and frustrate the physicians who work with them.

Both genetic predispositions and environmental influences bear on a patient’s health. Yet some fatalistic patients blame their lack of health on everything except their poor lifestyle choices. Armed with knowledge of genetic markers for diseases like alcoholism and obesity, these patients will deny responsibility for their conditions all the more and may stubbornly refuse to participate in their health care.

If patients test negative for breast cancer, would they conclude that they no longer need routine breast examinations? If a patient were determined to be susceptible to coronary heart disease because of his or her genes, might this cause him or her to ignore dietary and exercise advice? To the extent that genes are seen as more important than the environment, our actions may be viewed as genetically determined, rather than as a result of free will. For example, some criminals have attempted to use the XXY *defense* arguing that their genetic composition predisposed them to criminal activities beyond their control. The XXY defense generally has been rejected in court.

The focus on genetic disease should not pull society away from personal responsibility. Fortunately, most patients understand how lifestyle choices affect their health. When reporting results of genetic screening to their patients, physicians must reinforce the notion that genetic predisposition is but one determinant of disease and emphasize suggestions for minimizing disease expression.

Will Defective Genes Invite Discrimination?

Predictive genetic testing reveals asymptomatic conditions that can manifest themselves later in life or can remain unseen. This information is not only of interest to patients and their physicians but also to their prospective employers and insurers. A recent article described 41 cases of discrimination against otherwise healthy people based solely on their genetic risk. In most cases, the victims were refused health or life insurance. Some were refused jobs; others were banned from adopting children. According to a 1991 survey conducted by the Congressional Office of Technology Assessment, only 12 of 330 *Fortune* 500 companies reported they were conducting genetic monitoring or screening. Roughly half of these executives thought genetic monitoring or screening would be acceptable, either for the benefit of the employee or the employer.

The Americans with Disabilities Act (ADA) ensures that handicapped individuals are not discriminated against in the job market. Applicants are considered qualified if they are able to meet all the program’s requirements in spite of their handicap. Additionally, the employer could be required to provide reasonable accommodations to make employment possible. However, the Equal Employment Opportunity Commission, the federal agency for enforcing the ADA, has stated that “physical or mental impairment” does not include “characteristic predisposition to illness or disease.” This narrow construct could mean healthy people can be denied opportunities based on conditions to which they are predisposed, while the symptomatic are protected from discrimination. This is unfair and irrational.

Consider insurance companies. Currently insurers may be satisfied with gleaning information from genetic tests already performed and will undoubtedly be gathering this information from applicants through questionnaires or medical records. Already children with genetic disorders may lose their health insurance when they become adults; this potential loss has often prompted geneticists to avoid seeking a definitive diagnosis. Thus far, state insurance commissions in the United States have placed genetic information in the same category as other types of medical information that insurers could legally require as a condition of insurance. However, legislation has been introduced in several states to allow people to keep genetic information, including family histories, from insurers. Such legislation would help protect people from discrimination, but may overburden insurance companies, especially life insurance companies, in their underwriting practices. Insurers have argued that if they cannot access an applicant’s genetic profile they will be at an unfair disadvantage—some individuals, on learning that they could develop a serious condition, will buy large amounts of insurance.

Patients with genetic predispositions to disease must have the right to pursue happiness through financial stability and productivity. Employers and insurance companies have the right to make a profit. In the new genetics, a victory for society should not be at the expense of any of these players. Insurance companies should provide coverage for those with genetic risks, with such policyholders paying modestly higher premiums for their coverage. Employers should hire these people and when reasonable they should accommodate their predispositions. For example, if current or prospective employees test positive for Alpha-antitrypsin deficiency, reasonable accommodations ought to be made for them to avoid contact with noxious inhalants.

Should Carriers of Serious Genetic Disorders Burden Society with Their Offspring?

In a 1990 general population survey, 39% of the respondents believed that “every woman who is pregnant should be tested to determine if the baby has any serious genetic defects.” Twenty-two percent thought that, regardless of what they would want for themselves, “a woman should have an abortion if the baby has a serious genetic defect.” Nearly 10% believed a poor woman should be required by law to have an abortion rather than have the government pay for the child’s care.

As health care becomes increasingly rationed, taxpayers could resist having to pay for the support of disabled children if their births could have been prevented. If a woman undergoes a prenatal diagnosis and then decides to carry to term a baby with a serious, incurable, and costly problem she may be socially scorned. She could, of course, refuse prenatal diagnosis, but she would still be considered irresponsible for doing so. But many genetic tests contain only crude predictive value. A positive result often cannot predict the extent of potential penetrance and expression of a defective gene in an individual. A society that coerces women into having abortions based on the results of
genetic tests will force “throwing out many healthy babies along with the bathwater.” Private insurance companies in the United States have already tried to withhold reimbursement for medical care of children with cystic fibrosis who were diagnosed before birth and whose parents refused to abort. Thus far, state insurance commissioners have prevented this type of discrimination.8

Can a culture that places such high value on a woman’s right to choose abortion even consider limiting her right to choose life?

What is Normal?
People are special because they possess unique genetic characteristics expressed as strengths and weaknesses. Individuals and societies pencil the fine line between what is distinctive and extraordinary and what is peculiar and unacceptable. Prenatal genetic screening allows parents to make decisions for selective abortion. Some insist that parents should have full autonomy to terminate pregnancies for babies that seem inferior. Others argue that babies should be protected from those who would reject them because they do not meet an arbitrary standard.

The vast majority of Americans believe couples should have the right to abort a seriously defective fetus. About 80% would terminate a pregnancy if they were told their fetus had Down’s syndrome. A survey of parents of children with cystic fibrosis showed that 20% would abort for cystic fibrosis, 17% would abort for incurable disorders starting at age 40, and 7% for those starting at age 60.12 Greater than one in 10 would abort for obesity and another 2% to 3% would terminate a pregnancy if their fetus were diagnosed to have treatable diseases like cleft palate or nearsightedness. Some parents even feel that the sex of a child is relevant. A recent study of American genetic counselors concluded that a large percentage would perform prenatal testing for the sole purpose of sex selection.13

How would limits be placed on selective abortion? In an agricultural society, genes with potential for physical dearness rather than intellectual prowess would be valued. For the academic, the opposite might hold. For some couples, reproductive decisions can center on cosmetic issues and pregnancies could be terminated because of straight-hair genes or lack of height. Ideas such as normal and disabled are rooted in shifting societal values; even if restrictions for abortions after prenatal diagnosis were legalized, the determination of these boundaries would be formidable.

This analysis may seem out of place in a society that permits abortion on demand. And it would be pointless were it not for the impact of physician counsel on patient decisions. In a recent study, the parents whose doctors approved of an abortion for cystic fibrosis were nearly twice as likely to abort for cystic fibrosis than those parents with disapproving doctors.14

Well-informed, compassionate, and insightful physicians ought to assist patients in their own understanding of what normalcy is and guide them to make appropriate decisions.

Who Should Offer Genetic Services?
Many believe that genetic specialists should be the ones offering counseling and screening services.7 Geneticists are concerned that most physicians are not familiar with genetic concepts and lack the tools to serve as effective counselors. They demand a minimum of graduate-level training as a prerequisite. A recent study found that many primary care physicians, especially those who are not exposed regularly to genetics, are not familiar enough to serve as competent counselors.15

Although it is reasonable to assume that geneticists are more familiar with all the nuances in their field, it is equally true that primary care physicians are more informed about their patients’ individual and family needs and desires. These physicians can familiarize themselves with pertinent issues regarding the new genetics. But not every genetics counselor can come to know patients and their families with the intimacy their personal physicians can. Patients look to their primary care doctors to interpret many other laboratory tests and to give appropriate advice. Well-informed physicians who understand the limits, benefits, and risks of genetic testing should play the central role as advocates and advisors for their patients.

Genetic Therapy
The goal of genetic manipulation is twofold: First, to repair or replace defective genes in somatic or germ-line cells; and second, to improve the genetic makeup of the sperm, egg, or early products of conception to improve the attributes of descendants. The former is considered correction; the latter, enhancement.

Gene therapy involves the manipulation of somatic or germ-line cells to alter their genetic composition. Germ-line engineering produces genetic changes that become permanently encoded in the sex cells of the person, while somatic cell alteration affects only the individual and should not produce inheritable changes.

Somatic-Cell Therapy
Somatic-cell gene therapy is a treatment of existing gene pathology. Many clinical protocols are presently underway to offer therapy for individuals with adenosine deaminase deficiency and certain types of cancer. On the horizon are treatments for other diseases including Lesch-Nyhan syndrome, herpes simplex, melanoma, familial cholesterolemia, and many types of malignancies. Previously, no effective cures had been available for most of these conditions.

Somatic-cell gene therapy cannot abolish genetic disease. In fact, should it become widely successful, it will increase the number of gene carriers with homozygous disease who will face the certainty of passing problem genes to their children.9 This in turn will lead to a logarithmic increase in the need for somatic-cell therapy in future generations. Therefore, somatic-cell therapy alone is not beneficial in the long run.

Germ-Cell Therapy
Germ-line engineering of the human genome may become technically feasible within a decade. Specific techniques for the genomic alteration of germ cells has been demonstrated in animal models.17 Germ-line changes generally would be expected to affect the genetic make-up of all tissues and cells in the developing offspring and all subsequent generations with grave implications for both the individual and for society at large.8

Potential justification for germ-line alterations include the correction of genetic defects not otherwise amenable to somatic-cell treatment, permanent stabilization of genetic material in offspring of high-risk mating, or the elimination of the need for repeated prenatal diagnosis and selective abortion in genetically at-risk families.17 According to one view, a trial of genetic therapy would be justified only if the following conditions held: 1) the risk of treatment were no greater than the risk of being born with the given condition or of being destroyed
prior to implantation (the non-treatment options); 2) no other treatment were available that offered a superior risk/benefit ratio; 3) the purely research components of the trial did not pose substantial risk; and 4) consent had been obtained from an appropriate guardian.18

Dr Marc Lappe, professor of health policy and economics, argues that since changes in the germ-line potentially affect others in addition to the recipient of the altered germinal tissue (i.e., the offspring and future descendants), such experimentation raises novel questions of traditional research ethics. Foremost among these is the adequacy and acceptability of proxy consent. Germ-line interventions may subject at least one or probably two generations of future persons to experimentation before the phenotypic effects of the germinal change can be said to test out.19 Medicine is not an exact science. Many times patients are treated with well-researched FDA-approved drugs and develop serious side effects. Germ-line manipulation must surely be at least as problematic. Germ-line research presupposes direct experimentation on and destruction of embryos. The acceptability of this pivots on the acceptability of killing genetically altered but defective embryos or allowing their creation in the first place.7

Criteria to safeguard the direct genetic manipulation of the pre-embryo have been proposed. They include: 1) a specific correction of a defective gene will be made, 2) the procedure will not introduce any genetic errors or new genetic material that could have unpredictable effects in subsequent generations, and 3) such procedures include a check to ensure that the procedure has been carried out as intended, before allowing the pregnancy to proceed.16

In our fast-food and microwave society, quick processes tend to be over-esteemed. Nature already has a way of ridding the genetic pool of inferior genes via spontaneous abortion and natural selection. We cannot be assured that scientists in their laboratories will be able to better this process.

Enhancement of Normal Individuals

Germ line interventions can promote desirable genes or decrease deleterious ones to produce an improved genetic profile.17 For many, this eugenic goal stirs memories of the forced genetic and ethnic cleansing attempted by Germany and the Soviet Union and the legislated sterilization of the disabled in the United States.

Enhancement is one side of eugenics. Instead of removing bad genes, it hopes to improve on normal ones. As knowledge of the structure and function of the human genome expands, social pressures will mount not only to repair defects and disorders, but also to intervene at improving or perfecting the structure and function of the genome. Enhancing a child’s genes, one might argue, is analogous to giving a child a private education, a trip to Europe, or plastic surgery. If parents have the right to give their children these other benefits, do they also have the right to give them enhanced genes? Is the ability to pay determinative, and would this not serve to widen the gap between the haves and the have-nots?

As genetic enhancement becomes more frequently used, the cost of services may actually drop making the technology available for almost everyone. What then would our brave new world look like?

Conclusion

Ready or not, we are entering the age of the new genetics. Professional perspectives vary. Generally, geneticists are concerned about improving the gene pool, lawyers are interested in setting legal precedence, sociologists look beyond individuals to consider society as a whole, and entrepreneurs drool over the prospects of this new industry. Who, if not doctors, will lead us into this new era and advocate for and protect individual patients and their families?

Some physicians will remain largely ignorant or disinterested in these issues. Others will opt to refer their patients for genetic services, thus missing the opportunity to tailor-make plans for patients best known to them. Still others will become well-versed in the new genetics. They will recommend appropriate genetic services and expertly counsel their patients who trust them. They will also guide their patients in their decisions regarding screening and therapeutic options in the same manner they have guided their patients before the age of gene sampling, selection and cure.

Are primary care physicians prepared to lead? First, they must draw on the resources of the geneticists to understand the science; then they must look to the philosophers to appreciate the ethical implications. Legal issues, societal concerns, and financial matters must also be appreciated. These are the caring and responsible physicians who will set the cadence and direction of our march into the new genetics.

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References

Universal coverage requires cost containment. Working models of health care coverage from Hawaii, Oregon, and Singapore address different aspects of cost-containment. Hybridizing the three produces the following system: A percentage of an individual's salary is mandatorily set aside in an individual medical account. Using these savings, the individual purchases catastrophic medical insurance with a managed care organization. Residual funds are used as a deductible or co-payment and to purchase additional medical services as desired. Enough funds should accumulate during an individual's working life to enable continued coverage after retirement. The basic health care package needs to be limited and is defined by a systematic and rational process based on cost-benefit analysis and democratic consensus regarding priorities and coverage. Medicaid recipients get the same basic package from managed care organizations as that available to the rest of the population; low wage earners receive sliding-scale subsidies from the government. Co-payments and deductibles remain in place except for beneficial preventive services.

The two burning issues facing American health care policy today are universal coverage and cost containment. To address the first without considering the second is idealistic at best and deluded at worst; to address the second without addressing the first is unethical.¹

Hawaii and Oregon, and the newly industrialized country of Singapore, have recently reformed their health care systems with these precepts in mind. Their novel approaches to the problem of coverage with cost containment have unique strengths potentially complementary, integrating these strengths to create an affordable, just, and politically feasible model of health care in the United States.

Hawaii’s QUEST²
The burgeoning Medicaid bill in Hawaii ($64 million in emergency funds in addition to annual funding of $492 million in 1992, and even more required for 1994 and 1995) compelled the state to enact a strategy for indigent medical coverage—the Health QUEST Program. Managed care replaced fee-for-service. The various insurers in Hawaii, HMSA, Kaiser, Queen’s, Straub, compete to provide a standard benefit package to these patients for a prepaid set rate. Medicaid enrollees can have the provider of their choice from the participating plans. In the past, they saw any doctor they wanted so long as the physician accepted medicaid.

Patients with incomes greater than 133% of the federal poverty level pay a share of the premium as determined by a sliding scale based on income. The near poor and others previously excluded from government health insurance now have access to coverage.

Under regular Medicaid, those enrollees who needed medical care had to be declared disabled and show they had exhausted all their assets before they became eligible for health insurance. QUEST does away with this disability criterion. Part-time work or job failure no longer threaten medical coverage. Under QUEST, this fear is no longer a disincentive for returning to work.³

Health QUEST builds on the state’s employer mandate. Under the Prepaid Health Care Act, employers have been required to cover employees working more than 20 hours a week with a standard, state-established package of health care benefits. This mandatory coverage has reduced uncompensated care and cost-shifting. Furthermore, it has facilitated voluntary community rating by insurers with the young and healthy paying into the same pool. Consequently premiums are among the lowest in the nation and the general access to primary care has decreased high-cost service utilization.⁴

The implementation of Health QUEST has not been without some administrative confusion. Patients who are used to the previous system have to adjust to seeing only their designated primary care provider. However, the concept is sound and these growing pains should disappear in time.

Oregon’s Plan⁵
Oregon recently revamped Medicaid coverage for everybody below the poverty line by limiting the medical services provided or rationing. Oregon went through a painstaking and laborious open process to prioritize services. A list of condition/treatment pairs was generated using ICD-9 (International classification of diseases 9) and CPT-4 (Physicians’ current procedural terminology 4) codes. This list was then ‘ordered’ by computer using various criteria: The first condition was the ability of a treatment to prevent death. If any pairs were tied on this basis, they were then ordered on the average cost of treatment. This computer-ranked list was then reviewed by the Oregon Health Services Commission and further reordering was done by hand based on principles such as ranking preventive measures for a condition above treatments for the same condition. The opinions of Oregonians were polled at public meetings to finalize the
prioritization list. Comfort care, maternity and child health, family planning services, and communicable diseases were given a higher priority as a result. Cosmetic and infertility services, and treatment for self-limiting conditions, on the other hand, weren’t.

The cost of covering each service on the list was estimated by actuaries; the total cost at various cut-off points could be determined. The Oregon legislature then decided on the final cut-off line, in effect stating that services above the line were worthy of public funds, whereas services below it were not. A managed care capitated system with designated primary care providers acting as gate-keepers was installed to further control costs.

For this past year, the cut-off mark was item 568 in a list of 688 condition/treatment pairs. Excluded services included treatments for self-limiting conditions such as the common cold (rank number 636), non-vaginal warts (rank number 653) and viral hepatitis (rank number 586). Conditions with effective home remedies, eg, noninfectious gastroenteritis (rank number 590) and sprains (rank number 623) were also excluded, as were conditions for which treatment is ineffective or futile, eg, surgery for soft-tissue back injury (rank number 575) and treatment for cancer with distant metastasis where treatment offers less than 5% five-year survival chance (rank number 670). Cosmetic treatments, eg, nontoxic goiter (rank number 580), sebaceous cyst (rank number 688) and keloid scars (rank number 676) were also excluded.

Singapore’s Health Policy

The city state of Singapore’s health policy has as one of its basic tenets the promotion of individual responsibility for health by avoiding over-reliance on medical insurance or state welfare. The incentive for staying healthy is financial. By mandate, 3% of an individual’s salary and a matching contribution from the employer go into a medical savings account in the individual’s name (Medisave account). This money is deposited with the state and earns interest. The individual makes withdrawals as needed for medical expenses. In theory, enough money accumulates in an individual’s medical account during the course of a working life to pay for medical bills or premiums post-retirement and during the final years of life.

The government encourages individuals to purchase private or government catastrophic health insurance using funds from the medisave accounts.

To ensure that middle and low income Singaporeans can afford their co-payments, the government subsidizes the cost of a basic package at certain hospitals. Within these hospitals, wards are divided into three classes: A class beds are not subsidized and provide creature comforts such as air-conditioning and private rooms. B and C class beds are subsidized and offer fewer creature comforts (much like the classes in a train or plane, same destination but varying frills). If a patient does not have the medisave money to obtain basic services in a C class ward, fees may be waived or paid for by a government safety net fund from general taxation.

To moderate the excesses of the fee-for-service system, hospitals have revenue caps, and limits are placed on the fees private practitioners can collect from a patient’s medisave account—though not from his or her personal savings.

Two Themes in Cost Containment

The seemingly varied considerations in cost containment cluster around two main themes: Financial incentives, and the absence of a natural limit on health care demand.

Misdirected or absent financial incentives are a common thread running through issues like efficiency, supplier-induced demand, and individual responsibility. And medical demand, like greed, is potentially limitless. Technology and research lead to new and expensive treatments to prolong life, increase medical demand, and patient expectations. There is no obvious end point to either research or patient demands.

Hawaii’s QUEST program properly vests the financial incentives in the provider, Singapore’s efforts are remarkable for its emphasis on financial incentives to the consumer, and Oregon’s plan recognizes the need for clearly spelled-out limits on medical services. All three approaches are worthy of inclusion in a health care policy.

Financial Incentives

The demise of communism is enough reminder of the role of financial incentive or the lack thereof in human endeavor. Health care is no different—notwithstanding professionalism and ethics.

Hawaii’s efficiency-inducing and waste-reducing incentive is directed at providers through capitated reimbursement for managed care organizations. Capitated payment is an excellent incentive for providers to reduce waste, and to increase efficiency. It motivates providers to reduce demand by emphasizing primary care, disease prevention, and realistic expectations from patients (unlike fee-for-service where the incentive to providers is to increase demand). Furthermore, by pooling Medicaid patients, the state creates a large block of patients for whom the various managed care organizations compete.

Singapore, on the other hand, inspires the individual and the provider toward thrift. By using a system of individual medical accounts and high deductible catastrophic health insurance, the myth of the third party payer is shattered as one’s own cold cash is on the line. The individual can go with a basic government-subsidized health care package and government health insurance, see a doctor only when necessary, pay the deductibles and save what is left of his or her medisave account. Or one can fork out for plusher hospital rooms, interactive television, and medical services excluded from the basic health care package but available as insurance options or direct out-of-pocket purchases.

Limitless Demand

The absence of a natural limit on health care demand in the face of finite health care dollars compels a government, managed care organization or insurance company to define basic health care coverage. Failure to clearly limit the contents of an offered health care package allows treatments in the gray zone of minimal benefit or even clearly beneficial but exorbitant and unaffordable treatments to push up the price of health care. This situation can escalate as new technologies and treatments become available.

Recognizing that it had to choose between unlimited services for a few versus limited coverage for many, Oregon used social values and cost-effectiveness criteria to spell out clearly what was and wasn’t covered. Such definition not only facilitates cost-containment but is explicit rationing rather than the haphazard, implicit rationing that characterizes poorly defined health care packages. Implicit or hidden rationing can take a variety of forms including queueing, subtle social factors, and
administrative barriers to deter the delivery of services. By facilitating cost containment, predetermined and explicit rationing minimizes the need for administrative pressures and hassles on doctors. Furthermore, the rationing decisions can be made by the people who are actually paying the costs and getting the benefits.

Oregon appears to have succeeded in defining its package without having to exclude beneficial but expensive treatments, eg, heart-lung transplant for primary pulmonary hypertension and bone marrow transplant for multiple myeloma and chronic leukemias are funded. Whether such beneficial but expensive treatments will continue as technology and new treatments burgeon is uncertain.

Defining a Basic Health Care Package
A guiding principle for determining allocation in limited resource situations is the Utilitarian Ethic, "The Greatest Good for the Greatest Number," Cost-benefit analysis is potentially a sophisticated and rational tool for this ethic to wield.

Cost-benefit analysis quantitates what one often suspects, that the money being spent on a particular service might do more good spent elsewhere. One way of expressing cost-effectiveness is by using the QUALYs (quality-adjusted life years) approach pioneered by the British. QUALYs are calculated by an equation combining the number of additional years of life (obtained from a given treatment) with the quality of life in each of these years. Outcomes from across the spectrum of therapy can be quantified in this way. Procedures can then be ranked formally by cost per unit of benefit gained. Unfortunately, cost-benefit analysis is fraught with technical pitfalls and has not reached the maturity necessary to allow its unqualified use in ranking medical services. Oregon tried using cost-benefit analysis in its initial attempts to rank services but generated an inappropriate list. Furthermore, the federal government said that the quality of life weightages (as estimated by telephone poll of Oregonians) might be discriminatory against Americans with disabilities. It would be a shame, however, to completely discard cost-benefit analysis. With refinement, such an approach should be far preferable to non-formalized techniques of comparing treatments, especially when seriously contemplating the exclusion of services.

Some have suggested the establishment of centers for technology assessment and outcomes research. Such centers could guide, develop, and disseminate systematic knowledge about cost-effectiveness. With the data base on outcomes generated by such a center, the contents of a basic health care package can be rationally determined. Patient input can further improve the final product. To protect minorities and the disabled, antidis­crim­inatory laws should be enforced but without sledgehammering cost-benefit analysis altogether.

A Healthier Hybrid
Synthesizing the complementary features of the health plans of Hawaii, Oregon, and Singapore results in the following plan:

1. Individual medical savings accounts are created by mandatory employer and individual contributions.
2. Using these funds, the individual buys catastrophic insurance with the managed care organization of choice. Residual funds are used for inpatient deductibles and outpatient co-payments, and to purchase additional medical services as desired. If the total monthly contributions undercut the insurance premium, then a government subsidy makes up the difference.

Generic Smith works part-time for a fastfood restaurant. Five percent (hypothetically) of his salary and matching contribution from his employer that goes into his individual medical account is insufficient for a high deductible medical insurance premium. A government subsidy makes up the difference and Generic is covered.

Generic Smith undergoes vocational training and starts work for a car manufacturer at an annual salary of $24,000. Suppose 10% (shared equally by employer and employee) goes into his medical account. That's $2,400. He pays out $1,800 for his catastrophic insurance premiums and $50 as payments for two visits to the doctor. At the end of the year, he has $550 accumulated in his account. The bank awards his medical savings interest at the market rate. He changes his managed care organization once when shifting house. He attends his free health maintenance checks where both hypertension and hypercholesterolemia are noted and treated.

3. With careful budgeting, enough funds should accumulate during an individual's working life to enable continued coverage after retirement. Any funds in excess of a certain limit can be withdrawn for nonmedical purposes. Funds remaining at death can be used in funeral expenses and inheritance.

4. The basic health care package is defined with high resolution, service by service, using a systematic and rational process involving cost-benefit analysis and democratic consensus regarding priorities and coverage.

Generic Smith retires at age 60 with $30,000 in his medical account. His account depletes by $2,000 annually in premium payments. At age 62, Generic is diagnosed with multiple myeloma. He receives out-patient chemotherapy and pays the $3,000 deductible when admitted with pneumonia. His prognosis is poor and bone marrow transplant offers him the best chance of prolonged survival. This option is not included in the basic health care package, but Generic opts for it anyway. He pays the $100,000 bill with the remainder of his medical account funds and his personal savings. As his medical account was depleted after the transplant, the premiums and hospice deductible of his last years are paid for by the government.

5. To minimize reckless depletion of individual medical accounts, they can be used only to cover up to a part, eg, 80% of the charges for non-basic medical services.

6. Beneficial preventive services are exempt from co-pays.

7. The poor are assured the same basic package from managed care organizations, paid for with public funds.

Regular Joe is an unemployed alcoholic. He has the same catastrophic insurance policy as Generic Smith, paid for by the government. He too has access to preventive services and a designated primary care doctor. Regular Joe is diagnosed with multiple myeloma when he presents with a pathological fracture. His prognosis is poor, and he cannot pay for a bone marrow transplant, but he receives chemotherapy as standard treatment.

8. Additional refinements would include centers for technology assessment, outcomes research, and practice guidelines.

9. Changes in the malpractice laws and widespread use of living wills and durable powers of attorney also could prove effective in further controlling costs.
The Ethics of the Proposal

The ethical imperative of distributive justice (fair distribution of burdens and benefits) drives universal coverage. In our proposed system, everyone has access to the same adequate basic health care package, the contents of which are worked out logically and democratically. Mandatory catastrophic coverage and community rating distributes risk, while the high deductible apports burden to the individual according to usage. Also, those who want more will have to pay for it out of pocket; they increase their health benefit by increasing their personal financial burden. Such a system tries to balance equality, freedom, and responsibility: The equality is in distributing risk and providing access to all, the freedom and responsibility in allowing those who want more to personally pay the difference. It is a two-tiered system which can favor the rich in terms of choice. However, if the basic health care package is carefully defined, the actual impact of any increased choice on disease outcomes should not be significant. Futile or ineffective treatment at additional cost will hardly make a difference in patient well-being.

Employer mandates can result in a regressive mode of financing health care. In regressive financing, payments are an increasing percentage of income as income decreases.25 Jane Ordinary gets a $2,000 monthly wages and benefits package from her employer. As health insurance purchased by the employer is tax-deductible, the package includes a low-deductible health plan for $300 per month, or 15% of Jane’s salary. Rob Normal works for the same company for a $3,000 monthly wages and benefits package; the same health coverage costs only 10% of his salary.

In the system suggested, by taking medical account contributions as a percentage of income (and providing sliding-scale subsidies as needed), premium payments are proportional to income and therefore do not unfairly penalize the lower income classes. Proportional financing is ethically more desirable.

One concern is that financial incentives for doctors to limit services will result in inappropriate withholding of testing and treatment. However, this should be less frequent with explicit rationing compared to the implicit rationing now so widely practiced. Committees can advise if financial incentives to doctors to limit referrals are exceeding a dangerous level.

Managed care quality assurance bodies can be supplemented by independent or state watchdog bodies, and appropriate exercise of malpractice laws and practice guidelines will serve as additional safeguards.

The Politics of the Proposal

Sixty-seven percent of Americans say their problem is cost, not coverage.26 By defining a rational health care package in an open process, a balance can be struck between coverage and cost to suit the average American. Individual medical savings accounts can act as the political motivator for rationing health care by making even more apparent to the consumer (voter) the economic realities of health care cost. The proposed system places everyone on the same side, the side of cost-containment. It can abolish the sometimes adversarial relationship between insurers, consumers and providers.

The individual mandate (as opposed to single-payer systems) retains market place competition, an incentive to quality. It can replace Medicare in providing health care coverage during retirement, all while maintaining individual choice and continuity of care. It reduces the risk of uncompensated deductibles with catastrophic insurance coverage. By exempting indicated preventive services from co-payments, patients will not be deterred from seeking such services. By using private health care plans and financial institutions, public bureaucracy and inefficiency can be minimized.

Any objection to an individual mandate should be tempered by the realization that individuals are eventually paying for health care anyway—at the rate of $9,500 a year per household.27 The Hawaii experience has shown that mandatory coverage can reduce health care costs for all.4

High-resolution definition of basic packages in a service-by-service manner will necessarily be a laborious process depending on majority rather than unanimous decisions. The inclusion of new treatments in the basic package could be delayed as the same democratic assessment must be applied to them as for services already included in the package. If these new services are to be additions rather than replacements, there should be consensus as to their cost-effectiveness.

Conclusion

For universal coverage to become a practical reality, we need the right mix of financial incentives to both patient and provider, and a well-defined basic health care package. The three working models of health care in Hawaii, Oregon, and Singapore provide many of these ingredients. Bringing together their strengths can optimize cost-containment and facilitate universal coverage with hybrid vigor.

Acknowledgements

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References

13. Pence GE. Ethical options in medicine. Medical Econ Co 1990.
Bioethics tends to lack both breadth and depth; a theological perspective can provide the necessary lack. The essential role of a theologian has always been to direct attention to dimensions of human situations that may have escaped our notice, to account for the interpretive frameworks people bring to their experiences of health, medicine, suffering, and death within a vision of human nature and destiny.

Bioethics does well what it does—provide principles of analysis and resolution of complex dilemmas. But there is much that it does not do. According to Ron Hamel, "It tends to lack both breadth and depth. Its vision of the moral life is constricted and, in focusing so much on principles and actions, it fails to account for the interpretive frameworks people bring to their experience of illness, their search for health, and their struggle with death."

At the heart is the suggestion that a theological perspective can provide the necessary breadth and depth that shapes bioethics. The courage of the venture is dramatized by the statement of Rainer Maria Rilke: "We must assume our existence as broadly as we in any way can; everything, even the unheard-of, must be possible in it. That is at bottom the only course that is demanded of us; to have courage for the most strange, the most singular, and the most inexplicable that we may encounter. That mankind [sic] has in its sense been cowardly has done life endless harm; the experiences that are called "visions," the whole so-called "spirit-world," death, all those things that are so closely akin to us, have by daily parrying been so crowded out of life that the senses with which we would have grasped them are atrophied. To say nothing of god."

Increasing Talk about the Legitimate Role of Theology in Bioethics

Bioethics and its practitioners have not been terribly hospitable to religion and theology over the past 20 years or so. That is ironic since: "...as the field of modern medicine ethics took shape two generations ago, its articulators were at ease with theology and often even at home in theological seminaries. A generation later they and their colleagues had moved out, to clinics and universities, where religious questions were often alien and theology was excluded."

Today, we may be witnessing a shift in current. There has been and is more and more talk about the legitimate, and even significant, role of religion and theology in bioethics. A pioneer in this effort has been The Park Ridge Center, an institute for the study of health, faith and ethics. In its programs of research, publishing, and education, the center gives special attention to the relationship of religious beliefs on questions that confront people as they search for health and encounter illness. Other leading journals in the field are the Hastings Center Report which published a special supplement in its July/August 1990 issue, "Theology, Religious Traditions and Bioethics." The Journal of Medicine and Philosophy devoted its entire June 1992 issue to "Theology and Bioethics." The Kennedy Institute of Ethics journal published an article titled "Religious Ethics and Active Euthanasia in a Pluralistic Society," in its September 1992 issue. The Center for Ethics, Medicine, and Public Policy published a collection of essays entitled "Theological Development in Bioethics." The Second Opinion, a professional journal of The Park Ridge Center, has published many articles on the relation of theology and bioethics.

New Context, New Openings for Bioethics

The new role of theology in bioethics has been strengthened by the view of the universe described by modern quantum physics. The universe viewed by some physicists is a world of a complicated web of relations between various parts of a unified whole. The world is not made up of separate objects, but rather of a network of relationships that include the human observer in an essential way. "We have to remember that what we observe is not nature in itself but nature exposed to our method of questioning." So the subjectivity in the process of observation is intimately linked with the connectedness of everything. "If the world is a network of relationships, then what we call an object depends on how we delineate it, how we distinguish it from the rest of the network." In this sense what we see depends on how we look. Hence the traditional idea of an out there world is no longer appropriate. Neither is the notion of a purely objective world that follows strict casual chains of connection.

Implications of the Concept of Relations

The concept of relations—the patterns and processes of interdependence of all things in the world—has profound implications for theology and bioethics. It is a vision that will transform our view of who we are and how we fit into the way of nature. Some implications:

- We will seek the larger patterns of relationships that underlie the whole range of moral life and moral experience in the world. For example, could the appreciation of the interdependence of all life lead to a heightened ability to sense and actually experience our oneness with each other?
- We will raise questions about the common discourse of bioethics. Is it sufficiently rich to convey the full meaning of relevant theological language:
  - Covenant instead of contract.
  - Neighborly love instead of beneficence.

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We are members of one another instead of autonomy.

What theological language presupposes: The uniqueness of self is founded by co-presence of the other. We know ourselves only within our relationship with others.

We will enlarge the role of the primary narrators—patients, families, physicians, nurses, social workers. We will be dealing with a much denser complex of interrelationships that may affect the ethos of the context in which we do bioethics.

Theologians' Contribution to Bioethics

The focus here has shifted from theology to the person doing the theology, namely the theologian. The essential role of theologians has always been: Directing attention to dimensions of human situation that may have escaped our notice, "to account for the interpretive frameworks" people bring to their experiences of health, medicine, suffering and death within a vision of human nature and destiny. In doing this basic function, the theologian assists in placing a particular decision within the context of a fuller account of purpose and meaning in life. And when that is done, it can deepen our appreciation of the moral dilemmas we face and of the options available to us for responding to them.

One example of alternative to moral dilemmas is that of the physician-assisted suicide. A physician who opposes physician assistance in dying is physician-philosopher Leon Kass. In Why Doctors Must Not Kill, he argues:

The deepest ethical principle restraining the physician's power is not the autonomy or freedom of the patient; neither is it his [sic] own compassion nor good intention. Rather, it is the dignity and mysterious power of human life itself, and, therefore, also what the oath calls the purity and holiness of the life and art to which he has sworn devotion. A person can choose to be a physician, but he or she cannot simply choose what physicianship means.

One can respect the wishes of a physician who believes it is the deepest constitutive essence of the physician to respect the dignity and power of human life. Yet a theologian will raise another point of view, "to participate in covenant with their patients to explore the meanings of death which challenge all of us, not only as physicians but as human beings."1

References


Ethics, Standards, and TQM

Max G. Botticelli MD

The most important ethical issue for our profession is the responsibility to assure the care delivered by our colleagues and ourselves meets a self-imposed standard of excellence. There is anecdotal and experimental evidence that we have not fulfilled this obligation. Peer review has proven, for a number of reasons, to be ineffective; however, improvements in the epidemiologic sciences should provide better standards and total quality management (TQM) might prove to be of value in monitoring, comparing and improving the decisions made by physicians. Its promise lies in its emphasis on statistical analysis, its focus on systematic rather than human error, and its use of outcomes as standards. These methods, however, should not diminish our other professional responsibilities: Altruism, peer review, and in Hippocrates' words "to prescribe regimens for the good of our patients—and never do harm to anyone."

Now that we are an industry, medical economic concerns tend to dominate our professional debates. So it is refreshing to be a part of this special issue of the Hawaii Medical Journal focusing on medical ethics. Our profession should participate in the debates over ethical dilemmas such as the impact of genetic discoveries, society's responsibility to provide universal access to health care, the rationing of health care services, and the extent to which patients should have a choice in treatment decisions. To be an effective voice in these debates, however, we must resolve some internal issues that have been avoided. These relate to our ethical responsibility to assure that the care delivered meets a self-imposed standard of excellence.

Standards are a prerequisite for professions. Webster's New Collegiate Dictionary defines a profession as a calling requiring specialized knowledge and often long and intensive preparation. This narrow definition, however, does not do justice to the full import of the medical degree. The obligations, responsibilities and power of physicians go well beyond the intensive study required to obtain our specialized knowledge. Starr and Friedson have pointed out that the medical profession is a legal, institutional and moral privilege granted by society that must be earned by physicians through observing certain standards of behavior. According to these authors, standards of behavior include, at least, altruism, a commitment to improvement and peer review. I would add to these the admonition of Hippocrates, "I will prescribe regimens for the good of my patients according to my ability and my judgment and never do harm to anyone."2,3
Physicians are better decision makers than patients because
their years of intensive study have resulted in what economists
refer to as “asymmetries of information.” This means physicians
have more knowledge than patients so that medical care deci­sions are left to them. Furthermore, most patients expect and
want to rely on the knowledge of their doctors to help them
decide what they should or should not do when they are ill. No
amount of patient education is likely to change these asymme­tries, and thus relieve physicians of their responsibility, and
patients of their vulnerability. To use this knowledge “for the
good of my patient” is the most solemn ethical obligation of a
physician who wishes to earn the privileges of our profession.

On the other hand, physicians are subject to economic con­flicts of interest regardless of the method of reimbursement. In
a fee-for-service environment, the temptation is to provide more
services than required; in a capitated system the opposite is true.
To remain professionally responsible, the physician must resist
taking advantage of these conflicts. Furthermore, there are
potent noneconomic factors that can at times influence physi­
cian decisions adversely, including individual patient desires,
societal pressures, the physician’s desire for self-fulfillment and
her or his style of practice. So it is not enough to trust our “ability
and judgment,” which can be influenced by all of these factors
that are extraneous to the clinical situation. We must depend on
our profession to help us resist the temptations to which frail
human physicians are heir.

How effective has our profession been in fulfilling this respon­sibility? The apparent answer is: Fair to good but certainly not
perfect. The data is anecdotal and evidence based. McPheeters
has compared the utilization rates for laparoscopic and operative
cholecystectomy. He points out that patients who have
asymptomatic gallstones are being operated on much more
frequently now that the laparoscopic procedure has become the
technique of choice, and that this increase cannot be justified by
a change in indications for cholecystectomy. Previous studies
had suggested that as many as 14% of coronary artery bypass
procedures and 32% of carotid endarterectomies are
performed for inappropriate indications.

The observation of persistent differences in the way patients
are treated from one health care setting to another has been
referred to as the variation phenomenon. It was first described
by Wennberg who noted very large differences in the rates of
tonsillectomy, hysterectomy, and prostatectomy in different
small areas in Maine. The existence of this phenomenon has
been established beyond a doubt; the variations having been
observed in the care of patients of all ages and in all settings.
These differences cannot be explained by statistical or technical
factors such as differences in case mix, etc. Nor has a cause been
identified. Interestingly, studies designed to test the hypothesis
that inappropriate use might explain geographic variations did
not establish a relationship between the two phenomena.
Regardless, the fact that physicians often treat apparently simi­lar
patients in very different ways has raised doubts about the
scientific bases for their decisions. To some we have become
just another interest group struggling to maintain its economic
self-interest. And, while this is not true, it is easy to see how these
variations have eroded our stature as a profession. It is difficult
to fathom how these variations might be considered to be of
value.

Virtually every hospital or health care institution has a peer
review mechanism and that is presumably true of the institutions
in which these variations were documented. So it seems fair to
say that peer review has had limited value in standardizing the
level of care in different sites. Two incidents were reported by
surgical and medical residents recently that strengthen this
argument. Both involved patients who were operated on in spite
of the fact that their cancers were inoperable. These were
teaching cases and as such they were used ostensibly to teach
medical and surgical resident physicians how to make decisions.
In one of these instances, the surgery went so badly and the
surgeons were so cavalier during the operation, that the surgical
resident assisting at surgery was tearful as she described this
experience to her professor. To the credit of the Department of
Surgery of the University of Hawaii, these incidents are being
investigated to determine if the surgeon who performed these
apparently unnecessary operations is a fit role model for stu­
dents and residents. To the best of our knowledge, these cases
have yet to be peer reviewed in the hospital in which the surgery
took place.

There are of course technical problems that make peer review
difficult. First, most peer review processes are directed at
finding outliers, the assumption being that anyone who has had
a bad result has been a bad physician. Physicians have difficulty
doing this, especially in the closely knit culture of the medical
center. Second, the process has been heavily influenced by
lawyers so that the due process requirements are staggering.
Third, there has always been a reluctance on the part of physi­
cians to define quality in terms specific enough to be used as peer
review standards. Finally, it has not been in the financial interest
of the hospitals and medical centers whose responsibility it is to
support and underwrite peer review activities to insist that they
be done with conviction.

There have been advances, however, that should make us
optimistic. In the first place we have the advantage of better data.
Epidemiologic methods are improved and studies using these
methods have resolved critical treatment issues. For instance, it
is not difficult to identify treatment goals for patients with
diastolic and systolic hypertension and diabetes mellitus. There
is good data describing the preventive benefits of mammogra­
phy, pneumococcal and influenza immunization, and prenatal
care. The indications for coronary artery bypass procedures are
clear, although compliance is not always certain.

There has also been experimentation with other methods to
monitor, compare, and improve decisions made by health care
providers. Among the most controversial of these is total
quality management or TQM, alias CQI, QIP and IQMS. Whereas
this method is popular among health care administrators and
managers, it has not been utilized by physicians to help with peer
review. The reasons for this are many and complicated, although
perhaps the most important is that there is only anecdotal evidence
that it can, in fact, improve physician patient care decisions.
However, it has been used successfully in industry to
control variation and so it deserves more consideration.

Suffice it to say that three activities are emphasized as being
important to total quality management. Berwick used these
words to describe these activities as: 1) efforts to know the
patient and to link that knowledge to the day-to-day activities of
the organization; 2) efforts to mold the culture of the organiza­tion
to foster pride, collegiality, and scientific thinking; and 3) efforts to continuously increase knowledge of and control over
variation in patient care through scientific methods of data
collection and analysis and action on data. It is the third activity that has stimulated the development of specific tools which may apply to our profession’s responsibil­
ity for accountability. These tools basically provide ways to display and analyze data quickly. One of these is the control chart used in statistical quality control (SQC) (Fig 1). The vertical axis measures some aspect of health care that is considered important to quality. This might be mortality rates, morbidity rates, mammography rates, utilization rates, etc. The horizontal line measures time. The solid line represents the mean of the observed values and the dotted lines represent upper and lower control limits. These limits would define expected or acceptable variations. The value of such charts rest in their ability to demonstrate quickly when observed measurements fall outside expected or desired limits.

Because the standards of quality are statistical rather than empirical they are more objective. This is especially true if they define outcomes rather than process. Early attempts at quality control focused on process factors which were determined by consensus. In those systems there was much room for argument about quality as it was often impossible to determine if the process factors were of value in determining the outcome of care in individual or groups of patients. There is less room for argument if quality is defined by outcome, especially if that outcome is based on scientific data. Thus, a study that determines there is value in maintaining systolic blood pressure below 160 mm Hg in effect develops a standard against which the care of individuals can be measured. There will be some variation but most measurements of systolic blood pressure in an individual or a group of individuals should fall below this upper limit. There is activity now in the field of outcomes research to develop and validate such standards.

One advantage of this method of quality control is that it focuses on systematic factors rather than on finding bad physicians who make bad decisions. Criticism of a peer places physicians in uncomfortable dilemmas. Any quality-control method that mitigates the discomfort should be welcomed. There are reported anecdotes describing successful reductions in variation by using this methodology. The Department of Clinical Epidemiology at the Latter Day Saints Hospital in Salt Lake City used TQM to reduce the rate of post-operative infections from 1.8% to 0.4%. They started by noting that certain physicians had higher rates than others. Then they established that these physicians used different times of administration of pre-operative antibiotic prophylaxis. When these times were changed the infection rates dropped.

The rationality of TQM should not be used to diminish the requirement for the other activities noted. We must continually remind ourselves that:

Our profession's altruistic responsibility includes a commitment to make the benefits of health care available to everyone.

Peer review is a necessary part of our ethic even when it requires difficult decisions that involve our friends and colleagues. In order to make this process effective, standards of behavior must be clearly enunciated and strictly enforced. Unfortunately, these standards cannot always be objectively defined by a statistical analysis of outcome data. Those that define, for instance, the patient-physician relationship, the limits of accepting gifts from drug companies, the altruistic responsibilities of physicians, etc, can be developed only consensually by professional organizations. Membership should depend on conformance with these standards.

We should make every effort to determine what our patients need and want and direct our efforts to those ends. However, physicians are often in the best position to define futile care and it is their responsibility to refuse to prescribe such regimens regardless of the social and legal pressures to do so.

It would be exhilarating to re-experience the pride, joy, collegiality and scientific thinking that characterized our profession before it became an industry. Lifelong learning is critical to our profession, so continuing education should be its major priority. Professional organizations, schools of medicine and health care institutions should join to rekindle the fervor for knowledge that once inflamed our profession. It is especially important for these institutions to do so because they have been so influential in causing it to burn fitfully.

Unless there is a commitment to quality it cannot be achieved no matter how much data is collected or analyzed. Making such a commitment involves going beyond the materialism of economics and science into the spirit of our professional souls. It requires idealism, dedication, and sacrifice. If quality is to become a part of our professional ethos, it will be because we are sufficiently idealistic to define excellence, we are dedicated to its achievement, and we constantly challenge ourselves when we have not succeeded in doing so.

References
5. MacPheeters G. Have the indications for cholecystectomy changed? Department of Medicine Grand Rounds, 11/22/94. The Queen's Medical Center.
Informed Consent: Its Legal History and Impact on Medicine

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The doctrine of informed consent dictates that a physician has a legal duty to disclose to a patient sufficient information regarding the inherent risks and benefits of a proposed course of treatment, and alternatives to the proposed treatment so the patient can intelligently exercise his or her judgment about whether to undergo that treatment. The development of the law regarding informed consent both nationally and in Hawaii is examined along with the current status of the law and its potential impact on physician behavior and health care delivery in Hawaii.

When a physician fails to obtain informed consent from a patient before proceeding with treatment, he or she has failed to practice up to the professional standard of conduct expected of physicians and can be sued under a theory of negligence. The basic elements of a cause of action based on negligence are: 1) a duty or obligation recognized by the law, 2) a breach of that duty, 3) a legally recognized causal connection between the conduct and the injury, and 4) actual loss or damage to another. Element four, actual loss or damage, is an essential part of a plaintiff's case, and without that element, there is no cause of action.

National Case Law

Schloendorff v. Society of New York Hospital is the initial case involving the physician's requirement to obtain informed consent. It was in that case that Justice Cardozo said, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault." The court made no distinction between informed consent and consent. Forty-three years later, Salgo v. Leland Stanford Jr University Board of Trustees, established the legal duty of a physician to provide a "full disclosure of facts necessary to an informed consent." The Salgo court said physicians had a duty to disclose, but allowed the physician to use his or her best discretion as to what disclosure was necessary for informed consent. The court said:

Each patient presents a separate problem...the patient's mental and emotional condition is important and in certain cases may be crucial, and that in discussing the element of risk a certain amount of discretion must be employed consistent with the full disclosure of facts necessary to an informed consent.

Several years later in Natanson v. Kline, the court adopted the Salgo standard and held that the decision as to what to disclose was primarily a medical judgment; therefore, the duty was limited to disclosures that a reasonable physician would make in similar circumstances. The court concluded that under this professional standard "the patient is properly protected by the medical profession's own recognition of its obligations to maintain its standards."

Canterbury v. Spence, a federal court decision, changed the professional standard rule and developed a patient-centered standard of disclosure. The Canterbury court decided that "respect for the patient's right of self-determination on particular therapy demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves." The court, however, recognizing that a physician would be hard-pressed to know exactly what each-and-every patient might deem relevant in a given situation, adopted what has come to be known as the "objective patient standard," based on "the average reasonable patient...with due regard for the patient's informational needs and with suitable leeway for the physician's situation."

The court also acknowledged several exceptions to the disclosure requirement, including risks inherent in any procedure (such as infection), hazards that the patient is already aware of, and emergencies where there is no time to obtain consent and waiting for consent would greatly endanger the patient. In addition, the Canterbury court recognized the "therapeutic privilege" exception to disclosure of risk information. According to the Canterbury court this privilege occurs when a patient might become "so ill or emotionally distraught on disclosure as to foreclose a rational decision, or complicate or hinder the treatment, or perhaps even pose psychological damage to the patient."

In keeping with the negligence theory, the Canterbury court determined that, in addition to breach of duty, there must also be evidence of a causal connection between the breach and the injury, and that without injury or harm there was no actionable negligence unless the disclosure of risk information would have led the patient to opt for a different treatment, the failure to provide that information, while a breach of duty, is not sufficient for a cause of action under negligence theory. This should be objectively determined, ie, "what a prudent person in the patient's position would have decided if suitably informed of all perils bearing significance."

In summary, Salgo, Natanson, and Canterbury established failure to provide informed consent as negligence, ie, malpractice. Salgo and Natanson said that the decision as to what to disclose was a professional decision, while Canterbury said it was to be based on what the patient would view as important. While Salgo and Natanson did not need to address the issue, Canterbury said that causation, ie, whether the information would have changed a decision, was to be based on an objective "prudent patient" standard.

The court's hesitancy to trust the accuracy of the plaintiff's memory and judgment is well supported by empirical studies. Research demonstrates that people do not accurately remember even their own predictions, and therefore, end up exaggerating what they thought they knew at a previous time. "This research does not imply that hindsight is a knowing misrepresentation of fact, for individuals will be truthful in their hindsight recall. The
hindsight bias arises from cognitive limitations on people's ability to recall past perspectives accurately. ¹⁶ A recent study done in Hawaii confirmed the unreliability of patients' memories. Ninety percent of 144 patients who had been informed of the risk of death from gallbladder surgery were able to correctly recall that warning prior to surgery. However, only three weeks after surgery 54% of those who correctly remembered before surgery stated that they had not been told that death was a potential risk.⁷

**Hawaii Law**

In Hawaii, both statute and common law make failure to obtain informed consent a medical tort. In 1970, two years before the landmark Canterbury decision, the Hawaii Supreme Court, in Nishi v. Hartwell,⁸ established its position on the doctrine of informed consent. The court, citing the Salgo decision, stated:

The doctrine of informed consent imposes upon a physician a duty to disclose to his patient all relevant information concerning a proposed treatment, including the collateral hazards attendant thereto, so that the patient's consent to the treatment would be an intelligent one based on complete information...However, the doctrine recognizes that the primary duty of a physician is to do what is best for his patient and that a physician may withhold disclosure of information regarding any untoward consequences of treatment where full disclosure will be detrimental to the patient's total care and best interest.⁹

The court held that the standard to be used in determining whether adequate disclosure had been made was a professional standard, ie, "by reference to relevant medical standards."¹⁰ This meant the plaintiff had to prove with expert medical testimony that the relevant medical standard had not been met.

In 1976, in response to what was perceived as a medical malpractice crisis, the Hawaii legislature, to lend some potential protection to the physician, enacted legislation that attempted to develop standards for informed consent. The act stated: "The standards established by the board shall be prima facie evidence of the standards of care required but may be rebutted by either party."¹¹ The legislation also codified the common law exception to risk disclosure in the case of emergency treatment. The law did not directly address the standard of disclosure or the standard of causation.

In 1983 the legislature amended the statute to more clearly identify the scope of the disclosure. The statute stated: If the standards established by the Board of Medical Examiners include provisions which are designed to reasonably inform a patient, or a patient’s guardian, of:

1) The condition being treated;
2) The nature and character of the proposed treatment or surgical procedure;
3) The anticipated results;
4) The recognized possible alternative forms of treatment; and
5) The recognized serious possible risks, complications and anticipated benefits involved in the treatment or surgical procedure, and in the recognized possible alternative forms of treatment, including nontreatment, then the standards shall be admissible as evidence of the standard of care required of the health care providers.¹²

Again, the legislative language was ambiguous as to whether the standard of disclosure was patient centered or professional.

In 1985, in Leyson v. Steuermann,¹³ the Intermediate Court of Appeals examined the doctrine of informed consent. The Leyson court, noting ambiguity in the language of Nishi and HRS §671(3) (1976), did not address the standard of disclosure. The court did reaffirm, however, the previously discussed exceptions to the informed consent doctrine.

Applying the facts of the case to its interpretation of the law, the Leyson court described the tort of negligent failure to disclose risk information as:

1) duty to disclose...risks...2) breach...[of the] duty; 3) injury; and 4) breach of duty was a cause of injury in that:
1. [the] treatment was a substantial factor in bringing about [the] injury and b) [the patient], acting rationally and reasonably, would not have undergone the treatment had he been informed of the risk of the harm that in fact occurred; and 5) no other cause is a superseding cause.¹⁴

By defining element 4 b in terms of the specific patient "acting rationally and reasonably," the court broke with previous courts by blending objective and subjective aspects of a patient oriented standard of causation:

[We] opt for the application of a modified objective standard that determines the question [of causation] from the viewpoint of the actual patient acting rationally and reasonably.¹⁵

This new "modified objective" standard examined causation from the viewpoint of the "actual patient [subjective component] acting rationally and reasonably [objective component]."¹⁶¹

In Mcroczkowski v. Straub Clinic & Hospital, Inc,¹² the Intermediate Court of Appeals then held that before a plaintiff can argue that the duty to disclose a risk was negligently performed, he or she must prove that the harm complained about was a probable risk of the operation and that the defendant knew or should have known of that fact. The risks to be disclosed were "all recognized serious possible risks of harm and complications that the physician knew or should have known of, plus other information."¹⁷

Once again the court declined to address whether the question of seriousness of the risk was to be "answered from the point of view of the patient, the physician, or otherwise."¹²¹

Keomaka v. Zakaib¹⁸ is the most recent decision by the Intermediate Court of Appeals regarding the doctrine of informed consent. It then reaffirmed the need for causality to be established vis-a-vis both the treatment rendered and the nondisclosure of the risk, ie, that the injury was caused by the treatment and that if the risk had been disclosed the patient would not have undergone the treatment. The court also addressed the question of whether a patient can be contributorily (or more correctly comparatively) negligent when a physician attempts to obtain informed consent. This issue could turn out to be the most important aspect of Keomaka.

The court held, in firm and unequivocal language, that "contributory negligence has no place in an action for failure to obtain informed consent."¹⁹ The court stated the argument that Keomaka's failure to read the informed consent form was contributory negligence was without merit, and the duty to inform rests with the physician:

[B]ecause of the superior knowledge of the doctor with his expertise in medical matters and the generally limited ability of the patient to ascertain the existence of certain risks and dangers that inhere in certain medical treatments, it would be unfair and illogical to impose on the patient the duty of inquiry or other affirmative duty with respect to informed consent.¹³

The court specifically stated that the mere signing of a printed
consent form (even one that said the doctor had discussed all risks and alternatives) would not fulfill the physician’s duty and “is not a substitute for the required disclosure by the physician.”13

The court did not discuss whether or not the physician’s duty could be carried out through affirmative acts of other hospital personnel such as nurses or pharmacists, and if so, what duty the physician had to make sure that the information had been understood by the patient. This point is of more than academic interest because many hospitals now use nurses and pharmacists to provide patient education regarding disease and treatment.

Summarizing Hawaii law: Failure to provide informed consent is a tort, with the parameters of the tort defined in statutory and common law. Treatments, alternatives to treatment, and all recognized serious possible risks are to be disclosed. While ambiguous, it seems that a professional standard is to be used to decide what to disclose. A modified objective standard (the actual patient acting rationally and reasonably) is to be used to determine if the disclosure would have changed the patient’s decision. The plaintiff must prove both that a risk was not disclosed and that if it had been disclosed, the patient, acting rationally and reasonably, would not have undergone the treatment. Finally, in Hawaii the patient cannot be contributorily negligent by failing to ask questions, by signing a form that he or she has not read, or any other act of omission or omission related to the informed consent process.

Discussion

Current Hawaii law, pointing to the importance of protecting patient autonomy, requires physicians to obtain informed consent from their patients before proceeding with treatment. It is commendable and appropriate that Hawaii’s legislature and courts are interested in protecting patients. However, some of their assumptions about the role of informed consent in protecting a patient’s autonomy (and even what autonomy is) are open to examination. The autonomy rationale for informed consent argues that all human beings have a right to make their own decisions, and that any limitation on the information provided to patients is an affront and infringement on that right. Yet the Hawaii courts ignore at least two significant realities with their rulings:

First is the relationship between autonomy and responsibility. Hawaii law holds that the patient has no responsibility relating to the process of informed consent. Ironically, the court bases this idea of no responsibility on the very thing that it seems to question: The professional expertise and judgment of the physician. The court feels that the physician’s expertise vis-a-vis the patient places all responsibility for initiating, maintaining, and structuring informed consent on the doctor. This appears contrary to the idea that the patient is an autonomous individual, for if that were so, he or she would have some responsibility for the choices made, ie, to sign or not sign a form indicating that something had happened when in fact it had not. More important, the no responsibility standard negates the idea that the patient has any responsibility for the nature of the doctor-patient relationship and the communication that exists in that relationship. It seems the courts’ perception of the patient is passive, noncontributing, and not responsible is itself a paternalistic and demeaning view of the patient. If it is paternalistic of physicians to think that they know what is best for the patient, it is equally paternalistic of the courts to proclaim patients incapable of and not responsible for shaping the discourse between them and their doctors. It is this relationship between doctor and patient that is the key to true informed consent, and both parties must take responsibility for their part in that relationship.

The courts also continue to treat informed consent as an event rather than a process. They seem to think that medical decision making occurs at a fixed time and place, and that a course of treatment, once decided, is an essentially fixed recipe. The reality is that clinical decision making is an ongoing process that is constantly altered by numerous sources of feedback, including the disease and its response to earlier treatment interventions. A better view of informed consent is that it is a process between two people who are involved in a relationship with each other.

Burt14 and Appelbaum15 have discussed this view of informed consent and present a perspective that it much more relevant and meaningful to the actual context within which informed consent discussions occur. As they point out, the process of disease and death creates fear, anxiety, and/or uncertainty in both doctor and patient. As humans, both react to these emotions with attempts to control the situation, the doctor through prescribing a treatment and the patient through controlling what will be prescribed. Thus what is needed between physician and patient is less acquiescence of one to the other, but rather more dialogue, discussion, and understanding of the nuances of the bio-psycho-social situation in which the two people find themselves. In this manner each participant’s fears and uncertainties can be exposed and confronted. While the ultimate decision might or might not be the best or most rational, it will be made the way many decisions are made—on the basis of a relationship between two people who recognize the humanity of the other.

Finally, and from a somewhat different perspective, whatever is thought of the courts’ logic, its current ruling on the role of contributory negligence in informed consent cases may in fact affect aspects of patient care. By holding that the routine consent forms patients often sign on entering a facility have no legal significance in the absence of evidence that the physician actually performed his or her duty to disclose risk and alternative treatment information, it signifies a need to move away from the paper consent documentation via various forms, and instead to focus on physician documentation of actual discussions with patients. It should also lead to increased use of interpreters, so as to make sure that language limitations don’t result in lost information. Note that this action would also be consistent with Burt and Appelbaum’s views of informed consent processes.

In addition, adherence to both the spirit and letter of the law can improve patient care. First, physicians will be required to more clearly justify their clinical interventions, rather than to rely on the old saw that it’s the usual procedure. Instead they should be more reflective about their treatment recommendations and the effect on their patients. This may in turn change patient choices. For example, a program at Dartmouth Medical School documented that after viewing a video that gave information on watchful waiting versus surgery for benign prostatic hypertrophy, one-third of the patients who had favored surgery changed their minds.16 Second, because the process of informing patients often requires education about diseases, treatments and procedures, it is likely that other professionals will become involved. With their developing professionalism, nurses and pharmacists have increased their teaching activities with patients. For example, critical-care nurses17 and pharmacists are becoming more involved in patient education, and thus contributing to the process of informed consent.

However, hospitals might negate these gains if they interpreted the court’s holding on the physician’s duty to provide informed consent as insulating the hospitals from any liability for failure to obtain informed consent. It would be ironic indeed
if, in attempting to protect patient autonomy, the court's holding negatively affected this move toward increased patient autonomy by allowing hospitals to decrease nonphysician patient education activities.

In the past hospitals generally have not been held liable by courts in informed consent cases. However, recently there has been the suggestion that medical malpractice, including informed consent torts, should be viewed as enterprise liability. Under this theory, hospitals would become liable for the torts of the physicians on their medical staffs, and physicians would not need malpractice insurance for their hospital-based activities. Given the increasingly accepted view of a health care team and moves toward integrated delivery systems, it would be quite reasonable for the legal (and medical) system to focus on institutional liability and prevention.

The best vehicle for identifying and dealing with such incidents is the organization in which the doctor practices. The memory of the institution can serve to record and piece together patterns in a host of apparently idiosyncratic incidents. The collective wisdom of the hospital team can be pooled to devise feasible procedures and technologies for guarding against the ever-present risk of occasional human failure by even the best doctors...Not only does the organization have a greater capacity to establish such quality assurance programs, but it is also more likely to be influenced to do so by the incentives created by tort liability.

The third potential benefit associated with the imposed duty to inform patients of risks and alternatives was alluded to previously. Providing additional information may result in a decrease in unnecessary health care expenditures. As noted previously, the provision of additional information resulted in an increase in the number of patients choosing the less expensive medical treatment option.

The hidden dangers in excessive informed consent procedures are at least twofold. First is that out of defensiveness physicians and hospitals might expend precious physician and other personnel resources trying to achieve a level of informed consent that is attainable only in the world of law review articles and court pronouncements. The second is the real possibility that by providing excessive information on rare but possible risks, patients will be frightened away from procedures where the actual risk benefit ratio is highly positive.

Conclusion
The aim of Hawaii's legislature and courts has been to protect patient autonomy and to ensure that medical choices are made from an informed position. However, the nature of the legislative and litigation processes has kept them from addressing broader questions relating to how patients actually get information about their medical treatment, how that affects physician-patient relationships, and how we should work to change those relationships to provide better medical care while at the same time meeting our obligation to respect each patient's individuality.

References
2. 211 N.Y. 125, 105 NE 92 (1914).
5. 464 f 2d 772 (DC or 1972), cert denied, 409 U.S. 1064 (1972).
10. HRS § 671-3(b) (1989).
Honoring the Right To Die in Medical Emergencies

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On July 1, 1995, Hawaii's new DNR or comfort care only law will go into effect. Under specific circumstances, the new law allows and directs ambulance/emergency medical services personnel, first responder personnel, and others to honor the wishes of terminally ill patients who do not want to be resuscitated during a medical emergency. The law also protects emergency personnel from liability if they have a good-faith belief that resuscitation is necessary.

The Current Situation
Ambulance or other emergency personnel usually must use all available resuscitative measures if an emergency situation arises—even with acutely terminal patients—and even if it is against patients' wishes as expressed in their valid living wills.

This is often a no-win situation for everyone involved. For even the end-stage terminally ill person, the specific desire not to be resuscitated is ignored, and often their agony is prolonged. Family members must endure a sense of betrayal for not honoring the last wishes of a loved one. And the emergency ambulance personnel are often left with a feeling of helplessness because they must disregard a patient's wishes in order to perform their legal duty.

Effective July 1, 1995, this scenario will change, thanks to the enactment of Act 173, approved on June 21, 1994 by Governor Waihee, and now codified as Section 321-229.5 of the Hawaii Revised Statutes (HRS).

What the New Law Provides
HRS Section 321-229.5 allows emergency medical services personnel, first responder personnel, and health care providers to provide comfort care for terminally ill persons. The patients must be certified as terminally ill by their physicians and must have a written comfort-care-only document and an identifying bracelet or necklace.

Terminally ill persons can certify in the written document that they do not want chest compressions, rescue breathing, electric shock, or medication, or all of these, to restart the heart if their breathing or heart stops.

Comfort care includes administering oxygen, airway suctioning, splinting fractures, pain medicine, and other measures required for comfort.

The Documentation/Identification Required and Other Safeguards
In order for emergency personnel to honor a terminally ill person's wishes, the new law requires a written comfort care only document, signed by the patient, the patient's physician, and one other adult who personally knows the patient, certifying 1) the person is a terminally ill patient of that physician, and 2) the person directs emergency medical services personnel, first responder personnel, and health care providers not to administer chest compressions, rescue breathing, electric shock, or medication, or all of these, to restart the heart if the person's breathing or heart stops, and directs that person receive care for comfort only.

The original document, containing both certifications and all three signatures, is to be kept on file with the patient's physician. The patient receives two copies, one of which will be used to order the identifying comfort care only necklace or bracelet, prescribed by a physician.

The comfort care only document can be revoked at any time by the patient, either verbally or by removing the identifying bracelet or necklace.

In addition, the new law also provides that if the emergency medical services person, first responder, or any other health care provider believes in good faith that the provider's safety, the safety of the family or immediate bystanders, or the provider's own conscience requires the patient be resuscitated despite the presence of a comfort care only bracelet or necklace, then that provider may attempt to resuscitate that patient, and neither the provider, the ambulance service, nor any other person or entity shall be liable for attempting to resuscitate the patient against the patient's will.

Furthermore, the new law provides for an anonymous tracking system to ensure against abuse and to evaluate the success or failure of the system.

Background and History of HRS Section 321-229.5
The revised version of the bill was supported by testimony from the Executive Office on Aging, the Hawaii Department of Health, and the City and County of Honolulu, the Hawaii Chapter of the American College of Emergency Physicians, and the Hawaii Medical Association. The Hawaii Right to Life chapter did not submit testimony, but participated in drafting the language.
What's Happening Nationally
As of June of 1994, 22 states have statutes that authorize non-hospital “Do not resuscitate” orders.16

What Is Currently Being Done To Help Implement Hawaii's New Law?
The Department of Health Emergency Medical Services System branch is developing the protocol for the CCO-DNR order. According to program specialist Jamie Go, the DOH is reviewing bids for suppliers of identifying bracelets and/or necklaces. He expects to send information packets about the CCO-DNR orders to all physicians in February, 1995.

Checklist For Hawaii's New DNR Bracelet or Comfort Care Only Law
1. The new law is not effective until July 1, 1995.
2. The patient must be at least 18 years old.
3. The patient must be diagnosed with a terminal illness.
4. The physician should discuss the situation with the patient and explore the various options, including a living will and comfort care only—do not resuscitate (CCO-DNR) order.
5. If a patient requests a CCO-DNR order, the physician should fill out the form, which should be signed by the physician, the patient, and an adult witness who personally knows the patient.
6. The physician should keep the original, signed CCO-DNR form in the patient’s medical records, and give two copies to the patient.
7. The patient should keep one copy of the form for his or her personal records and send the other copy to the designated supplier of the identifying CCO-DNR bracelet or necklace.
8. The bracelet or necklace supplier sends the copy of the CCO-DNR form to the state emergency medical services office for monitoring purposes.
9. The patient wears the CCO-DNR bracelet or necklace, which will be honored by emergency medical services personnel, first responder personnel, and health care providers absent a good faith belief as described in the law.
10. If a patient changes his or her mind and wants to revoke the CCO-DNR order, he or she can remove the bracelet or necklace, or convey their change of mind to the emergency medical services personnel, first responder personnel, or other health care providers.

Acknowledgements
The authors gratefully thank Mr. Jamie Go, EMT, of the Department of Health emergency medical services branch. He has cheerfully shared all his information, was instrumental in drafting the bill and helping it get passed, and is currently setting up procedures for the law’s effective implementation.

References
1. Emergency medical services personnel are mobile intensive care technicians or emergency medical technicians who are certified or licensed in Hawaii. HRS 321-222 (eff 7/1/95).
2. First responder personnel are those who have successfully completed a U.S. Department of Transportation-approved first responder course in emergency basic life support, for example, firefighters and lifeguards. HRS 321-222 (eff 7/1/95).
3. Health care providers are licensed, certified, or otherwise authorized or permitted by Hawaii law to administer health care in the ordinary course of business or practice of a profession; doctors, nurses, hospice workers, and nursing home personnel. HRS 327D-2.
4. HRS 321-229.5 (a) (1) (A) (eff 7/1/95).
5. HRS 321-229.5 (a) (1) (C) (eff 7/1/95).
6. HRS 321-229.5 (a) (1) (B) (eff 7/1/95).
7. HRS 321-229.5 (a) (2) (eff 7/1/95).
9. HRS 321-229.5 (a) (1) (B) (eff 7/1/95).
10. HRS 321-229.5 (a) (3) (eff 7/1/95).
11. HRS 321-229.5 (b) (1) (eff 7/1/95).
12. HRS 321-229.5 (b) (3) (eff 7/1/95).
13. HRS 321-229.5 (b) (2) (eff 7/1/95).
14. House Bill No. 2553, originally proposed as an amendment to HRS Chapter 327D, pertaining to medical treatment decisions and the Living Will statutes. The Committee on Health agreed policies would be more appropriate as an amendment to the Emergency Medical Services Statutes under HRS Chapter 321, and the bill was accordingly amended.
An Efficient Way to Do the Wrong Thing

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Britain’s national health system (NHS) has been embattled since Thatcherism undertook to privatize it. This Britannic version of the new medicine is a hybrid of a neglected, underfunded shadow of the NHS and robust free-market capitalism. The NHS that the Tory government administers is aptly described as topless, bulging in the middle, and suffering chronic battle fatigue at the bottom. The quality of leadership in the NHS has plummeted at the same time thousands of middle managers have been added to prod the frontline caregivers.

The Britannic New Medicine has thrown the medical profession into a deep re-think of its very purpose. Recently, the head of a major hospital trust announced: “A physician’s first loyalty is to the hospital trust, then to his profession and then to his patients.” The outcry from physicians was strong, but clearly the embattled profession is nearing exhaustion. “Everywhere big, ugly buyers are assuming greater power, consumers are more sophisticated, new technology is revolutionising practice, and old ethical issues are being broached in awkward new ways.” The engine of change that is afoot is found throughout society—it faces lawyers, accountants, civil servants, university faculty, and now quite acutely, doctors. In business the new arena is global and the conditions for survival are unclear and ever-changing requiring continuous retooling, redundancies, and retraining. In health care a major feature of this new era is that these sea-changes are taking place in a world where resources for medicine are limited.

Problems of resource allocation within medicine arise at a number of different levels. How much of a society’s resources should be devoted to health care at all, as opposed to housing or defense? Given some overall allocation of resources to health care, how should these resources be distributed among various different sorts of health care expenditure: For example, primary versus hospital care, or preventive medicine versus care of the already ill. Within such broader categories, how should different specializations be allocated: For example, in the case of hospital medicine between cardiac and obstetric units. And both within and across specializations, what should be the relative allocation for different specific forms of treatment: Kidney transplants versus renal dialysis or hip replacements versus by-pass surgery. Questions of this sort are lumped together as problems of macroallocation. When faced with the relevance of the cost of care, the morally squeamish invoke the macro/micro distinction, asserting that economic considerations are morally relevant only to macro allocation decisions and that cost has no relevance in the micro medical/moral decisions of clinical practice.

Health Economists’ Proposal of QALYs
Health economists have devised a vehicle for resource allocation—the Quality Adjusted Life Year or QALY. The QALY analysis in the eyes of NHS managers is now on even terms with the status quo decision making which has been characterized as MSW (management by shroud waving). In the words of Mooney: “MSW where individual clinicians press for more resources for their patients by ‘announcing publicly that unless resources are increased patients will suffer and die unnecessarily.’ Each individual clinician has, after all, spent his professional life assessing his patients’ distress and disability and the risk to their lives posed by disease.” MSW calls on the physician’s abilities as ravers rather than reasoners, and thereby leaves them searching for a better method for allocation decisions.

Economists with an interest in health care introduced the concept of QALY in the 1980s as the key to rational resolution of resource allocation decisions in a time of scarcity. Initially, such economists offered QALYs as a cure for the haphazard or otherwise ethically inappropriate allocation of scarce medical resources without distinguishing between macro and micro allocation decisions. Currently, most major advocates see QALYs as a macro allocation tool while others would apply it throughout health care including case-by-case decisions in clinical practice.

The health economist argues that we should prioritize interventions in terms of the quality of well life measured in quality adjusted life years (QALYs) produced by the intervention per unit of cost. This implies that an intervention that takes N people from a bad condition (including dying) to the state of healthy for X years should have priority over an intervention that takes N other people from the same bad condition to a state of moderate illness for the same number of years. This sort of analysis gives confidence to resource managers, and those who have a consequentialist view of morals. There does seem to be something right about an attempt to rationalize the allocation of scarce medical resources, to examine our priorities in light of argument and evidence of their relative efficacy. The health economist view as represented by Alan Williams appears positively benign: “The objective of economic appraisal is to ensure that as much benefit as possible is obtained from the resources devoted to health care.”

Elaboration of QALYs
A natural response to allocation problems is to say: One should put one’s resources where they will do the most good. Perhaps one should, but what does one mean by “the most good”? One kind of good that health care can achieve is saving lives. So one measure, albeit a very crude one, of the good that health care does would be the overall extension of life expectancy that it generates: Years of life gained. This is where QALYs come in. An extended passage from Britain’s major advocate of QALYs is in order.

“The essence of a QALY is that it takes a year of healthy life expectancy to be worth 1, but regards a year of unhealthy life
expectancy as worth less than 1. Its precise value is lower the worse the quality of life of the unhealthy person (which is what the ‘quality adjusted’ bit is all about). If being dead is worth zero, it is in principle, possible for a QALY to be negative, i.e., for the quality of someone’s life to be judged as worse than being dead.

The general idea is that a beneficial health care activity is one that generates a positive amount of QALYs, and an efficient health care activity is one where the cost per QALY is as low as it can be. A high priority health care activity is one where cost-per-QALY is as low as it can be. A high priority health care activity is one where cost-per-QALY is low, and a low priority activity is one where cost-per-QALY is high. Thus an activity that generates only two QALYs but costs only £200 (so that each QALY costs £100 to produce) is more efficient than one that generates 5 QALYs but costs £2,000 (so that each QALY costs £400 to produce).12

What is new or special about QALYs? The QALY is a measure which: First, combines a) life expectancy, b) quality of life, and c) reflects the values of the community served; second, it is welfarist, i.e., designed to promote the greatest welfare (health) of the community served; third, it incorporates democratic and egalitarian features; and fourth, it is a rational/objective decision procedure—as scientific as one can get in the social sciences.

There are four assumptions that are required for a QALY analysis: 1) objective of health care system is to improve health, 2) the general public is competent to express its preferences on health, 3) it is possible to elicit meaningful valuation statements from people about differing degrees of health, and 4) it is possible to aggregate these valuations.

How are QALYs constructed or computed? Williams points to research that shows there are numerous ways for health economists to do this, one of which is called the Rosser illness states index. The initial phase of obtaining the “quality adjustment” involves Rosser’s system of describing eight states of health13 and four degrees of distress (none, mild, moderate, and severe). These illness states are meant to be very general so that they could cover a wide range of actual experiences of ill-health. Matched with the four distress levels the illness states generate 32 possible disability-distress states.

Rosser obtains the values (Table 1) by asking participants to rank 29 states (three lack meaning) in order of best to worst. State I-A (No disability, no distress) is clearly the best, but views vary considerably about the worst state. Respondents are to assign “1” to the healthy state, “0” for death, and a negative value for worse than death. Thus one might assign a .5 to state VI-C, with the implication that two years of life expectancy in that condition is of equal value to one year of healthy life expectancy.

The values found on the table provide the matrix derived from 70 respondents. The concept of QALYs does not depend on acceptance of Rosser’s index, many others have been devised by busy social scientists. At this point we need only grasp what these health care economists are up to.

Once we get this far it is a matter of arithmetic. We take what we know about the costs of procedures, probability of outcomes of treatments/procedures, and with the Rosser index, we are able to compute the QALY and the comparative efficiency of our medical efforts. A hypothetical example from Williams and his formula: “A treatment may offer a 0.8 probability of 10 QALYs, a 0.1 probability of none, and a 0.1 probability of -5 QALYs (ie, the loss of the equivalent of five years of healthy life expectancy)...we could say that the ‘expected’ value of the benefits from treatment is (0.8x10) + (0.1x0) + (0.1x-5) which is 8 + 0 -0.5 or 7.5 QALYs.”14 Given adequate information health economists can generate tables that report the “cost per QALY” of practices and procedures from family practitioner’s advice to stop smoking to hospital dialysis (Table 2).

Advocates of the QALY approach are quick to point out that they are not offering a precise answer to the question, how many QALYs a given period of life adds up to. Rather they are offering a rational approach to determine how resources should be allocated. Not only does their method reveal that some treatments are more cost-effective that others, but it produces the same outcome even if we experiment with the assignment of values we put in the equation. This is part of what Williams meant earlier when he says that the QALY analysis does not depend on the Rosser index, other indexes result only in differences in degree and leave in tact the rankings of treatments as found on Table 2. Given the situation of limited resources and more than enough beneficial procedures to exhaust resources, some beneficial procedures cannot be undertaken. QALYs provide us with an objective guide to make the needed choices.

It is difficult to sustain a convincing skepticism about a proposal that offers a method that reveals a way to select among treatments/procedures which will confer greater aggregate benefit than less. It is for this reason that the QALY analysis is being taken seriously in decisions regarding allocation. But this is not

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**Table 1.**—Rosser’s Valuation Matrix: 70 Respondents

<table>
<thead>
<tr>
<th>DISABILITY RATING</th>
<th>DISTRESS RATING</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A</strong></td>
<td><strong>B</strong></td>
</tr>
<tr>
<td>I</td>
<td>1.000</td>
</tr>
<tr>
<td>II</td>
<td>0.990</td>
</tr>
<tr>
<td>III</td>
<td>0.980</td>
</tr>
<tr>
<td>IV</td>
<td>0.964</td>
</tr>
<tr>
<td>V</td>
<td>0.946</td>
</tr>
<tr>
<td>VI</td>
<td>0.875</td>
</tr>
<tr>
<td>VII</td>
<td>0.877</td>
</tr>
<tr>
<td>VIII</td>
<td>-1.028</td>
</tr>
</tbody>
</table>

Fixed points: Healthy = 1 , Dead = 0

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**Table 2.**—Cost per QALY Estimates for North America 1983 Data

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Cost per QALY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coronary artery bypass grafting (CABG)</td>
<td>4,200</td>
</tr>
<tr>
<td>for left main coronary artery disease</td>
<td></td>
</tr>
<tr>
<td>Neonatal intensive care (1000 to 1499 gm)</td>
<td>4,500</td>
</tr>
<tr>
<td>T4 (thyroid screening)</td>
<td>6,300</td>
</tr>
<tr>
<td>Treatment for severe hypertension in men aged 40 plus (diastolic 105 mm Hg)</td>
<td>19,100</td>
</tr>
<tr>
<td>Treatment for mild hypertension (94 to 105 mm Hg)</td>
<td>19,100</td>
</tr>
<tr>
<td>Estrogen therapy for post-menopausal symptoms in women without prior hysterectomy</td>
<td>27,000</td>
</tr>
<tr>
<td>Neonatal intensive care (500 to 999 gm)</td>
<td>31,800</td>
</tr>
<tr>
<td>CABG for single vessel disease, moderately severe</td>
<td>36,000</td>
</tr>
<tr>
<td>School tuberculin testing program</td>
<td>43,700</td>
</tr>
<tr>
<td>Continuous ambulatory peritoneal dialysis</td>
<td>47,100</td>
</tr>
<tr>
<td>Hospital dialysis</td>
<td>54,000</td>
</tr>
</tbody>
</table>

Table distributed at a BMA conference, 1986, Oxford, England
to say that QALY considerations should be regarded as decisive. QALYs need to be measured against considerations of just distribution of the harms and benefits.

Supposing that we are clear about what it is that we are trying to measure, there would still be room for considerable skepticism about the extent to which it was possible to measure it. The idea of putting a yardstick up against a life and reading off some numerical value representing its quality is worrisome, if not preposterous. Philosophers have long debunked the efforts of those who have attempted to divine ways to compare the value of one year of life under circumstances A with those of circumstance B even if it were the same life. It is clear that the QALY analysis involves troublesome interpersonal comparisons and asserts that it is a common measure in which everyone’s claims of happiness are in some sense comparable and additive. This is a classical problem for utilitarian efforts to compare “utilities” and the health care economists seem to be up to much the same business. Many of the numerous objections to classical utilitarianism have a bearing on the plausibility of the efforts of the health economists. The ongoing discussion about utilitarian theory is robust, indicating that many issues are still quite unresolved.

Doubts about QALYs

Economists say that in allocation decisions the key question is a matter of efficiency, more health for the same money. The health economists seem to be engaged in a bit of covert imperialism by eclipsing the ethical dimension of the question for which there is no scientific (economic) answer. Furthermore, the apparent objectivity of the economic approach is very seductive to those who have budget targets to meet and thereby is extremely dangerous.

The problem of ranking values is an ancient one and a great deal of human genius has been expended an effort to quantify value. The ancestry of the modern efforts is easily traced to the British utilitarian philosophers and social reformers, most famously, Jeremy Bentham. There is rich literature detailing the unsatisfactory efforts to develop a felicific calculus.

Who’s pleasure (happiness) is to count? Well anybody’s and everybody’s. The objective of government is to create a harmony of interests such that the happiness of as many people as possible is promoted. Where arianism goes wrong is that it is promoting happiness in the abstract rather than the happiness of persons (it separates the individuals from the happiness by abstracting the happiness). Utilitarianism is the combination of welfarism, sum-ranking, and consequentialism. Such a theory separates value from valuers and merges the utility bits together as one total lump. Welfare economics and preference theory are efforts to overcome these difficulties.

Some concerns that shed serious doubts on the moral status of this method of resource allocation: The concerns can be arranged as 1) questions about valuing, 2) the distinction between descriptive and normative ethics and the relevance of democracy to morals, 3) questions about justice, and discrimination against the elderly and the disadvantaged.

Questions about Valuing

Recently there have been numerous efforts to determine what we value in health care and how we would rank services and interventions. The community consensus-building method used in Oregon to rank health care interventions is one effort. Social scientists have conducted numerous studies to establish health indexes. A study conducted in New York of health graduates and health professionals had results that should raise doubts about objective, democratic efforts to determine preferences. The subjects were asked to assign numerical values to saving lives of people in different states of illness in relation to saving lives of healthy people. The priority was clearly for the healthy. For instance, saving the life of a healthy person was considered approximately equivalent to saving the lives of two people with visual impairment, and three people sitting in wheelchairs and unable to work.

Recent studies in Norway suggest that Norwegians reject the primary value of health economists, efficiency, in favor of life itself. Thus, efforts to prioritize on the basis of gained life years is rejected as incommensurable with gained lives. The vast majority in this study held the view that individuals are equally valuable and equally entitled to treatment irrespective of differences in their health or levels of disability.

The health economists are quick to point out that the QALY approach is not dependent on any particular index. But from the two examples mentioned a very pressing question comes to mind: What is it that we have when we have the QALYs based on any index? What is the moral basis or foundation for this standard? Whether we use the Rosser, New York, Norwegian, Oregon, or other indexes what we have is a standard based on a quantification of the values of those in the study. Nothing more.

If we are a mean society we will do X, if we are sympathetic, we will do Y. Such an analysis does not tell what we ought to do, nor does it tell that X or Y is morally defensible. Niggardly and liberal societies will produce different QALYs.

Another concern that must be mentioned has to do with our ability to measure “quality of life” in any meaningful way. Part of the skepticism about any index that the health economists will use is based on doubts about measuring “quality.” There are serious unresolved problems about quality measurements, especially interpersonal comparisons and evaluations. These indexes at best tell us about the people who participate. The community consensus-building method used in Oregon to rank health care interventions is one effort. Social scientists have conducted numerous studies to establish health indexes. The ongoing discussion about utilitarian theory is robust, indicating that many issues are still quite unresolved.

Descriptive and Normative Ethics

Two points need to be made at this juncture. First, the outcome of such studies are merely a reflection of the different study groups. Surely the inheritances of the past and the differences in cultural conditioning affect the preferences of the subjects. The Norwegian adherence to the principle of equal entitlement to treatment has long been reflected in their national health service with very limited out-of-pocket payment. Thus they do not make good subjects for QALY index studies. On the other hand it is not surprising that in the American studies economic considerations are emphasized in these indexes of values. Bernard Williams points out: “Utilitarianism is not surprisingly the value system for a society in which economic values are supreme; and also, at
the theoretical level, because quantification in money is the only obvious form of what utilitarianism insists upon, the commensurability of value. The differences between the New York and the Norwegian study does not surprise and raises serious doubts about the "objective quality" of the QALY standard for allocation decisions.

The echo of utilitarian ethics runs strong through the QALY approach. In its narrowest form utilitarianism seeks the greatest happiness of the greatest number when happiness means pleasure and absence of pain. The health economists seek to eliminate inefficiency (reduce pain at the lowest cost) through discovery of a common measure, QALYs. But a central element of the common measure that they have devised is an uncritical account of the attitudes and values of the subjects of the index generating studies.

Second, ethicists are not given to doing ethics by opinion poll or the results of social scientists' descriptive studies. Allocation decisions based on QALYs utilize a democratic approach of determining the values of society and conclude that such an allocation is morally right. Such a conclusion does not follow. Even if their index was sufficiently representative and free from value loading by the evaluators that does not justify the move from an account of what their sample believes about states of life to how resources ought to be allocated. If their index is of how matters ought to be, the question remains what makes democratic majorities morally right? If on the other hand the index does not purport to tell us "how matters ought to be," then the health economists are not addressing our ethical problem. They are not answering the question: What would be a morally defensible allocation? Rather they are telling us here is an objective method of determining what collectively we would do. Mind you, not what we ought to do, just what we would do to most efficiently use our resources.

Reformers and advocates for the disadvantaged in society know better than appeal to what is commonly done or thought. The status quo is what they are trying to change. Rather they appeal to moral or legal arguments in order to obtain equal or sensitive treatment. Descriptive morality does not answer the normative question.

Questions about Justice

Allocation according to QALYs seem unjust in that it would favor those who are more healthy or fortunate. Unlike the classical utilitarianism of Bentham where "everybody to count for one, nobody to count for less than one," the health economists by counting QALYs will allocate to the fortunate, healthy, or young over their unfortunate, unhealthy, or elderly counterparts. Consider two candidates for a treatment where the only difference is that one is suffering from a condition (say, emphysema) unrelated to the immediate problem and the other is not. Assume that the quality of life of the emphysema patient is significantly impaired but there is no reason to suppose it will in any way affect the chances of the treatment under consideration proving successful. Assume also that both patients have an equally intense wish to go on living. Under the QALY assignment of resources the treatment goes to the person without the emphysema. It is a straightforward matter of arithmetic and probabilities. The QALY value for the treatment goes up for every year the one person is likely to live over the other. Clearly this system favors the fortunate and visits further misfortunes on the unfortunate by denying benefits in allocation decisions.

A parallel account works for age or any disability that shortens a person's life. Replace "emphysema" with "age/older" and you get the same result. Other things being equal, more QALYs are generated by expenditures on the young than the old and on the healthy than on the disabled. QALYs favor the young and the more healthy in any given selection.

A central value of health care has always been to assist those most unfortunate. Paying attention to the unfortunate, those whom nature has dealt a poor hand, has long been a measure of the moral quality of a society. Theories of social justice, certainly since Rawls, have had to be sensitive to a principle that requires that those least well off must be benefited if anyone else in society is to benefit. The health economists' QALY allocation scheme is not only utterly blind to this principle of justice, QALYs fail to require that the worst-off groups' level of well-being is raised whenever another groups' is to be raised. In fact they allocate in a manner that often increases the disadvantages of those with whom nature has dealt harshly. Rejecting QALYs as an allocation tool Harris enjoins: "What we should not do is abandon those whose quality is poor to concentrate on the fortunate. QALYs require us to do precisely this."

Williams has denied that QALYs are ageist by pointing out that they support the funding of hip replacements, an intervention overwhelmingly for the elderly. This denial is unconvincing because the ageism remains within the group in need of hip replacements, other things being equal, the QALY approach would select the youngest candidates. There is a sense that QALYs themselves are not ageist or sexist or anything but blind, and their outcome takes us back to decisions insensitive to our sympathies for our fellow humans. Whereas Rawls' theory of justice has firmly advanced the difference principle, (if we are to treat people differently, then the least well off must benefit from such treatment), the QALY accounts have retreated even further.

This explanation of the QALY approach and analysis challenges the ethical suitability of QALYs, in both macro and micro health care allocation decisions. This discussion suggests that whatever the mechanism of allocation it must pass the constraint imposed by ethical considerations of social justice. Furthermore, we have come to see that in QALYs health economists have found an efficient way to do the wrong thing.

References
7. Maynard A. The ethics of medical decisions: An economic perspective, delivered to BMA, Oxford, 4-49.
13. Rossier's illness states are 1) none, 2) slight social disability; 3) severe social disability and/or slight impairment of performance of work, 4) choice of work or performance at work severely limited, 5) unable to undertake any paid employment or continue any education, old people confined to home, 6) confined to chair or to wheelchair or able to move around in the house only with support from an assistant, 7) confined to bed, 8) unconscious.
15. Williams A. 1985:5.

HAWAI MEDICAL JOURNAL VOL. 54 APRIL 1995
State of the art in approaching several of the most disturbing problems involving end-of-life decision-making in an intensive care setting is applicable to other contexts as well. Developed as part of the curriculum at the John A. Burns School of Medicine at the University of Hawaii, the material is intended as a reflection of current work in health care ethics, strongly supported by literature, and generally consistent with current legal trends. But it also has developed into something of a consensus document, having been widely circulated in various versions, repeatedly presented to professional audiences dozens of times in Hawaii, and improved by countless comments and suggestions. The focus here is on the standards for withholding and withdrawing treatment. It should be noted that some important types of ethical problems are not covered: In particular, scarce resource problems (including some related questions involving medical utility), maternal-fetal and pediatric issues, and questions involving the notification of potentially affected third parties.

Decisionally Capacitated Patients

For decisionally capacitated patients, it can be axiomatic that health care professionals must secure informed consent prior to treatment. There is almost no debate about this issue. The little discussion is occurring only at the distant margins—refusals by pregnant women and patients with MDR TB. And even in these cases it cannot be said there is a consensus that contradicts the axiom. In essence, where informed consent has been withheld or withdrawn, health care professionals, lacking needed permission, are not at liberty to treat. Refusals of treatment by decisionally capacitated, informed adults are decisive: Relatives and health care professionals have no ethical or legal authority to overturn their medical decisions.

Competency and Decisional Capacity

All adults are presumed to be competent and decisionally capacitated. This assumption is rebuttable. In this context, the term "incompetency" must be distinguished from "decisional incapacity," by far the more useful of the two concepts. The former is a legal status that is imposed by courts. A judge, generally following the testimony of a psychiatrist, can find an adult to be legally incompetent and will therefore appoint a guardian who is empowered to make decisions on behalf of the adult, now a ward. Judicial declarations of incompetency are rarely required in the ICU. On the other hand, capacity and incapacity are action-specific concepts that are often clinically applicable. As regards some health-care decision, a patient is sufficiently capacitated to make that particular decision if, at a minimum, he or she has the capacities 1) to understand the problem, 2) to understand the risks and benefits of the available alternatives (including no treatment), and 3) to express a choice. It is possible for a legally incompetent patient—for example, a mature minor—to be decisionally incapacitated. Likewise, a competent patient may be decisionally incapacitated, as when a patient is in denial about the medical problem.

Informed Consent

Consistent with this analysis of decisional capacity as a minimum standard, a patient is sufficiently informed to give informed consent if he or she:

1. Understands the medical problem,
2. Understands what the health care professional proposes to do,
3. Understands the available alternatives, including no treatment, and
4. understands the risks and benefits attaching to each of these alternatives.

What counts as a risk and what counts as a benefit is based on the patient's values. A facial scar can have one assessment to a fashion model and quite another to a Prussian military officer.

Ethically and legally, informed consent is at the heart of the relationship between health care professionals and patients. The question is whether the health care professional has accurately set out the facts but, rather, whether the patient has understood. Informed consent is a process of patient education and assessment of the patient's knowledge. The underlying condition is explained, the options, and the risks and benefits attaching to each option (including the option of no treatment).

Time is allowed for questions and the patient's comprehension is tested, going back over what has not been understood, and then reassessing comprehension. Contrary to the opinion of many, the signature on the form is not the informed consent but merely rebuttable evidence that this process has been successfully carried out. In giving informed consent, a patient assumes a measure of responsibility for the decision to implement the medical procedure and gives health care professionals permission to carry it out.

The Patient's Values

Decisional capacity is often said by commentators to require, in addition to 1 to 4 above:

5. some relatively stable set of personal values and
6. the capacity to employ reason in applying these values to situations.

This higher standard is met when the patient can, so to speak, "tell a story" in which the decision, under the circumstances, makes sense against the background of his or her personal values. In assessing decisional capacity it may sometimes be appropriate to explore the patient's values and how these have been applied to the medical alternatives. Where, for example, a patient is rejecting a relatively non-burdensome intervention that promises significant subjective advantages, it is permissible to seek to understand the patient's values, stability, and how these are being applied. A simple and effective way of determining whether conditions 5 and 6 are met is to ask: "Please help me understand why you are making this decision."

In seeking to understand how the patient's decision is supported by the reasoned application of relatively stable values, it is important that health care professionals be able to honor the patient's values, even if these are very different from their own. Caution should be exercised to ensure that the standard of rationality that is applied to the patient is not outcome-based; ie, not set so high that only agreement with the physician's recommendation could count as adequate evidence of decisional capacity.

Determinations of Capacity

Ideally, determinations of decisional capacity (minimum standard) should be made and charted before the patient is asked to express a choice. If, however, there are questions about the reasoned nature of the choice—as when the patient is refusing low-burden, high-benefit treatment—it is recommended to ask the patient to explain why he or she has chosen that alternative: "Please help me understand why you want to do this." But the willingness to respond to such questioning is not a prerequisite for honoring consent in an adult patient. (The ability to respond coherently to such questions, however, might be relevant in rebutting a minor's presumed incapacity.) Referrals to the hospital ethics committee and/or an ethics consultation (where available) are advised in enigmatic refusal cases, where patients are unwilling to reveal their reasons for refusing treatment.

Psychiatric consults are appropriate to determine whether a psychological state, such as the adoption of unusual beliefs or a shift in personal values, is traceable to mental illness. But note that mental illness calls decisional capacity into question only when it directly affects the patient's decision. A diagnosis of mental illness is not the same as a determination of decisional incapacity, for mental illness can preserve capacity in some areas while compromising it in others. Accordingly patients with psychiatric symptoms and/or diagnoses may well be decisionally incapacitated. However conditions such as dementia, delirium, depression, mania, and delusions specific to treatment may well call decisional capacitiation into question.

Decisionally Incapacitated Patients

Decisionally incapacitated patients have the ethical standing to make medical treatment choices on their own. The discussion above sets out what are essentially standard criteria for distinguishing between patients who are decisionally incapacitated in this sense and those who aren't. Where patients are found to be decisionally incapacitated, the literature is again fairly consistent in recommending a three-step process. First, determine if there is an advance directive. Second, if unable to obtain an advance directive, endeavor to apply the "substituted judgment test" (See below). And third, in the event that the substituted judgment test cannot be applied, apply the "best interests" test. In all of these cases, the ideal is to approximate, as well as possible, the patient's own autonomous decision.

Advance Directives

Where an adult patient has lost decisional capacity, medical decisions should be made, ideally, in accordance with some previously executed advance directive: A living will or a durable power of attorney. Advance directives are indicated where:

a) incapacitation is anticipated (eg, Alzheimer's disease) and/or
b) conflicts are anticipated with or within the patient's family.

Neither relatives nor health care professionals have the legal or ethical power to countermand the provisions in an advance directive.

Advance directives are fundamentally of two types. There is the "living will" containing instructions for medical treatment in the event the patient becomes incapacitated. The document specifies some set of medically determinable conditions (Two common ones are "in the event that I am terminally ill" and "in the event that I have lost the capacity to participate in medical treatment decisions with no reasonable expectation of regaining that capacity") and a set of instructions to follow when it is determined that the listed condition or conditions obtain. And there is the "durable power of attorney" which delegates the authority to make medical treatment decisions to some third party who is required to act in accordance with the patient's values. (See the discussion below on the "substituted judgment test." Sometimes the two documents are combined, including instructions, as living wills do, but also designating a proxy decision-maker in the event it become unclear how the instruc-
tions are to be interpreted.

Where a physician has personal reservations about carrying out its provisions, the care of the patient should be transferred in a timely way to a physician who can give effect to the patient’s decision. Health care professionals should be aware that the provisions of advance directives may vary. These should be studied with care.

The “Substituted Judgment” Test
Where a patient who has lost decisional capacity lacks an advance directive, medical decisions should be made in accordance with the “substituted judgment” test. It is critical, in discussions with the patient’s friends and family, to frame the question properly. Those who have been close to the patient should be asked for information about the patient’s hopes, beliefs, values, goals, concerns, etc., with the intention of identifying the course of action that the patient would have chosen under the existing circumstances.

It is a good idea to begin a family conference by specifying that the concern is to try to reach agreement about the best decision rather than determine who has the right to decide. If everyone can agree about what is the right thing to do, there is no need to reach the question of who is the one to decide. Note that relatives should not be asked for their decision nor should they be asked about their own preferences. They should instead be asked for specific information that can assist in reaching a shared understanding of how the patient would have made the decision.

The conversation should focus exclusively on what those assembled know about the patient: The stories, the quotes, the insights into the patient’s deepest commitments. “Did he or she ever say anything about how these decisions should be made or about how these problems should be approached?” Only after these issues have been amply explored—with everyone having had a chance to contribute and hear what others have to say—it should be asked, “How can we best respect what this person stood for?” Using this approach, medical decisions should reflect the patient’s values, as these are discerned by those who have been closest to the patient, those best situated to be able to report reliably on what those values were. On some occasions, but only when this approach has failed, relatives and friends may be polled on the question of which person is the one the patient would have been most likely to entrust with such a decision.

Conversations very like this are also appropriate where there is a proxy decision-maker who has been designated by a durable power of attorney. Though, in these cases, the designated proxy does have a right to decide, he or she is still required to make that decision in the light of the patient’s expressed values. Hence the exchange of information can be essential in confirming what those values were.

The Best Interests Test
When a decisionally incapacitated patient has no advance directive and where information is not available about how the patient would have decided — either the patient has never been capacitated or is a “John Doe”—medical decisions should be made using the “best interests” test. For never-capacitated patients, it often makes sense to ask, “What do we know of this patient’s sensivities?” (Warmth, comfort, freedom from pain, etc.) For formerly capacitated patients it can be helpful to ask, “What would the reasonable person in the patient’s position choose?” These cases should be referred to the hospital ethics committee.

Contraindicated Treatment
Above All, Do No Harm
The ethical principle, Above all, do no harm, prohibits the imposition of burdensome medical treatment that is not expected to provide the patient with any subjective benefit. This principle is most likely to be violated when relatives and other decision-makers are given too free a hand in medical decision-making. Guilt and denial may compel relatives to press for aggressive treatment that the patient is known not to have wanted. Attention to the standards set out in the substituted judgment test can prevent this from occurring.

Medical Futility
There is no ethical obligation to commence or to continue futile treatment modalities, procedures that are not expected to provide the patient with any subjective benefit. Questions of medical futility can arise when patients and families are in agreement that “everything” should be done. In these cases it is critical that patients and families are clear about what outcomes can and cannot be expected as a consequence of aggressive treatment. The focus should be shifted away from the treatment modalities that are available to the outcomes that can be reasonably expected to flow from those treatments. (See Competency and Decisional Capacity: Minimum standard for informed consent.) Most cultures have venerable rituals associated with death: Ceremonies that acknowledge the importance of the person who is dying and that solemnize the seriousness of the occasion. It is unfortunate that health care settings are often prepared to respond to familial apprehension only by imposing medical treatment: A kind of high-tech shamanism. What may be more appropriate to families is intensive spiritual care; a mobilization of social support systems that can assist the family through its loss and transition.

Psychiatric consults may be indicated if, for example, denial or some other delusion specific to a treatment decision is playing a role in the demand for futile treatment. Consultation with an institutional Ethics Committee may also be appropriate in cases where patients and families persist in demanding treatments that do not promise benefits that are subjectively valued by the patient.

Withdrawal and Withholding of Life Support
Where a treatment modality is not owed to the patient (where consent has been withdrawn or where the procedure is not expected, on balance, to provide a benefit to the patient) this treatment modality may be withdrawn or withheld. The same conditions that justify withholding treatment also justify withdrawing it. There is no presumption that, once begun, no matter how futile, life-sustaining medical procedures must be continued. The maintenance of organic life is not, in and of itself, a benefit to the patient. “Benefit” here is to be understood as relative to the patient’s values, as discussed in Decisionally Capacitated Patients. Note that the decision to withdraw or withhold life support is not a decision to abandon the patient. Other treatment modalities, especially pain control and comfort care (“aggressive palliative care”), may be required.

Brain Death
Therapeutic treatment modalities are decisively contraindicated for all patients who are dead, including patients who are “brain dead.” It is generally unwise to use the expression “brain dead”
Physicians involved in the care of elderly patients are often faced with end-of-life decisions including withholding or withdrawal of tube feeding. More than 80% of deaths take place in the hospital or nursing home and the prolongation of life by medical technology has replaced natural processes. We believe the availability of life-sustaining medical technology including tube feeding does not make physicians ethically obligated to use it once it is known that health and function cannot be restored and the burdens outweigh the benefits. Patients and their surrogate decision-makers have a right to refuse life-sustaining medical treatment they find burdensome. Tube feeding as a medical treatment, withholding of tube feeding as equivalent to withdrawal of tube feeding, the benefits versus the burdens of tube feeding, and the decision-making process involved in the withdrawal of medical treatment are considered Hawaii’s statutes as they apply to decision-making and examples of cases to illustrate how these concepts are pertinent to patients whom we encounter in clinical practice are discussed.

Tube Feeding as a Medical Treatment
Some individuals view enteral feeding as basic supportive care that is ethically obligatory, and therefore, should not be withheld or withdrawn. The provision of food and water is believed to be symbolic of caring, comfort, and compassion. However, the majority ethical and legal position at this time is to regard enteral and parental nutrition and hydration as life-sustaining medical treatment with proportionate benefits and burdens that must be assessed individually from the perspective of the patient. As with all other forms of medical treatment, tube feeding can be refused or might not be appropriate. It is the obligation of the physician to obtain informed consent prior to the initiation of tube feeding. Over the last decade there have been numerous court cases supporting the right of the competent individual to refuse life-sustaining tube feeding and have expanded this legal concept to include incompetent individuals and individuals not imminently dying (patients who are in persistent vegetative states or who are very debilitated). In 1990, Justice Sandra Day O’Connor, writing in a concurring opinion for the United States Supreme Court in the Cruzan case, stated unequivocally that artificial feeding should be considered a form of medical intervention. Despite emerging legal consensus, in several states feeding tubes are explicitly excluded from the types of life-prolonging treatment that may be rejected in an advance directive such as a living will. Since July of 1991, Hawaii’s statute has explicitly addressed whether the declarant wants or does not want tube feeding. Patients should, therefore, have an updated declaration.

Tube feeding is a medical treatment, but we contend that all health care treatments, whether regarded as basic supportive care or medical intervention, are subject to a benefit/burden analysis and can be accepted or rejected by an adequately informed patient or surrogate decision-maker.

Withholding Versus Withdrawal of Tube Feeding
Decisions concerning initiation, withholding and withdrawal of life-sustaining enteral nutrition are very difficult to make. There is not always a clear sense of whether to start tube feedings. When the prognosis is not clear and there is evidence to suggest that nutritional support can help a person regain health and function or allow time to recover, the more prudent decision is to initiate a time-limited trial of tube feeding. Tube feeding can be withdrawn when it becomes clear that therapy is not effective, or that the burdens of prolonging life with tube feeding outweigh the benefits, or when the patient’s prognosis or wishes have been clarified.

Ethicists and the courts equate the act of withdrawing a treatment with the act of withholding a treatment once the appropriate individuals have reached a decision. If withdrawing a treatment is considered more problematic than withholding one, physicians will withhold treatments when they are uncertain as to their benefit, rather than risk not being able to withdraw the treatment later. This denies many patients potentially beneficial treatments.

Many health care providers believe it is psychologically and emotionally more difficult to withdraw treatment rather than
withholding treatment, and this may be more true with tube feeding than with other life-sustaining treatments. However, for the reasons outlined above, we support the view that there is no significant ethical difference between withholding and withdrawing tube feeding if the essential considerations regarding medical indications and goals, patient preferences, and benefits and burdens are the same.3

**Benefits Versus Burdens of Tube Feeding**

The benefit of enteral feeding is the improvement of the nutritional status of individuals who are unable to tolerate feeding by mouth. Tube feeding may decrease the risk of infection, pressure ulcers, and aspiration pneumonia. The burdens of tube feeding include discomfort from the tube and the need for restraints to prevent dislodging of the tube. The probability of aspiration pneumonia may actually increase for some patients following the initiation of tube feeding. Patients undergoing gastrostomy are at risk of infection, painful insertion sites, wound dehiscence, hemorrhage, prolonged ileus, pyloric obstruction and gastric prolapse. Those undergoing jejunostomy incure the dangers of anesthesia and the risk of diarrhea and associated dehydration. Hospitalization is required for both gastrostomy and jejunostomy and may be a stressful experience for cognitively impaired elderly patients.6,7 These are the quantitative benefits and burdens. The qualitative benefits and burdens are just as important, if not more so.

Some individuals believe in the sanctity of life itself, and to these individuals the prolongation of life under any circumstances is a benefit. Proponents of sanctity of life may insist that diminished quality of life never justifies the removal of life-sustaining treatment. Most people, however, believe that prolongation of a life of minimal quality is a burden and not a benefit. The evaluation of quality of life of an individual lacking decision-making capacity must be based on that individual’s prior preferences, values and goals of life. The objective evaluation of quality of life, however, may be difficult in that the personal beliefs and values of the surrogate decision maker may interfere. Jonsen et al8 suggest that broad, if not universal, agreement would be possible on the following descriptions:

a. *Restricted quality of life* is an appropriate description of a situation in which a person suffers from severe deficits of physical or mental health. It is a judgment that might be made by the one who lives the life or by others who observe that person.

b. *Minimal quality of life* is an appropriate description for the situation in which an observer (such as the physician or family member) views a patient whose general physical condition has deteriorated beyond recovery, whose ability to communicate with others is severely restricted, and who appears to suffer discomfort and pain.

c. *Quality of life below minimal* is an appropriate description of the situation in which the patient suffers extreme physical debilitation and complete and irreversible loss of sensory and intellectual activity. It might even be suggested that this state would be better described as having no quality, since the ability for subjective evaluation has presumably been lost by the person in such a condition. This description applies to persons in a persistent vegetative state.

Most of the available literature and key landmark court cases support the withdrawal of tube feedings in patients with persistent vegetative state or permanent unconsciousness.13 These cases do not reflect the majority of situations that clinicians face in their daily practices. Elderly individuals with severe irreversible neurological damage such as those with severe dementia and stroke are much more common.4 These are the kinds of patients with a quality of life considered minimal by the description suggested above. Advance directives are valuable in situations such as these because they select out those patients who consider such a life burdensome and would not choose to be in such a condition.9,11

Many patients also consider the burden they will impose on their caregivers. Although some ethicists think this consideration is not appropriate, other individuals believe any burdens a patient wishes to consider are appropriate, and the concerns of elderly patients have for their family members should not be minimized by physicians.4 Tube feeding may necessitate institutional placement. To some individuals life in a long-term-care facility may represent a burden.

Prolongation of life with tube feeding also poses a burden to society. While the cost of medical services and the allocation of resources must never be allowed to intrude into medical decision-making for an individual patient, the cost to society in general is very real. As of 1988, there were an estimated 280,000 Americans in long-term care institutions on tube feeding.7 In 1989, the number of persons who were 65 years and older was 31 million, or 12.5% of the population. In 2030, there will be 65.5 million elderly persons in the United States, or 22% of the population.12 Dementia is the most prevalent diagnosis in long-term care facilities. There is already a shortage of beds and personnel needed to care for patients requiring long-term care. Chronic tube feeding in patients with severe dementia and other forms of severe irreversible neurological damage increases the need for skilled nursing services for this population of patients. If public policy does not support the withholding and withdrawal of life-prolonging tube feedings as requested by informed surrogate decision-makers, then the public needs to plan to provide and pay for the additional services that will be required.1 It is interesting to note that many British physicians do not use feeding tubes on long-term care wards and are reluctant to insert them in patients who are unable to give consent to placement.13

**The Decision-Making Process**

Both legal and ethical consensus support that an adult patient who has decision-making capacity and is appropriately informed has the right to refuse all forms of medical treatment including life-sustaining treatment. An adult patient who no longer has decision-making capacity should continue to have the right to refuse all forms of medical therapy. In order of priority, decisions should be based on advance directives, substituted judgments, and the best interests of the patient.14,15

Decision-making capacity refers to a patient’s ability to make an informed decision as assessed by health care professionals. Persons whose cognitive ability is not normal should not be disqualified as decision-makers. For example a patient may not be fully oriented to time and place, but still understands the medical issues before him or her. The central test of competence is the evidence that a person understands the nature of the issue and the consequence of the choice he or she is making. It is also helpful to place any choice in the context of a person’s own life history and values and ask whether the particular choice is
consistent with these. This is sometimes called the “authenticity” of the choice. A third element of decision-making capacity is the ability to communicate meaningfully. We also find consistent responses over time to be helpful in determining decision-making capacity. A patient may have decision-making capacity for certain issues and not for others. Decision-making capacity should be assessed in relation to the decision at hand.

Advance treatment directives are useful in patients who no longer have decision-making capacity: Natural Death Acts, durable powers of attorney for health care, and living wills. Natural Death Acts are statutes passed by state legislatures affirming a person’s right to make decisions regarding terminal care and provide direction about how that right can be effected after the loss of decision-making capacity. They typically contain a model (sometimes mandatory) document.

Durable powers of attorney for health care or health care surrogate is also a statute passed by a state legislature. It authorizes an individual to appoint another person who is familiar with his or her preferences and values to act as the agent to make health care decisions after he or she becomes incapacitated.

Living wills are advance directives communicated by a person to physicians, family and friends in a less formal, less legalistic fashion. Prepared living wills are available, or patients can choose to compose their own form of the living will. In some states, these personal documents are given legal standing. Even if there is no explicit legal recognition of personal documents, physicians can act on them as expressions of their patient’s preferences.

Hawaii’s statute, “Medical Treatment Decisions” (Chapter 327-D), appears to be a form of a Natural Death Act and seems to imply legal recognition of living wills, either written or documented verbal statements to a physician. We believe that a couple of points need to be made regarding Hawaii’s Medical Treatment Decisions statute. First, after careful reading, the definition of terminal illness is nonsensical. Terminal illness is defined as “any incurable or irreversible disease, injury, or condition which...will...serve to delay the moment of death of a patient.” Second, Hawaii’s statute applies to non-terminally ill as well as terminally ill patients. The sample declaration states, “If I should develop a terminal condition or a permanent loss of the ability to communicate...I do not want to have my life prolonged.” The definition of permanent loss of ability to communicate includes not only patients who are permanently unconscious, but patients with severe neurological or brain damage, with no reasonable expectation of regaining this capacity. Withholding or withdrawing tube feedings in these cases is sometimes contested by families or professionals. There have been situations in which patient surrogates have contested that patients never fully understood the implications of the declaration. For these reasons, physicians and patients need to document clearly that this is the actual intent of an executed declaration.

Hawaii also has a Uniform Durable Power of Attorney Act (Chapter 551D) which defines durable power of attorney for health care decisions. The attorney-in-fact is able to make decisions about life-prolonging procedures for patients who develop a terminal condition or a permanent loss of the ability to communicate concerning medical treatment decisions with no reasonable chance of regaining the ability. This statute states that the durable power of attorney for health care does not grant the authority to withhold or withdraw life prolonging treatment unless explicitly stated. This statute is restrictive, and it is proposed that a statute that explicitly grants an attorney in fact authority to make all health care decisions would be more useful.

In the absence of advance directives, the right to refuse medical therapy is exercised on the patient’s behalf by an appropriate surrogate decision-maker. Physicians have traditionally turned to the patient’s family for consent to provide or terminate treatment, but the legal status of the family to give consent is not always clear. Surrogate decision-making by family members is authorized by statute or case law in approximately half the states. In Hawaii, such a statute has been proposed but has not yet been legislated. In the absence of a family consent statute, a physician justifiably might be uneasy about relying on the authority of the family when making treatment decisions. However, most courts have declined to require judicial intervention as a prerequisite to withdrawal of life-sustaining treatment from an incompetent adult.

With the assistance and advice of a physician, the surrogate decision-maker is asked to make a decision on behalf of the patient, judging as best as he or she can what the patient would have wanted. This judgment is based on the patient’s previously stated preferences, values and goals in life. This process is known as substituted judgment. When no information about the patient’s prior wishes, values and goals of life are available, the surrogate decision-maker must decide on the basis of what he or she believes is in the best interests of the patient. Determining the best interest of the patient is based on weighing the benefits for the patient of starting or continuing a certain life-sustaining therapy against its burdens on the patient. When there are conflicts, hospital ethics committees can provide assistance. The courts usually are not involved unless there are conflicts that otherwise cannot be resolved.

Cases
The following cases represent hypothetical patients based on true clinical experiences. These cases illustrate and expand on some of the points presented.

Case 1
Mrs A was treated with gastrostomy tube-feeding following a right intracerebral hemorrhage manifested by left hemiparesis, dysphasia and dysphagia. She was incontinent of bowel and bladder, nonambulatory, and required assistance for transfers and all activities of daily living. She had been residing in a skilled nursing facility for two years when she began to point to the tube feeding bottle, then to herself, and then straight upward. She did this repeatedly over a period of time. This was interpreted by her husband as a request to discontinue tube feeding and allow her to “go to heaven.” She was evaluated by her physician who witnessed these gestures. A nurse indicated that Mrs A was able to consistently answer yes-no questions by using head shakes and hand squeezes. It was agreed that she understood that death would ensue if tube feeding were withdrawn. Furthermore, Mrs A had a living will indicating that she would not want tube feeding in the event that she had a terminal illness or permanent inability to communicate.

This case illustrates that a person whose communication and cognition are not normal should not be disqualified as a decision-maker. It also shows that communication needs to be
facilitated if necessary. If Mrs A is judged to have the capacity to make an informed decision by health care professionals involved in her care, then she has the right to refuse all forms of medical treatment including life-sustaining tube feeding. The right to refusal applies equally to withholding and withdrawing treatment, and this right is based on the ethical principal of autonomy and the common law right of self-determination. Goldstein and Fuller propose the following guidelines in interpreting nonverbal behavior: 1) Look for consistent responses over time; 2) attempt to verify your interpretation of the behavior with people who know the patient well, and 3) analyze your own reactions to the behavior, and attempt to minimize the projection of your own wishes to the patient. The advance directive, although not applicable at this time, shows that beliefs are consistent over time.

Case 2
Mr B underwent excision of a meningioma. Following surgery he remained lethargic and confused. Verbalizations were sparse and unintelligible. Mr B had a living will that indicated he did not want his life prolonged by tube feeding if he had a terminal condition or permanent loss of ability to communicate concerning medical treatment decisions. He also had a durable power of attorney for health care. He had clearly stated to this individual that he did not want to be "put out to pasture" in a nursing home and that he did not want to be maintained on tube feedings as his wife had been. Following a discussion, the patient's family, including his attorney-in-fact, elected to observe how Mr B would recover from his surgery over the ensuing months and gastrostomy tube feedings were initiated. Mr B failed to improve and he was transferred to a skilled nursing facility. Neurology and neurosurgical reevaluations were requested. A CT scan did not show hydrocephalus and EEG did not demonstrate any seizure activity; there was bilateral slowing. Tagamet and Dilantin were discontinued. Mr B became slightly more arousable but all verbalizations remained unintelligible. Mr B's attorney-in-fact asked that tube feeding be discontinued.

This case demonstrates the use of a time-limited trial of tube feeding may be preferable to withholding treatment when prognosis is not clear. Tube feeding can be withdrawn when the prognosis for recovery is clarified. It also illustrates the need to optimize the patient's medical condition when assessing decision-making capacity, i.e., hydrocephalus and seizure activity were ruled out and medications were adjusted. The most important point illustrated by this case is the significance of advance directives in facilitating and guiding medical decision-making involving an incapacitated patient. This patient had a written declaration and a durable power of attorney for health care and had made clear verbal statements regarding his wishes.

Case 3
Mr C, a 60-year-old, had a cardiac arrest. Cardiopulmonary resuscitation was initiated immediately and continued for more than 2 hours. At the time resuscitation efforts were discontinued, Mr C had a spontaneous pulse. He was unresponsive and was believed to have hypoxic encephalopathy. Tube feedings were initiated shortly after his admission to the hospital. An EEG done initially and repeated 1 month later demonstrated no clear cortical activity. Based on clinical findings, a diagnosis of persistent vegetative state was made. There was no recovery over the next 3 months and Mr C's wife and children asked that tube feeding be discontinued.

This case serves as a point of discussion about withdrawal of tube feeding in patients in persistent vegetative state (PVS). The American Medical Association's council report on "Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support" provides a definition, clinical criteria, and differential diagnosis of PVS. This report also offers guidelines in determining prognosis in patients in PVS. For example, of prognostic relevance in this case is that few if any patients who remain vegetative following cardiac arrest recover after 1 month and essentially none will regain cognition after 3 months. Furthermore, prognosis for cognitive return is poor in patients over 40 years old when compared to those younger than 40.

There is an emerging ethical and legal consensus supporting the withdrawal of life-sustaining treatment including tube feeding in patients in PVS. It is the opinion of Jonsen et al that physicians are acting within the law, as currently understood, when they decide to withhold or withdraw life-supporting interventions, unless there is specific law to the contrary in any particular jurisdiction. The conditions required for this decision are: 1) It is virtually certain that further medical intervention will not attain any of the goals of medicine other than sustaining organic life; 2) the preferences of the patient are not known to be contrary and cannot be expressed; 3) quality of life clearly falls below minimal; and 4) family and members of the staff are in accord. They suggest institutions should request their legal counsel to prepare clear instructions for the medical staff in view of prevailing local law. Other than advance directives, Hawaii does not have statutes that specifically address the withdrawal of life-sustaining treatments in a patient in PVS. The AMA's council report similarly indicates that once a diagnosis of permanent unconsciousness has been made, decisions to withhold or withdraw life-prolonging medical treatment ordinarily can be implemented without resorting to the courts. Although judicial intervention has been sought for a variety of reasons by a variety of parties, it is appropriate only when there is a dispute among family members or other guardians about the patient's wishes or interest or among the physicians regarding the diagnosis.

Case 4
Mrs D is 85 years old and resides in a nursing facility. She has had a diagnosis of Alzheimer's disease for 8 years. At this time, dementia is severe. Speech is limited to a few words. She no longer is able to walk, is confined to a bed or chair, and is dependent in all activities of daily living. Mrs D does not recognize or interact in any meaningful way with family members or nursing staff. Supplemental tube feedings were initiated at an earlier stage of her disease. She is not able to swallow and requires total enteral nutrition. Based on what Mrs D had valued in life, her husband and children indicate that she would not want to live in this manner. They request that tube feedings be discontinued. Mrs D does not have advance directives.

Case 5
Mr E is a 78-year-old who was admitted to the hospital with an
extensive left middle cerebral artery stroke with right hemiplegia and global aphasia. Tube feeding was initiated shortly after admission. Stroke rehabilitation was initiated but Mr E failed to make any gains in physical, occupational or speech therapy because of lethargy. Over the next several months, there was no improvement in neurological function. He remained dependent in mobility and activities of daily living, incontinent of bowel and bladder. He also continued to be lethargic and aphasic. There was no evidence of a reversible cause of his altered mental status. Mr E’s daughter stated that her father would not want to live this way based on his previously stated preferences and beliefs and his joys in life. She requested that tube feeding be discontinued. There were no written or documented verbal advanced directives.

Although a degenerative disease such as Alzheimer’s disease or stroke can result in PVS, Mrs D and Mr E are clearly not in PVS. These cases reflect the types of situations that clinicians face in their practices. Based on the preferences, beliefs, values, and goals of life of these patients, their surrogate decision-makers claim they would regard their current quality of life as minimal and burdensome. Cases 4 and 5 are offered to illustrate the need for a clear family consent statute.

Summary
The majority ethical and legal position at this time is to regard tube feeding as medical treatment and the act of withholding and withdrawal of treatment as equivalent. An informed adult patient with decision-making capacity has the right to refuse all medical treatment including life-sustaining treatment and this right is based on the principles of autonomy and self-determination. Advance directives extend this autonomy and significantly facilitate and guide end-of-life decisions of incapacitated patients. Only 8% to 15% of Americans have written advance directives. We believe physicians need to be knowledgeable about the local statutes pertaining to medical treatment decisions and that it is their responsibility to assure their patients have explicit advance directives in the form of written declarations and/or documentation of clearly expressed verbal statements. In the absence of advance directives, an informed surrogate decision-maker should have the right to refuse medical treatment on the patient’s behalf and statutes are needed to clarify the role of surrogate decision-makers. Finally, discussions of the ethical and legal issues regarding the withdrawal of tube feeding in patients with severe irreversible neurological impairment with minimal quality of life are needed.

References
2. Jonsen AR, Siegler M, Winslade WJ. Clinical Ethics: A

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Market forces are driving the delivery of health care into managed care. New alignments among health care providers, payers, utilization reviewers and hospitals create new legal liability. Better-informed patients, concurrent credentialing by hospitals and payers, and new incentives to reduce hospital and physician-related costs have resulted in new federal legislation and agencies that reshape health care delivery and legal liability.

Introduction
Managed care is coming to Hawaii. Indeed, it is in place to a great extent in many areas of this country. The politicians in Washington may differ noisily as to how delivery of health care should be retooled, but the inexorable forces of the marketplace are moving the delivery of health care into managed care. Some insurers and physician groups are purchasing hospitals. Some hospitals are dispensing with independent medical staffs and are employing physicians directly. Like it or not, we must anticipate what managed care will bring. Part of what managed care will bring are new alignments among insurers, hospitals, and physicians, and with those realignments both major and subtle changes in legal liability within a managed care system will be seen.

A review of the forces driving us toward managed care yields insight into what those legal liability changes probably will be. Using a medical analogy, if we evaluate what the disease within the system is, we can anticipate the attempted cure and the side effects of the cure.

Economic Forces Driving Toward Managed Care
In 1994 the United States acknowledged its participation in a global economy. NAFTA and GATT thrust us anew into the global marketplace. Current discussions and negotiations with Pacific Rim countries will undoubtedly yield even more formal agreements between the United States and its Pacific Rim trading partners. Increased participation in the global economy means, among other things, that anything spent on goods and services that cannot be exported and sold abroad will make us less competitive in the international marketplace. Unquestionably, exploitation of medical technology and know-how is, and should be, a significant component of our trade overseas, but expenditures for health care within our country are a resource not favorably affecting the balance of trade. Unnecessary expenditures within a wasteful health care delivery system renders us less competitive in the global marketplace.

Health Care Finance and Review demonstrates vividly the increasing percentage of gross national product consumed by U.S. national health expenditures (Fig 1). Under the current system, a full 32% of gross national product will be consumed by health expenditures by 2030. A jump from 5.3% of GNP in 1960 to 32% in 2030 would destroy any attempt for this country to compete internationally.

In 1990, health care expenditures in the United States were almost twice that of our primary Pacific economic competitor, Japan, and almost four times that of China (Fig 2, 3). The remarkable statistic of 1.9% for Singapore is probably the result, in large part, of a system called Medisave. In Singapore, whatever portion of an annual health care expenditure allotment an individual does not spend is deposited into a pension plan for that individual. This system of incentives to save money can be argued to support a system under managed care into which incentives can be built. Such incentives will undoubtedly yield interesting twists in the area of health care practitioner legal liability.

A given then is the percentage of gross national product spent in this country on health care as one of the significant factors that reduces our global economic competitiveness.

The disease is a costly health care system. A look at the most expensive components of the system points out what the attempted cure will include (Fig 4). Of particular interest is the fact that hospital care constitutes 38 cents of each health care dollar spent in 1990. Physician services are the next largest single cause of health care expenditures. Therefore, it is not unreasonable to project that a managed care system will ultimately be in place that will 1) be incentivized to reduce total health care expenditures; 2) target, in particular, the cost of hospital care; and 3) will be designed to reduce the cost of physician services.

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<td>26.5</td>
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<td>2030</td>
<td>$49,936</td>
<td>$15,969.6</td>
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What is Managed Care?

Managed care within the context of the delivery of health care services is a carefully planned system within which the following are important components:

1. An agreement by a hospital or related organization to provide certain health care services;
2. Those certain health care services are subject to a system designed to assure proper utilization and quality of care;
3. In exchange for a payment by a third-party payer.

This management of care may be imposed solely by the payer, by hospitals, or medical service organizations in concert with payers, physicians, and hospitals. There are almost countless potential configurations of interrelationships among components of managed care systems. There is no indication which configuration of the many possibilities will be implemented eventually in Hawaii. Currently physicians, medical center and clinic CEOs, and attorneys are attending many seminars and programs being offered with a view toward deciding on and implementing managed care systems in Hawaii.

With the foregoing components of managed care in mind and reflecting on the economic forces driving us toward managed care, it can be predicted with probability that managed care in Hawaii will utilize a variety of devices to eliminate or minimize to every extent possible the economic uncertainties of the present health care delivery system. Under the present system, a third-party payer, such as HMSA, will reimburse a fixed percentage of approved services. Although reimbursement is for approved services only and at a fixed percentage, there is enormous financial uncertainty within the current system. The current system is tantamount to a system of property insurance in which an insurer agrees to reimburse a homeowner 80% of whatever the replacement cost may be of a home destroyed by fire. To be sure, a replacement home under those circumstances will be considerably grander and more expensive than if the home were replaced under a system in which the insurer imposed a fixed limitation on the cost of a replacement home.

A concept of capitation will incorporate into managed care the fixed limitation on the amount available for health care for each patient/participant in the program. As an example, if the system allocates for each patient/member of a particular managed care program a total of $5,000 a year for total health care costs, including hospitalization, physician charges, drugs, etc, the managed care system will make money if less than $5,000 per patient is spent. Money will be lost if more than $5,000 is spent per year per member for health care expenditures. A similar system is already in place in Hawaii and throughout the Mainland in the form of health maintenance organizations (HMOs).

Major and Subtle Changes of Legal Liability of Managed Care

A look at the economic forces driving us toward managed care, and the realignment of hospitals, physicians, and insurers within a system of capitation, suggest what the legal liability issues will be in a managed care system.

Independent medical staff will lose its meaning in a system in which physicians own a hospital or in which a hospital employs physicians. Hospital administration will not have available to it the defense that it exercises no control over a physician’s independent practice of medicine within its physical facilities. The hospital will have total vicarious liability for the acts and omissions of the physicians whom it employs. Therefore, a hospital-employed physician will no longer have the incentive to point the finger of liability at hospital employees and, conversely, the hospital will not have the incentive to point the finger of liability at the physician, who is no longer a member of an independent medical staff. Indeed, the same attorney may represent both the hospital and the physician when both are sued by a patient. Under the present system, a patient may sue a hospital and also name as a defendant nurses employed by the hospital. Just as there is usually no conflict of interest for one attorney to represent both the hospital and the nurses in that...
even greater polarity between payers and providers resulting in finger-pointing between payers and providers if a patient alleges failure to provide sufficient services.

Concurrent credentialing by hospitals and payers or their affiliated utilization review organization will cause a retooling of peer review confidentiality and protection. Traditionally, hospitals are concerned with the competence of a physician. Under the present system a hospital’s credentials committee will rarely concern itself with a physician’s utilization track record. Again, what with an attempt to reduce hospital census and reduce the frequency of physician visits under a capitation system, credentialing will be based on both the physician’s competence and utilization track record. A hospital may conclude that a physician is competent, while the payer component of the managed care system may wish to exclude the entry of a physician into the system because of a track record of over-utilization.

The credentialing process will, therefore, incorporate into it a much greater emphasis on a physician’s morbidity and mortality track record. Not only will morbidity and mortality statistics become an integral part of credentialing decisions, but such statistics will become available to patients in formulating an informed decision in selecting physicians.

Because hospitals and payers will each conduct their own credentialing process, peer review protection will either have to be broadened to include credentialing by payers or may be reduced or eliminated altogether as morbidity and mortality statistics are considered important information to be made available to patients in making health care decisions.

Agency for Health Care Policy and Research Section 6103 of OBRA 1989

The major functions of the Agency for Health Care Policy and Research section 6103 of OBRA 1989 creates a new Title IX of the Public Health Service Act:

1. To conduct and support research, demonstration projects, evaluations, training, guideline development and the dissemination of information on health care services and systems for the delivery of such services including activities with respect to: a) the effectiveness, efficiency and quality of health care services and procedures; b) the outcomes of health care services and procedures; c) clinical practice, including primary care and practice-oriented research; d) health care technologies, facilities, and equipment; e) health care costs, productivity and market forces; f) health promotion and disease prevention; g) health statistics and epidemiology; and h) medical liability. This legislation also will assess health technology and establish an advisory council for health care policy, research, and evaluation.

What will probably be the most controversial and discussed component of this new legislation is the establishment of the Office of the Forum for Quality and Effectiveness. This office will arrange for the development, periodic review and updating of clinically relevant guidelines that may be used by physicians, educators and health care practitioners to assist in determining how diseases, disorders and other health conditions most effectively and appropriately can be prevented, diagnosed, treated and managed clinically.

Further, the Office of the Forum for Quality and Effectiveness will develop, review periodically, and update standards of quality, performance measures and medical review criteria through which health care providers and other appropriate
entities may assess and review the provision of health care and assure the quality of such care. Such guidelines, standards, performance measures and review criteria are to be based on the "best available research and professional judgment" and are to be presented in formats appropriate for use by physicians, health care practitioners, providers, medical educators, and medical review organizations, and in formats appropriate for use by consumers of health care. This will include treatment-specific or condition-specific practice guidelines for clinical treatments and conditions, and forms appropriate for use in clinical practice, educational programs, and in reviewing quality and appropriateness of the medical care.

Priorities in establishing such practice guidelines, standards, performance measures and review criteria will be prioritized based on needs of Medicare, particularly high-cost or controversial items and items with substantial variation nationally. Among those areas of clinical practice selected for application of the guidelines, standards, performance measures, and review criteria are:

- Post-operative pain management
- Urinary incontinence in adults
- Prediction and prevention of bedsores
- Benign prostatic hypoplasia
- Low-back pain problems
- Depression treated by primary care physicians in an out-patient setting
- Evaluation and management of early HIV infection
- Management of cancer-related pain
- Treatment of pressure ulcers in adults
- Quality determinants of mammography
- Otitis media with effusion in children
- Heart failure: evaluation and care of patients with left ventricular systolic dysfunction
- Post-stroke rehabilitation
- Screening for Alzheimer's disease and related dementia
- Cardiac rehabilitation
- Diagnosis and management of unstable angina
- Smoking prevention and cessation
- Diagnosis and treatment of anxiety and panic disorder in a primary care setting

Definitions within this new legislation are as follows:
- Practice guidelines: Systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.
- Medical review criteria: Systematically developed statements that can be used to assess the appropriateness of specific health care decisions, services and outcomes.
- Standards of quality: Authoritative statements of 1) minimum levels of acceptable performance or results, 2) excellent levels of performance or results, or 3) the range of acceptance performance or results.
- Performance measures: Methods or instruments to estimate or monitor the extent to which the actions of a health care practitioner or provider conform to practice guidelines, medical review criteria, or standards of quality.

"Cookbook" Medicine from a Legal Liability Viewpoint

There are seemingly insurmountable obstacles in developing practice guidelines in some areas, such as treating back pain. Once the obstacles are overcome and practice guidelines are developed and put in place, the question arises as to whether deviation from the guidelines can be used by a patient in a lawsuit against a physician. Physicians argue that the establishment of practice guidelines that cannot possibly apply in every instance to every patient will now provide patients and their attorneys with even more ammunition in medical malpractice lawsuits.

Once practice guidelines are enacted, won't this give patients and their attorneys new ammunition to use in lawsuits against physicians? Maine and other states have confronted this potential problem by decreeing by statute that only the defendant physician may refer to practice guidelines in his or her defense. In other words, practice guidelines cannot be raised initially by the patient's attorney to prove a deviation from the guideline and, thus, care and treatment below the standard of care. Initially, only the physician's attorney can utilize as evidence a practice guideline to show conformance with the guideline as a defense for a medical malpractice lawsuit. Therefore, in Maine and the other states, a practice guideline in a medical malpractice lawsuit is not a spear, it is a shield.

Whatever the legal liability implications may be of practice guidelines or practice parameters, the demonstration project in Maine appears to have some profound impact on the practice of medicine. A Wall Street Journal article said that 80% of practicing physicians in Maine are participating in the demonstration project, it is reported that prior to the imposition of practice parameters, 95% of all victims of falls and car accidents were ordered to have $170 neck x-rays at the emergency room of Maine Medical Center. Following the imposition of the practice parameters, that percentage was reduced to 50%. It is also reported that anesthesiologists are now doing fewer blood tests.

Fig 5.—Sample Protocol in Maine Medical Liability Demonstration Project Excerpts

MEDICAL LIABILITY DEMONSTRATION PROJECT
OBESITICS AND GYNECOLOGY PRACTICE PARAMETERS

CONTENTS:
I. Procedure: Cesarean Delivery for Failure to Progress
II. Procedure: Assessment of Fetal Malperty prior to repeat Cesarean delivery or elective induction of labor
III. Procedure: Hysterecmy, abdominal (68.4) or vaginal (68.5)
IV. Procedure: Hysterecmy, abdominal (68.4) or vaginal (68.5)
V. Procedure: Tubalps
VI. Condition: Premature Eclampsia in a clinically stable patient
VII. Condition: Singleton Effect Presentation
VIII. Condition: Fental Herpes Simplex Virus Infections
IX. Condition: Intraperitoneal Fetal Distress
X. Topic: Antepartum Management of Prolonged Pregnancy

IV. PROCEDURE: HYSTERECTOMY, ABDOMINAL (68.4) OR VAGINAL (68.5)
A. Indication: Abnormal uterine bleeding in women of reproductive age (626 all, except 626.0, 626.1, 626.3, 626.7)

Confirmation of indication:
1. History of all of the following:
   a. Endometrial cancer in women.
   b. Tumor or cervix or endometriosis.
   c. Fetal death.

B. Actions Prior to Procedure:
1. Determine that attempted hormone treatment (e.g., progestins) was unsuccessful or contraindicated or refused.
2. Hemoglobin or hematocrit documented.
3. Document and attempt to correct anemia if present.
4. Offer autologous blood donation if appropriate.
C. Communication:
1. Desire to maintain fertility.

References: Quality Assurance in Obstetrics and Gynecology, 1989 ed. Other diagnostic and procedural criteria include 627.2, 627.01, hypermenorrhea (606.5).

For example, large pain, gushes, irritation on activity.
(See Note V 74, Section 1991/White Senate 1991)

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and chest x-rays before surgery. Radiologists are saying that the guidelines are one reason why they no longer require as many patients to stay overnight in the hospital after certain blood vessel x-rays.

One thing is certain: When practice parameters/guidelines are in place and a consumer version of the practice parameters is published for use by patients, the often-heard allegation of "lack of informed consent" will be heard less and less. Some health care practitioners may view the prospect of a dialog between practitioner and patient, each with his or her version of the relevant practice guideline in hand, as yet another burden for the health care profession to carry. Patients who are armed with their own practice guidelines when they come to the physician's office will certainly have more questions and will initiate more discussion regarding the proposed treatment. This may consume more time and affect the bottom line because fewer patients will be seen. However, when a physician charts reference to the practice guideline and the fact that the patient was referred to the consumer version of the practice guideline, and there was full discussion about the practice guideline, it will be extremely difficult for that patient to claim later that he or she lacked informed consent before the care/treatment/procedure began. Therefore, the patient who is armed with knowledge may be viewed as an irritant, but ultimately, that patient will have less to complain about if a recognized risk of the procedure is encountered post-operatively.

When practice parameters are discussed in the Hawaii Legislature, it is proposed that the treatment/procedure guidelines be included along with alternatives, the risks, so there can be no question about a patient's having participated in a discussion about these issues and the material covered in guidelines, such as those proposed in Maine. If practice parameters include a thorough discussion of the recognized alternatives and risks of a procedure, a physician who follows the guidelines and who furnishes to a patient the consumer version of the practice guidelines should never lose a case on the issue of lack of informed consent. This is particularly important because a recent Hawaii Appellate case says, in effect, that a patient who signs an informed consent form on which all of the pertinent information appears with respect to providing informed consent is not conclusive evidence that informed consent was obtained from the patient before a procedure.3

Legal Liability Fallout Under Managed Care

Maintenance of morbidity and mortality statistics with respect to practitioners such as surgeons will mean more stringent controls on the delivery of health care and, therefore, clearer guidelines for evaluating which physicians should and should not be licensed, have staff privileges, and how their care can be evaluated. Therefore, there will be a new balance struck between a physician's right to a license, to staff privileges, and cost-effective reasons for precluding or removing a license and staff privileges. We will see more administrative alterations between licensing authorities and physicians, and credentialing bodies in hospitals and physicians.

We will see more lawsuits against hospitals for negligent credentialing. Because there will be greater emphasis on affording privileges within much more stringent control parameters, patients' attorneys will look increasingly to the information available or what should have been available to an institution before a practitioner was granted staff privileges.

Market forces will move us toward capitation and reduction of hospital and physician-related costs. Therefore, we will see an expanded role of nurses and the creation of new areas of nursing liability. As an example, if patients are discharged earlier from hospitals to reduce post-operative hospital care costs, it will probably be nurses and not physicians who will go to the home of a patient for post-operative evaluation. This will require a higher level of decision-making among nurses and will require a heightened level of communication between nurses and physicians.

Of all the things that feel uncomfortable and are disliked most is change. In discussions with groups of physicians regarding what managed care will mean in terms of the law and liability, it is extremely obvious that physicians are anxious, fearful and angry about the prospect of the changes managed care will bring. Whether it's lawyers who represent patients and cases against physicians, lawyers who handle the corporate and business aspects of a changeover into managed care, or lawyers who represent physicians in a medical malpractice lawsuit, physicians are now of the mind that all lawyers are the enemy and managed care is what lawyers are creating. This is not true. Economic forces are driving the health care delivery system into managed care. Although non-lawyers do not like to view lawyers as victims, the economic forces behind managed care are in fact victimizing attorneys as much as physicians. The economic forces are bigger than the medical and legal professions. Whether we are physicians or attorneys, managed care is coming and both professions are well advised to adapt as much as they can, rather than fighting the process along the way.

References
1. Title IX of the Public Health Service Act, Agency for Health Care Policy and Research, Section 6102 of OBRA 1989.
Empathy and Medical Education

Irwin J. Schatz MD

Empathy is the feeling generated in physicians by patients when “I and you” becomes “I am you.” 1 Spiro, in his elegant recent message, called it “an almost magical phenomenon.” 2 Freud defined it as “the mechanism by which we are enabled to take up any attitude at all towards another mental life”; others said it was “a feeling of being at home with the object contemplated as a friend,” and “it includes a merging of the viewer with the viewed.” 3

Empathy is experienced often by physicians when they can identify sufficiently with their patients so that they feel some of the same elation, frustration, depression and pain of those for whom they provide care. It is an emotion that must be distinguished from sympathy, the major component of which is a feeling of wanting to help or of feeling sorry for someone. Obviously, too much empathy impairs the diagnostic and therapeutic process; there is a fine line between an overwhelming and unproductive identification with the patient, and an unfeeling excess of distant objectivity.

Unfortunately the process of both undergraduate and graduate medical education seems almost designed to drive empathy from the student and resident. Medical educators teach science. We stress objectivity. The collection of data is paramount. The goal of undergraduate medical education is that the student acquire the necessary skills, habits, attitudes, values and knowledge sufficient to interview a patient, collect, synthesize and integrate the clinical data and formulate an appropriate diagnostic and therapeutic plan successfully. 4 Nowhere in this curriculum (promulgated initially by the Association of American Medical Colleges) is there mention of empathy.

The student is transformed into a physician during the clinical clerkship—a crucial and central event in his or her education. This is preceded by a variable period of immersion in the basic sciences, sometimes attached to clinical problem solving. Success is measured by objective testing of data recall and problem-solving skills. The matrix from which all of these efforts emerge is one of competition. This is the framework around which the efforts of pre-med students, medical students and residents are centered. Competition pervades our system of medical education. Intellectual elitism is our standard; it is not the most compassionate or empathic student or resident but that student who achieves the highest grades on test scores whom we honor. It is no wonder that the lessons learned by our trainees are that the relationship with a patient has a low priority, that performance is measured best by grades, and that achievement is reflected by the prestige of the medical school and of the residency program at which the student is accepted for further training. 5

Nowhere in this construct is there room for teaching or learning empathy—what Martin Buber has called “the I and thou.” It is true that the threshold between empathy on the one hand and lack of caring on the other is fuzzy. Too much empathy, an excessive identification with the patient, could paralyze clinical efforts. For instance, the emotions generated even in the most hardened physician who cares for the child dying of leukemia, can overpower and suppress the critical need for objective clinical assessment and action. Such empathy becomes counterproductive. Osler told us to maintain equanimity; yet although there should be some emotional distance from the patient, this should not be so much as to remove passion from the encounter.

Unfortunately, today this balance is out of kilter. Too often, in the modern environment of catastrophic illness and technical overkill, we lose sight of the patient as an individual. Too often at morning report or on ward rounds students and residents are heard talking about taking “hits,” joking or laughing at the expense of a patient, or ignoring simple and heartfelt needs for empathy.

Spiro feels that “the increased emphasis on molecular biology to the exclusion of the humanities encourages students to focus not on patients, but on diseases.” 6 This is conventional and traditional wisdom, but interest in the humanities does not necessarily imply a humanistic or empathic physician. 7 There clearly is a difference between the humanities and humanism; those interested in the humanities might turn out to be humane and sensitive physicians, but this is more likely related to self-selection than it is to effective immersion in humanities, transforming a previously narrowly focused student into the compassionate and empathic clinician hoped for. A consistent cliche in this area is the belief that the compassionate physician cannot be scientifically minded. As Seymour Glick has stated, “focusing on the humanities as playing the pivotal role in compassion is misplaced and represents a misunderstanding of what humanities can and cannot accomplish. After all, the humanities, particularly the arts, are ethically neutral. They provide important aesthetic values but inherently embody few ethical values. Some of the world’s most heinous crimes were perpetrated to the strains of Haydn and Mozart by individuals immersed in the works of Goethe and Heine.” 8

Selecting a pre-medical student with a broad background in the humanities, or requiring that medical students read poetry and critique modern literature should not imply that these acts will create a humane physician; there are countless examples of...
Finding a Connection
The single most important measure that we could take to teach empathy is to promote a connection between the patient and the physician. This can be taught by example and, perhaps, should even be required. Such a connection implies a human relationship and a transference of emotion from one person to the other. The history taker should no longer remain only a passive recipient of data whose role is to extract relevant objective information from the patient. He or she must first and foremost develop a true and clear identification with the patient as a person.

The induction of empathy is dependent on the initial patient encounter and how it is structured. There are several mechanisms that can be established which can create and maintain empathy between the trainee and the patient:

1. Develop a connection by finding out who the patient is. This means that the usual and traditional way of taking a history by asking the name, the chief complaint, and the history of the present illness is misplaced. The first step should be for the student/resident to introduce himself or herself, and ask the patient for name and age and then say something like, “I’d like to get to know you a little bit before discussing the reason why you are in the hospital. Tell me about yourself.” As meticulously as the experienced history taker would be in extracting information about the details of illness, so he or she must exploit this open-ended invitation to learn about the patient. This must provide a glimpse into the patient’s life, personality, sensitivities and environment; it will generate the kind of empathic connection that is essential for the humane physician. Only after the historian determines that he or she knows the patient as a person—and it does not take very long to generate this sense—should the standard, traditional history be taken.

2. The trainee should focus on the most important symptom and relentlessly pursue it. Most patients will not fully describe the major reason for coming to the hospital without being prompted. For instance, if the patient complains of shortness of breath, far more time should be spent on the description of that symptom—what the patient experiences, how the patient perceives it, what emotions are engendered by it, what the patient fears about it—than in an unrelated and time-consuming pursuit of remote past illnesses. We see this most prominently in the student historian who has not yet learned to take a history efficiently; five or 10 minutes may be spent exhaustively searching for information about irrelevant family history in an elderly patient, but not adequately obtaining information about the principle symptom.

Why such a focus on the major complaint, even in excess of the need to understand it for clinical reasons? Because it generates empathic feelings even in the most hardened caregiver and because it provides the historian an opportunity to feel for the patient (compassion), with the patient (empathy), and sorry for the patient (sympathy).

3. During training each student or resident should have experience in what it feels like to be a patient. I would divide these into the following categories:

Loss of Identity Experiences
Each student should be required to be admitted to the hospital for a day, have all familiar bedclothes removed, and wear a hospital gown. He or she should have an enema and have a portion of abdominal or pubic hair shaved.

Gurney Experiences
Students and residents should lie face-up on an open gurney, with or without a thin blanket covering them, in a radiology department, apparently unattended and waiting for a procedure. No matter what the disability, the student or resident should lie perfectly flat, facing the ceiling. As an alternative site, the trainee on the gurney should be placed with the same attire in a patient and staff elevator during a busy time of the day when students, house officers, attending physicians, housekeeping personnel, crash carts, and various equipment are all transported at the same time. Preferably this should occur late in the day, when students and residents will be discussing “hits,” difficulties with recalcitrant patients, and plans for the weekend. The acute diminution of personal worth and self-esteem generated by such experiences will be interesting and enlightening for the trainees.

Procedure and Disability Experiences
• Each student or resident must, during training, experience a series of rectal and/or pelvic exams, usually by groups of trainees. Furthermore, each student or resident must have at least one endoscopy performed (sigmoidoscopy or upper GI).

Each subspecialty trainee should be required to experience the following in their particular disciplines:
• The orthopedic fellow should be required to wear a non-weight-bearing cast for a week.
• The ophthalmology trainee should have his or her eyes patched to create temporary blindness for two days.
• The gastroenterology fellow should undergo jejunal biopsy and colonoscopy.
• The cardiology fellow should undergo right heart catheterization.
• The hematology/oncology trainee should undergo a bone marrow aspiration.
• The urology fellow should undergo a transrectal ultrasound examination of the prostate gland.

There will be other procedures and/or temporary disabilities with an acceptably low risk that should be identified as relevant for other trainees.

These are serious suggestions. It is remarkable how sobering such experiences can be for those who provide care. Unfortunately, periodic reinforcement may be necessary.

4. Each supervisor/teacher must be required to demonstrate empathy. This is not an outlandish suggestion—just as we each demonstrate the proper technique of auscultation of the heart or palpation of the abdomen, so should we be required to show that as practitioners and teachers we can and will develop empathy with our patients.

Summary
Spiro has said, “computed tomographic scans offer no compassion and magnetic resonance imaging has no human face. Only men and women are capable of empathy.” Empathy is an essential and required part of our roles as caregivers. We must enhance this natural emotion that exists in each of us; we can do so by carefully designing a curriculum, much as we would for
learning about the physiology of the liver.

The roots of our need for detachment and equanimity go back to Sir William Osler, but the pendulum has swung too far, and the need for retention of millions of data bits overwhelms our souls. Although excessive emotion is destructive and counterproductive, we must not suppress our passion—but control it. The best physician both feels with the patient and prescribes for the patient at the same time. To do one without the other is inadequate care. As medical educators our task is clear.

References

Nonclinical Use of Medical Skills: Beneficence Lost?

Kim Marie Thorburn MD

The first time that I was asked to probe a rectum to search for sequestered drugs remains fresh in my memory. The correctional lieutenant, commander of the watch, seemed more menacing than the convict suspect as I attempted to explain my refusal to participate. “Yes, I am employed by the prison, but I am a physician. My profession’s code of ethics prevails.”

It may have been the first demand to apply my medical skills to a body-cavity search but the issue of nonclinical use of medical skills was not new to me. The incident took place at San Quentin Prison, site of California’s gas chamber. State regulations call for doctors to pronounce cessation of vital signs during executions. Before accepting a position at the prison, I sought assurance that I would not be expected to work in the death chamber in the event of an execution.

The ethical principle in these examples is beneficence. We physicians use our special skills for the good of our patients.

It could be argued that there are times when our skills must be applied for the good of the community. Retrieval of sequestered drugs, for example, might benefit the prison community by preventing access to harmful substances, needle sharing and accumulation of debts. However, Jonsen et al argue that competing ethical responsibilities must be prioritized and the patient’s medical interests receive greater weight than public good.

Beneficence is grounded in a fundamental medical premise: The patient must trust the physician. The physician’s skills signify life or death, health or illness; violation of the trust disrupts the patient-doctor relationship. The physician loses the opportunity to intervene and help the patient with his or her substance abuse, the opportunity for a potentially more sustained benefit than a one-time interruption of drug trafficking.

Doctors’ involvement in executions might seem a clear-cut misuse of clinical skills. However, it was not until 1980 that the American Medical Association resolved that physicians should not participate in executions. Most states that execute have statutory or regulatory requirements for physicians to be present. Even after the AMA pronouncement, some physicians have argued there is a role for doctors at executions because the death penalty is legal. Determination of competence to be executed is still controversial. The AMA awaits action by the American Psychiatric Association on whether it is prohibited participation in executions. In 1986, the United States Supreme Court decided that it is cruel and unusual punishment to execute condemned people who, because of mental illness, do not understand their wrongdoing or the consequences of the penalty. (Prior to 1986, this was also customary law.) Psychiatrists are asked to render opinions on measures of competency, opinions that can contribute to the killing of the person whom they examined.

One argument that favors psychiatrist involvement in competency-to-be-executed assessments (and other judicially mandated evaluations) is that forensic medicine is a bona fide field of specialty in which doctors do not have patients. Forensic psychiatrists and others serve important legal functions and work as objective experts for the courts and other quasi-legal entities. Beneficence is not an issue.

Could this be a slippery slope?

What then about demands for application of medical skills in the interest of the military, a prison, or an industry? The primary mission of these institutions is defense and war, detention and punishment, or manufacturing and production, not medical care of soldiers, prisoners, or workers. These institutional missions could easily corrupt professional values if doctors readily used their skills to serve military, prison, or industrial purposes.

Other demands for physicians’ clinical skills are more insidious. Some may arise from the adversarial nature of the legal system. There is a tendency to cast many societal decisions as polar, an individual’s needs against the public good. The medi-
cal profession is sought to render opinions about an individual’s needs. Disability assessments are an example. We are also involved in welfare decisions, child placements, insurance eligibility and other situations in which we apply our skills for purposes other than to care for the patient.12

It is true that our assessment may help the individual, such as a truly needy patient who receives disability benefits. But it is also possible that we may contribute to a decision not to render benefits. Such a decision can be quite disruptive of the doctor-patient relationship. The risk arises because these are nonclinical uses of medical skills—beneficence lost.

The contemporary transformation of the delivery of medical care could further erode the principle of beneficence as a premier ethical premise of the medical profession. More and more, physicians are finding themselves in institutional relationships. In contrast to the prison or military or industrial physician, the institutions do not seem to be at cross-purposes with our professional mission. They are institutions, such as health maintenance organizations and other managed-care entities, whose purpose is to organize health care for patients. Problems will arise because institutions serve groups. Physicians care for individuals. The principle of beneficence is more important than ever as a guide to our practice of medicine.

References
2. Kipnis K. Professional ethics in correctional health services: Clearing the ground. Corhealth (newsletter of the American Correctional Health Services Association). October/November 1990;4-5.

Consent for Children as Organ Donors

Rodney W. Williams MD, JD

The use of children as organ donors has been a source of legal and ethical concern since transplantation became generally available.

Introduction
The number of diseases in children successfully treated by bone marrow and solid organ transplantation continually increases. The availability of a histo-compatible minor sibling as a donor has raised ethical and legal issues since transplantation became available. Organ donation represents a significant risk to one child (the donor) while the benefit accrues to a second child (the recipient). Parents who decide for both children must deal with this conflict.

St Francis Medical Center has devised a consent procedure that attempts to avoid parental conflict of interest, recognizes the emerging competency of the child donor, and provides a measure of protection for the donor.

Sophie’s Choice
In Sophie’s Choice,1 a mother was forced to decide which of her two children would be killed in a Nazi concentration camp. Early commentators portrayed parental consent for their child’s organ donation similarly, refusing to acknowledge that organ donors benefited from the donation:

[T]he parents should not be allowed to deprive a child of one of his vital organs without his consent or his intelligent comprehension...[I]t is considered almost impossible to support the view that parents should be allowed to consent to the removal of organs from minor children. Actually, legislation should be passed to prohibit children under a certain age from acting as donors.2

The Supreme Court of the United States in a different context has stated that while parents may be free to become martyrs themselves, it does not follow that they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.3

Parents are given broad authority to enter into contracts for their children and to consent to medical treatment. Since organ donation is not medical treatment, however, consent should not extend to procedures such as organ donation where the benefit accrues to one child while the risk is borne by a second. Does the decision presented to the parents differ from Sophie’s choice only in degree and not in kind?

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Solomon's Decision

In one of the earliest recorded cases involving disputed parentage, King Solomon, without the benefit of DNA testing, awarded custody of the child to the mother who acted in the child’s best interest by refusing to consent to the child’s hemicolectomy. The courts have adopted this standard routinely approving intrafamilial donation and recognizing that the organ donation actually would be in the best interest of the donor.

In Kentucky, in the case of Strunk v. Strunk, a 27-year-old mentally incompetent ward of the state was the only medically acceptable kidney donor for his 28-year-old brother. Psychiatric testimony in that case supported the court’s conclusion that the donation would be beneficial to the incompetent because the psychological benefits and the continuing close relationship of the siblings outweighed the minimal risks of the procedure.

Similarly, in a 1979 Texas case, the court authorized the mother of a 14-year-old girl to consent to the donation of one of her kidneys to her brother, again finding the “substantial psychological benefits” of donation outweighed the minimal risks involved.

In other circumstances involving family members, the courts have refused to authorize the procedure when no benefit could be demonstrated. In one of these cases, the father of twins sought to compel testing to determine if they were suitable donors for their half-brother, his leukemic son. The mother of the twins had never been married to their father and had sole care and responsibility for the twins. The court, in refusing to allow the twins even to be tested as potential donors, noted that, though the potential donors and recipient shared the same biological father, there was no evidence that they had or would have a close relationship and, therefore, there was no benefit to the potential donors.

Similarly, a Wisconsin court was asked to authorize a kidney donation from a catatonic schizophrenic to his sister. After hearing testimony that the donor was “indifferent to his environment” and that his disease was a “flight from reality,” the court refused consent, finding that there was absolutely no evidence that any interests of the ward would be served by the transplant.

The American Medical Association in a Code of Ethics report agreed with the best-interest approach when it made the following statement:

The merits of a best-interest standard include its ability to incorporate the preferences of children as evidence of what is in their best interests without relying solely on a fictional determination of what they would want were their values more mature. Best interest also allows for the consideration of potential psychological benefits, when they exist, and weighs the medical risks of transplantation, rejecting transplantations which pose an unacceptably high risk to the minor source...[E]vidence of future benefit to the minor source should be clear and convincing. Possible benefits to a child include the following: Continued emotional bonds between the minor and the recipient; increased self-esteem; and prevention of adverse reaction to death of a sibling. Whether a child will capture these benefits depends on the child’s separate circumstances.

The AMA position recognizes the benefits to the donor, but also concedes that these benefits are not absolute and must be balanced against the risks. A decision about bone-marrow donation is comparatively easy—there have been no deaths associated with the procedure, and the bone marrow regenerates. Kidney transplant involves the permanent loss of a kidney and a higher perioperative mortality. According to Livingston Wong MD at St Francis, eight kidney donors have died in the perioperative period. Would the benefits described in this excerpt justify a lung donation?

Judicial Procedure

Early skepticism about the value of organ donation to the donor paralleled a societal debate about the proper forum in which such bioethical concerns could be addressed. A Massachusetts court in discussing the use of a guardian ad litem to make decisions for the mentally incompetent, as opposed to the patient’s family and family physicians and hospital committees stated:

We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent...We do not view the judicial resolution of this most difficult and awesome question...as constituting a ‘gratuitous encroachment’ on the domain of medical expertise. Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that would form the ideals under which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the ‘morality and conscience of our society,’ no matter how highly motivated and or impressively constituted.

When consent for the minor donor is sought through the legal system, the court usually appoints a guardian ad litem to represent the child’s interest. A guardian ad litem would typically determine that the procedure was necessary; the risks to the donor were minimal; the donor was willing to help his or her sibling; the parents were fully informed about the risks to the donor and consented. The judicial process also involves other steps that are time consuming and costly to the patient, the hospital, and the health care providers involved.

After careful evaluation of the guardian ad litem process and discussion with Mainland transplant centers, St Francis Medical Center decided the judicial process was too cumbersome, time consuming, and costly. The medical center now uses an alternative procedure to the traditional judicial system. The objectives are 1) to adequately consider the interests of the prospective minor donor; 2) to utilize impartial advocates who have no involvement in the bone marrow transplant procedure; 3) to be expeditious, because of the time pressures created by the instability of the potential recipient’s illness; and 4) to not impose additional financial or emotional burdens on the family already under stress because of the seriousness of the illness.

This alternative procedure utilizes an ad hoc committee, which is different in each case. The committee consists of a child psychiatrist/psychologist, a pediatrician, and another member of the medical staff with no direct interest in the case. The committee members are chosen for their ability to communicate with children and their knowledge of child development.

The proposed donors are interviewed individually by the committee in a supportive environment to determine their understanding of their role in the transplant procedure and whether or not their decision-making is free from duress and based on adequate information. The interviewing process is informal and begins with questions about the donor and his or her interests. The committee asks how the decision to donate was made and if he or she wants to donate.
One concern of the committee is the degree of parental influence on the potential donor. Recently, an ad hoc committee was chatting informally with a minor donor and her parents prior to an individual meeting with the child. All attempts to engage the donor, a 14-year-old, failed. When asked a question, she would frequently shrug noncommitally or look at her parents who were quick to answer for her.

While meeting with the committee alone, the child readily disclosed her fears regarding the procedure, especially the needle sticks involved, as she had already undergone one bone marrow biopsy and aspiration.

Q (from a committee member): Well, have you talked about these fears with your parents?
A: Yes.
Q: And what did they say?
A: They said, "You must be strong."

Clearly the parents were not giving this adolescent much room to make her own decision.

The committee explored the family structure a little farther and found that there was a grandmother who was a prominent member of the family and a significant person in the life of the donor.

Q: Did you discuss this with your grandmother?
A: Yes.
Q: And what did she say?
A: She said I could do whatever I wanted and I didn't have to do this if I didn't want. It was my decision and she would still love me.

On further questioning with the donor, she disclosed a similar conversation with her recipient sister.

Q: And what did your sister say?
A: She also said that I should make my own decision and that I didn't have to do it if I didn't want to.
Q: And what did you decide?
A: I decided to help my sister. We fight a lot, you know, but I still want to see her get better and help if I can.

Based on the conversation about the grandmother and recipient, the committee decided that she did make her own decision to support her sister. She was able to articulate her fears and talk about the pressure from her parents but still had sufficient presence of mind to consult other significant family members and, most important, her recipient sister. Her conversation about her fears, her parents, her grandmother, and her sister undoubtedly mirrored the conflicts in her own psyche. Articulating the pros and cons in the manner she did and making a choice convinced the committee that the child was indeed mature enough to make this decision and that the parental influence, though a factor, was not determinative.

Conflict of interest usually occurs when the parent or parents are asked to put a healthy child at risk to assist the ill child. However, it can also occur when the child is asked to be the donor for a parent. One father, when asked about the decision to use his child as the donor for his wife, the child’s mother, responded, "Of course there is a conflict. Although the risk is minimal for my child, there is still a risk. The risk for my wife is high, but there is still a chance. But he said he wanted to do it no matter what. He knows the risks and he also understands that no one else can be the donor. The major conflict is not with me, but with my son. If he decides not to be the donor, his mother will die; if he is the donor, he will experience some discomfort, but he has the knowledge that he tried to help her. Doesn’t that outweigh any risks or conflicts?"

The case went to the ad hoc committee. The committee agreed that the child was very knowledgeable about the transplant procedure and all of the risks involved. The child did not experience any adverse reactions from being the donor.

The ad hoc committee has been utilized only for minor donors who were developmentally appropriate for their age. The procedure could also be used for developmentally delayed donors. Adult retarded patients, however, may present a different set of issues as they may already be under the care of a guardian or a ward of the state. In that scenario, the decision would be made by the responsible entity. Nonetheless, the ad hoc committee would still be an appropriate forum in which the guardian could obtain the information necessary to make the decision for the ward.

Although the use of the ad hoc committee has been effective in Hawaii, it may not be as effective in other states where ohana is not as important. The committee is efficient and less costly than the judicial system, but is not without its problems. Such problems include finding members who are willing to participate, are available on short notice, and who are qualified.

Although the ad hoc committee may not be the universal answer, it does provide a forum in which the particular needs of the child donor can be more accurately determined and addressed than under the traditional judicial system.

References
4. Holy Bible (Kings, Chapter 3).
8. In re Guardianship of Pescopo, 87 Wis 2d 4, 226 NW 2d 183 (1975).

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Toward An Exit Visa—Regulating Health Care Decision-Making

James H. Pietsch JD

Societies around the world continue to grapple with the problems of making choices about health care, including choices for people who cannot choose for themselves. As the world population continues to age, the number of persons who become mentally incapacitated before they die will increase. As a popular retirement location, Hawaii will not be immune to this worldwide phenomenon. In spite of educational efforts, legislative and regulatory activity, it is not uncommon to find many individuals still have not made any provisions for the care or for the protection of their own persons.

Legislation that would statutorily recognize surrogate (commonly called "family consent" or "default") health-care decision-making was considered by the Hawaii state legislature in its 1995 session.1 Surrogate decision-making statutes have been enacted in at least 24 states and the District of Columbia.2 Generally, surrogate decision-making statutes designate which persons are empowered to make health care decisions on behalf of an individual who has not already made any advance decisions and who is no longer considered capable of making decisions for himself or herself. One of the stated purposes of the proposed legislation is to assure that an individual’s autonomy and rights under state law are protected.

As in other states, Hawaii’s health care decision-making legislation has developed in fits and starts, usually in reaction to troublesome situations. As a result, we now have a somewhat fragmented, incomplete, and sometimes inconsistent set of rules that attempt to address how decisions are made for individuals who are either no longer able to make decisions for themselves or who are perceived to be unable to make decisions.

Doctors, other health care professionals, and lawyers often encounter patients or clients with varying levels of mental capabilities. Under most circumstances, of course, the client or patient can be assisted without the need for legal intervention. Many clients are fully able to make decisions for themselves. Others may appear to be questionably, partially or only intermittently, able to make or communicate decisions. A few will be totally unable to make or communicate decisions. Still others will not want to make a decision or would want somebody else to decide for them.

Increasingly, in the realm of decision-making, the fields of law and medicine intersect. Lawyers are seen serving clients in hospital and nursing home settings. Doctors are asked to provide opinions about the mental capacity of individuals who are being asked to sign legal documents. Lawyers are asked to participate in hospital ethics committee deliberations. Doctors are asked to provide testimony in guardianship actions. Medical students have a legal component to their studies. Law students have an opportunity to study health-care law.3 Some individuals are both doctors and lawyers. Others find themselves weaving in and out of the two worlds, often by chance. Ethicsists, nurses, paralegals, and social workers often form the link between law and medicine. In this aging world, doctors and lawyers are working closer than ever in facing incapacity issues, often with the same patient or client.

Incompetency or Incapacity

In working with patients or clients the question often arises as to whether the individual has "competency" or the "capacity" to make decisions. Distinguishing the ostensibly comparable concepts of (in)competency and (in)capacity may be of some assistance in differentiating these terms. Initially it is important to recognize that adults are presumed to be competent and to have the capacity to make decisions although this presumption is rebuttable.

The concept of incompetency is generally considered to be a legal status imposed by courts. Judicial findings of incompetency are infrequent. When judicial involvement is considered necessary, it is most often in the context of determining whether the appointment of a guardian or commitment to a mental health institution is appropriate.4 Following presentation of evidence in a hearing, a judge may find an individual to be legally incompetent and appoint a guardian to make decisions on behalf of the "ward" or "protected person" or, if applicable, subject an individual to involuntary mental health treatment. The evidence usually includes the testimony of a psychiatrist or other medical authority skilled in the field of the purported disability of the subject of the proceeding.

The concept of capacity (and incapacity) is more related to specific activities and the determination of decisional capacity is considered to be within the domain of the medical profession. Decisional capacity is usually considered to be present when an individual is sufficiently able (capacitated) to make a particular decision if, minimally, he or she has the ability to understand the nature of the problem or activity he or she is facing, to understand available alternative courses of action (including no action), to understand the possible risks and benefits attaching to each of these alternatives, and is able to express a choice. Each specific activity which involves a decision, such as provision of informed consent for medical treatment, execution of a will, trust, living will, or power of attorney may have a different

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required level of decisional capacity to be considered “valid.” The legal profession is beginning to realize that it must do a better job of addressing current dilemmas concerning decision-making capacity. More attention is being given to looking at means of using more functional, decision-specific capacity evaluations. As in other professions, this increase in attention has been accelerated in part by the increase of such devastating mental afflictions as Alzheimer’s and related diseases.

Since the terms “(in)competency” and “(in)capacity” are still used almost interchangeably, even in statutes, it is useful to look at the context of the situation to determine whether the wording is used as a legal term or as a medical term. Hawaii statutes, as do many other state statutes, generally use the terms “capacity” and “incapacity” when addressing judicial proceedings involving the questions of legal competence. In order to clarify what type of situation is being addressed, it may be best to use the general term (in)capacity and then mentally add modifiers (ie, legal (in)capacity (pertaining to one’s legal status) and decision (in)capacity (pertaining to ones capability to make decisions) as appropriate.

From the outset it should be emphasized that an adjudication of incompetency represents a dramatic intrusion on the basic civil rights of the subject of the proceeding. Since a determination of legal incompetence can have a dramatic and long-lasting effect on a person’s life, it was suggested at the July 1988 ABA National Guardianship Symposium that “incapacity should be supported by evidence of functional impairment over time” and that “age, eccentricity, poverty or medical diagnosis alone should not be sufficient to justify a finding of incapacity.”

To complicate matters, there are different standards for determining incapacity. The standard to be applied depends on the type of decision or instrument or proceeding involved. For example, although an individual may be determined to be incompetent for the purposes of appointing a guardian for that person, the same individual may be deemed competent to execute a will. Likewise capacity to execute a will may require less “competency” than the power to make a gift or to enter into a contract.

**Parens Patriae**

There are, of course, legal guidelines to determine legal incapacity. The state, in exercising its parens patriae (Latin for “father of the country”) powers, has the authority to place limitations on the rights and autonomy of a legally incapacitated person. While there is a presumption of legal capacity, when an individual can no longer make decisions necessary to personal affairs or property, someone else may need to be appointed to make those decisions. This is usually accomplished through the guardianship process. In Hawaii, Hawaii Revised Statutes Section (§) 551-1 states that “family courts have jurisdiction to appoint guardians of persons and circuit courts have jurisdiction to appoint guardians of the property.”

Hawaii law (Hawaii Revised Statute § 560:5-304) provides that the family court may appoint any competent person, whose appointment would be in the best interest to the alleged incapacitated person, as a guardian for the person as requested if it is satisfied that the person for whom a guardian is sought is incapacitated and that the appointment is necessary or desirable as a means of providing continuing care and supervision of the person of the incapacitated person.

There is often a stigma attached to an adjudication of legal incapacity and a concomitant loss of civil rights. Usually the old concepts of a global or a complete approach to a determination of legal incapacity is utilized.\(^7\)

**Determining Legal Incapacity**

There is no single conclusive test to determine capacity in court but it is usually based on a medical diagnosis and prognosis. Three main approaches\(^8\) to determining capacity seem to have been developed:

1. The outcome approach—decisions that are inconsistent with the values of the helping professionals are conclusive of the person’s incapacity.
2. The status test approach—an individual’s capacity is judged by his or her physical or mental status or diagnosis without further inquiry about how the status actually affects the person.
3. The functional approach—focuses on the individual’s personal ability to function in decision-making situations. Capacity is determined on a decision-specific basis. Capacity is not treated as an all-or-nothing affair. Partial capacity is not the same as incapacity. Capacity may wax and wane.

In 1982, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research suggested that in making determinations about a patient’s competency, a clinical assessment should be made to include an inquiry into the extent to which a patient possesses:

1. a set of values and goals
2. the ability to understand information and to communicate
3. the ability to reason and to deliberate about his or her choices and their consequences.

No matter what approach is taken in any particular guardianship hearing, the court has the power to appoint a guardian *ad litem* to defend the interests of the person who is the subject of the proceeding.\(^9\)

**Capacity Issues Outside of Guardianship**

There are yet different standards for determining incapacity outside the guardianship arena. The standard to be applied depends on the type of decision or instrument involved. For example, although an individual may be determined to be legally incapacitated for the purposes of appointing a guardian in a guardianship action, the same individual may be deemed competent to execute a will. Applicable standards and tests for determining capacity historically are well developed, especially in the areas of trusts, wills, advanced medical instructions, and powers of attorney.

**Powers of Attorney**

A power of attorney is a written instrument through which an individual appoints another person as his or her agent (or attorney-in-fact) and grants that person authority to act on his or her behalf to perform certain acts. Powers of attorney traditionally were the written manifestations of the creation of an agency relationship for financial, business or legal purposes. They continue to play an important role, especially in dealing with financial issues relating to a person’s institutionalization and payment for health care. It was only rather recently that this legal tool has been utilized to make health care decisions. This health care aspect of powers of attorney will be discussed in the following section concerning advanced medical instructions.
and informed consent. Durable powers of attorney are statutorily recognized by law (in Hawaii Revised Statute §§551D). It should be noted that there is no specific requirement under Hawaii law that powers of attorney be accepted by third parties.10

**Informed Consent and the Patient Self-Determination Act**

It is clear that all competent individuals have the fundamental right to control the decisions relating to their own medical care, including the decision to have medical or surgical means or procedures calculated to prolong their lives provided, continued, withheld, or withdrawn. The basis for making decisions center around the concept of informed consent and a person’s constitutional right to refuse unwanted medical treatment.1

Hawaii has adopted a strong public policy in favor of the person’s right to accept or refuse treatment. Hawaii law provides that “all competent persons have the fundamental right to control the decisions relating to their own medical care, including the decision to have medical or surgical means or procedures calculated to prolong their lives provided, continued, withheld or withdrawn. The artificial prolongation of life for persons with a terminal condition or a permanent loss of ability to communicate concerning medical treatment decisions, may secure only a precarious and burdensome existence, while providing nothing medically necessary or beneficial to the person.”12

As of December 1, 1991, all states and most health care facilities must comply with new Medicare and Medicaid rules regarding patients’ right to control their health care treatment. The amendments are known as the Patient Self-Determination Act (PSDA).13

The purpose of the PSDA is to help individuals understand that they have strong rights regarding their medical treatment and to help them exercise those rights if they wish. This law was intended to help avoid problems and litigation over the initiation or continuation of unwanted life-prolonging medical treatment. The PSDA prohibits the health care organization from conditioning the provision of care or otherwise discriminating against patients based on whether or not advance directives have been executed. The PSDA also requires each state to develop a written description of state law regarding advance directives. This description is to be distributed by providers to all adult patients upon admission. In an interesting twist, regulators seem to be using the PSDA to force guardianship on individuals who did not execute any advanced directives.

**Living Wills**

One of the most widely recognized and utilized written advance directives is the living will, or medical treatment declaration. A person can make a living will declaration directing the provision, continuation, withholding, or withdrawal of life-sustaining procedures in the event that he or she is no longer able to communicate medical treatment decisions.14

Living wills do not control all health care decisions but only control decisions related to life sustaining medical treatment upon certification by the attending physician that the patient has suffered a permanent loss of the ability to communicate concerning medical treatment decisions. Living wills, for example, do not normally apply to emergency room situations. They do not apply to consent for ordinary medical treatment decisions. They do not apply to consent to admission to a health care facility. They normally do not affect DNA (do not resuscitate) orders. Many people do not know that a patient who suffers cardiac or respiratory arrest in a hospital will routinely be resuscitated unless there is a written DNR order in the medical record. The DNR order is only an order to forgo the otherwise automatic initiation of cardiopulmonary resuscitation and it does not alter other treatment decisions. Of course, patients should be encouraged and prepared to discuss these matters with a physician and to determine what tools can be utilized to address them.

Of course, it is clear that it is not (yet) always necessary to have a validly executed living in order to make decisions about lifesustaining medical treatment.15 The question of who decides who makes the decision may not be as clear.

**Durable Power of Attorney for Health Care**

A Hawaii law enacted in 1992 made changes to Hawaii’s Durable Power of Attorney Statute and recognized the right of an individual to appoint an attorney-in-fact or agent to make health care decisions.16

If properly drafted, the durable power of attorney for health care also can be quite useful in allowing an attorney-in-fact to talk to the principal’s doctors, to have access to medical records and to enforce the principal’s decisions through court action if necessary. The durable power of attorney for health care can be included in a living will, or it can be used separately, either alone or in conjunction with a living will.

A competent person who has attained the age of majority may execute a durable power of attorney authorizing an agent to make any lawful health care decisions that could have been made by the principal at the time of election.17

At the heart of the new law is the provision that states “a durable power of attorney for health care decisions is presumed not to grant authority to decide that the principal’s life should not be prolonged through surgery, resuscitation, life-sustaining medicine or procedures, or the provision of nutrition or hydration unless such authority is explicitly stated.”17 In other words, a person needs to state whether he or she is granting the authority to make such decisions.

There are certain limiting aspects of the new law which doctors should understand,18 but under appropriate circumstances and if properly drafted, a durable power of attorney for health care can permit a patient to appoint an agent who can make legally recognized (and enforceable) decisions.

**Proposed Surrogate Decision-making Legislation**

Living Wills and Durable Powers of Attorney for Health Care must be made when individuals still have the capability to understand what they are doing. Unfortunately a large percentage of people who are considered to be unable to make decisions for themselves and who enter a health care facility or otherwise need health care treatment have not provided any such advanced medical instructions.

Historically, health care providers have turned to family members for consent in situations where an individual is no longer able to decide for himself or herself. This traditional approach to caring for one’s own family members has been considered to be an accepted community practice in the health care community. Although there is a growing sense that this community practice is no longer legally adequate, there is no
actual legal prohibition against such a practice.

There has been, of course, an increase in federal and state regulation of the health care industry and an increased emphasis on preserving the autonomy of citizens. Further, the phenomenon of the increasing numbers of elderly citizens with chronic conditions, often accompanied an inability to make medical decisions is now forcing the community to reconsider how to make choices in medical decision-making in situations other than life-sustaining or life prolonging.

Federal regulations promulgated by the Health Care Financing Administration for long-term care nursing facilities have been interpreted by regulators as requiring any facility resident determined to be decisionally incapacitated to have his or her rights exercised by a person appointed in accordance with state law to act on a resident’s behalf. In cases where a resident has not been adjudicated incompetent by the state court, the regulators go on to indicate any legal surrogate designated in accordance with state law may exercise the resident’s rights to the extent provided by state law. Since Hawaii does not have a statute which provides for surrogate decision-making in the absence of prior health care instructions (except for limited purposes under the living will statute), regulators have concluded that this situation may lead to a requirement for guardianship actions in court. Threats of citing facilities for noncompliance are increasing.

Whereas the current health care decision statutes do not, apply to such ordinary health care decisions as treating a cold or admitting a person to a long-term-care facility, Hawaii could end up with a rather peculiar result in the way it treats incapacitated individuals. Under certain circumstances its seems there would be less difficulty withdrawing or withholding life-sustaining medical treatment and permitting an incapacitated person to die than admitting the person to a health care facility or treating him or her. Current interpretations of regulations seem to require commencement of a guardianship action in court when an incapacitated person has neglected to make an advanced medical instruction and needs to be helped. With the time and expense it takes to go to court, it can seem easier to some to do nothing. There are, of course, advantages to considering a legally recognized and an expanded version of the traditional “family consent” practice. Certainly, regulators will approve of added legislation to fill the current gap in the decision-making spectrum and health care providers may find some comfort in the protections that traditionally accompany such legislation. As long as a statute provides authority and protection, it may be that regulators and health care providers do not really care about the mechanisms involved in the surrogate decision-making statutes but the way that they are written could have a dramatic effect on the lives (or deaths) of the incapacitated person.

Most surrogate decision-making statutes have a listing of individuals (in a priority ranking) who may be looked to when health care decisions need to be made. This listing (or “hierarchy” of authorized decision-makers) usually gives highest priority to a person’s spouse or another person who is most closely related to the individual, usually by blood. The theory is that these surrogates will be in the best position to know what the incapacitated individual would have wanted or what is in their best interest.

There can be distinct disadvantages to these surrogate decision-making laws. One disadvantage is the lack of flexibility involved in creating a hierarchy of decision-makers. Arguably, it is not always the person who is the closest blood relation who is the most appropriate decision-maker. Nontraditional families have the most to fear from a legislatively determined order of surrogates since the person who actually has the most significant ties to the individual who lacks capacity may not be included in the statutory scheme. Under a surrogate decision-making law, would a family and doctor somehow bypass a patient who is mentally incapacitated much of the time but may have moments of lucidity? Could a doctor follow directions of a surrogate that are inconsistent with the patient’s previous statements? These concerns have been addressed to some degree in later drafts of the proposed legislation presented to the Hawaii state legislature. Safeguards pertaining to these concerns may or may not survive the next legislative process.

Much energy has been expended by many people in attempting to respond to the intimidating actions of the regulators. Perhaps we should be asking whether we really need another law on the books to tell doctors and health care facilities under what conditions they can take care of an individual’s health care needs. Perhaps the rules cited by the regulators should be examined in light of the mood in Washington, DC to de-regulate government. It may be time to ask why we are so worried by the regulators and what would they actually do if we did not respond to their citation threats? Would they close down all health care facilities or stop health care providers from admitting or treating patients? Would they force us to flood the courts with guardianship actions?

On the other hand, perhaps the debate over surrogate decision-making will conclude that new laws or regulations are needed. If so, it may be the time to revisit the way we make all health care decisions, including decisions to forgo life-sustaining medical treatment. Rather than continuing in our fragmented, incomplete and frequently inconsistent method of approaching health care decisions, we might consider our predicament in a holistic and common sense manner. Otherwise any new law attempting to rectify this newest crisis may only add to the confusion.

Let us carefully consider these significant matters affecting the way we make choices. Let the choices be ours as a community. If we continue to demonstrate to the regulators that we will react to their every threat, we should not be surprised when they demand more and more governmental and legal involvement in health care decisions. It may not be so far-fetched to hypothesize that, ultimately, the regulators would embrace a requirement for an exit visa, prepared by an attorney and properly executed by a judge, prior to permitting a person to leave this world. If we let this happen, all we can hope is that those who oppose such a requirement be greeted (as expressed in Camus’ Stranger) with cries of execution!

References and Notes
1. Senate Bill No 570, A Bill For An Act Relating To Health Care Decisions. This bill did not become law but other attempts to enact such legislation will likely be made in future sessions.
4. For an overview of incapacity issues, see for example, Planning for the Elderly or Incapacitated Client by S. Schlesinger and B. Scheiner, Published by Commerce Clearing House, Inc., 1990.
5. For an attorney there are also professional ethical issues to take into consideration in dealing with a questionably incapacitated individual. In the Hawaii Rules of Professional Conduct, Rule 1.14 states: "(a) When a client’s ability to make adequately considered decisions in connection with the representation is impaired, whether because of minority, mental disability, or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client."
(b) A lawyer may seek the appointment of a guardian or take other protective action with respect to a client, only when the lawyer reasonably believes that the client cannot adequately act in the client's own interest.

6. A few definitions may be helpful to an understanding of guardianship. Under HRS § 560-101: "Guardianship proceedings" is a proceeding to appoint a guardian for a person of an incapacitated person. "A presumptive proceeding" is a proceeding to determine that a person cannot effectively manage or apply the person's estates to necessary ends, either because the person lacks the ability or is otherwise incapacitated.

7. HRS § 660-5:04 requires that the courts may specify areas in which the ward shall retain the power to make and carry out decisions concerning the ward's person. HRS § 660-5:312 states the court may appoint the incapacitated person's guardian if the person has the same powers, rights, and duties respecting the guardian's ward that a parent has respecting the parent's unemancipated minor child...

8. For property matters HRS § 560:5:04(3) provides that the court may directly or through a guardian of the property has all the powers over the person's estate and affairs which the person could exercise if present and not under disability, except the power to make a will. Fortunately for the protected person, at least orders under these guardianship of the property proceedings have no effect on the capacity of the protected person. (See HRS § 560:5:04 (3).) Combine these proceedings with guardianship of the person proceedings, however, and many rights are in jeopardy.


10. To be valid, a power of attorney should be executed properly and a person must know: what authorities are being given; to whom they are giving authority; the nature of the document in question. The Restatement 2d of Agency suggests that a person must have capacity before the act or she can delegate authority to an attorney. See Restatement 2d of Agency, Section 20 (1958). Creation of a power of attorney requires that the principal be mentally competent at the time of execution. See, for example, Testa v. Roberts, 542 N.E.2d 654; 44 Ohio App. 3d 161 (1988). In order to determine whether an individual has the requisite mental competency to execute a power of attorney, courts have developed tests for this specific area. In Tests, the court stated that the test to determine mental competency to execute a power of attorney is the principal's ability to understand the nature of property, and extent of business he or she is about to transact. A power of attorney may be terminated under three circumstances; death, incapacity (or disability) or revocation. Death automatically terminates the power of attorney. Unless a power of attorney contains specific language providing that the powers shall continue (or commence) during periods of incapacity, the power will terminate during such periods and the power of attorney is not considered "durable." However, an agent without notice of a principal's death or disability may still exercise the given authority if acting with good faith and in accordance with the granted authority. See HRS §§ 5510-4(a),(b) and Gellner v. Horton. 715 P.2d 1225 (1985).

11. The State of Hawaii Board of Medical Examiners establishes standards for health care providers to follow in giving information to a patient, or to a patient's guardian if the patient is not competent, to insure that the patient's consent to treatment is informed consent. The standards can include the substantive content of the information to be given, the manner in which the information is to be given by the health care provider and the manner in which consent is to be given by the patient, or a patient's guardian. These standards are contained within the HRS § 671-3 (informed consent; board of medical examiners standards) which provides, in part: "(a) The board of medical examiners, insofar as practicable, shall establish standards for health care providers concerning giving information to a patient, or to a patient's guardian if the patient is not competent to give an informed consent. The standards may include the substantive content of the information to be given, the manner in which the information is to be given by the health care provider and the manner in which consent is to be given by the patient or the patient's guardian. (b) The standards established by the board of medical examiners include provisions which are designed to reasonably inform a patient, or a patient's guardian of: (1) The condition being treated; (2) The nature and character of the proposed treatment or surgical procedure; (3) The anticipated results; (4) The recognized possible alternative forms of treatment, including non-treatment, then the standards shall be admissible as evidence of the standard of care required of the health care provider."
The New Hawaii Comfort Care Only—Do Not Resuscitate Law

The new Hawaii law creating the Comfort Care Only-Do Not Resuscitate order allows terminally ill patients to be treated by ambulance personnel for comfort and pain control, and to not be resuscitated when they are near death.

There is a new law in Hawaii that is designed to resolve the pre-hospital dilemma of terminally ill patients who want access to medical care for physical comfort, but want to avoid undergoing attempted resuscitation when they start to die. Will the roles change for emergency medical services (EMS) personnel, first responders, and health care providers, including the terminally ill patients’ private physicians under this new law?

This new Hawaii law was passed following years of consideration by legislators, EMS personnel, medical directors, religious and community groups, and the general public. It was signed into law in July 1994. Under this new Hawaii law, a patient can issue a “Comfort Care Only—Do Not Resuscitate” order if that patient is a competent adult and it has been certified by his or her physician to be terminally ill.

Competent adults have been held to have the legal right to refuse unwanted medical treatment by both Supreme Court decisions and federal legislation. This refusal can be expressed in advance of the unwanted treatment. The most effective inpatient mechanism to exercise this right in advance is the Living Will, an “advance directive” that says, in advance of an actual occurrence that could result in unwanted treatment, to withhold unwanted treatment.

The concept of Living Wills for inpatients in hospitals and nursing homes is accepted in this country and many others. The Patient Self-Determination Act (part of the Omnibus Budget Reconciliation Act of 1990) requires that written information regarding Living Wills be offered to patients during admission to facilities participating in Medicare or Medicaid funding (including hospitals, skilled nursing facilities, home health agencies, prepaid health care organizations, and hospice programs). However, the federal government has not addressed the pre-hospital situation.

The pre-hospital situation is unique in these two respects: The concept of presumed consent, and the extremely limited time to decide to resuscitate. It has long been legally presumed that patients want to be rescued and treated in an emergency setting if found unconscious or incompetent. An advance directive (Living Will) can overcome this presumption if it can be determined to be valid and applicable to that emergency setting and treatment—but how can its existence, applicability, and validity be determined in seconds?

Several states have tried to deal with this problem by enacting legislation to address the pre-hospital recognition of advance directives. Some states require time-consuming procedures, including reading and interpreting the documents themselves and then communicating with one or more physicians prior to honoring the advance directive. Other states, including Hawaii, have enacted laws that allow for a method of immediate identification of terminally ill patients who choose not to be resuscitated. In Hawaii immediate identification is to be facilitated with a bracelet or necklace of a specified size and shape with “Comfort Care” engraved on one side, and the patient’s name, date of birth, ethnic group, CCO number, and State of Hawaii engraved on the other side. Note that this CCO-DNR order is a different kind of advance directive than a Hawaii Living Will. Living Wills allow individualized instructions for different patients, do not require illness, and do require two unrelated witnesses and notarization. Every Living Will must be read and interpreted before it can be honored. Since paramedics have only seconds to make decisions, some patients with Living Wills are undergoing attempted resuscitation. In contrast, a CCO-DNR order is between the patient, his or her physician, and one witness, and is more likely to be really private. The patient can wear a CCO-DNR necklace under his or her shirt and can keep his or her condition confidential; he or she is immediately identifiable as terminally ill and wanting comfort care only, not resuscitation.

Many EMS personnel say the Hawaii CCO-DNR law is long overdue. They have been forced to perform CPR on patients with terminal conditions whose families did not want resuscitation, they just wanted to be made comfortable and allowed to die in peace.

An information packet regarding the new CCO-DNR order has been prepared and includes information in both written and flow diagram formats. It also includes a sample CCO-DNR order and information regarding ordering the CCO-DNR bracelet or necklace and answers such questions as the following:

- What is a CCO-DNR order?
- Who can get a CCO-DNR order?
- Who can follow CCO-DNR orders?
- Guidelines for consideration by EMS personnel, first responders, and other health care providers (both individuals and organizations) when they see the CCO-DNR bracelet or necklace.
- Anticipated questions and answers.
- Revocation of the CCO-DNR order.
Age–Based Rationing of Health Care

Patricia Lanoie Blanchette MD, MPH

The U.S. has focused attention on the rising costs of health care coincident with the increasing age of the population. Arguments have been made to overtly ration care to older persons; however, general acceptance of the need to ration scarce resources, whether or not such a policy is actually formalized, can lead to covert rationing. Some overt rationing has already occurred, some of the data put forth to justify that rationing needs to be challenged, and ethical principles need to be applied to provide appropriate and perhaps less costly care.

Given the temporal relationship between the increasing numbers of older people and the nation’s attention to the costs of health care, it seems evident that aging is the major determinant of increasing costs. The image of demented oldsters avariciously consuming the legacy of our children springs to mind. An incomplete and biased recitation of health care statistics appears to support this conclusion, leading to serious proposals to ration health care for older people. A careful examination of the facts begins with an acknowledgment of the potential for bias, the willingness to question what appears obvious, and searching beyond those data which serve to support a predetermined conclusion. Decisions about health care must be guided by objective information and by illustrating the ethical and moral principles to enlighten decisions about limits on the public money allocated for people of all ages.

In considering the costs of health care it is easy to be bated into an inter–generational contest, pitting the costs of providing increasingly sophisticated care to increasingly younger, potentially chronically impaired neonates, against the costs of caring for the nation’s elders. Although the potential life expectancy of babies as a whole is much longer than that of elders, this is often not true when individual lives are compared. It is also possible to make the argument that elders may have contributed to the public good for many years and are now more deserving of care. However, basing decisions on whether an individual is deserving of care presupposes a wisdom that we may not have yet achieved and is to be strenuously avoided.

The use of public monies or health insurance being used for infertility treatment in a country concerned with overpopulation is certainly questionable. Our culture is one that cherishes children and childhood, at least in the abstract. We are most likely to accept the costs of raising a child and seldom stop to total up the costs of the years of dependency. Are we less likely to appreciate the personal fulfillment, redefinition of productivity and inter–generational significance of old age. The importance of completing psychological development and the rooting of successive generations by the presence of elders is undervalued.

However, in considering the allocation of resources it is futile and intellectually inadequate to pursue the avenues of intergenerational conflict. It should be evident that people’s lives are priceless at any age. A fully developed society should be guided by principles equally valid across an age spectrum. A consideration of the allocation of resources requires that we examine the quality of the data, understand the age prejudice that exists in our culture, and be primarily guided by the ethical grounds for limiting care at any age.

Population Aging and Costs

Is there a primary cause-and-effect relationship between the rapid aging of the population and health care costs? People over age 65 today comprise about 12% of the U.S. population and account for one–third of the nation’s annual federal health care expenditures, or $300 billion of an estimated $900 billion in 1993. By 2020, when baby boomers will be in their mid to late 70s, the population over 65 is estimated to be 20%, with the actual number of people over 65 doubling from today.

However, when examined closely, less than 10% of the
increased costs of health care can be accounted for by population aging. Further, while it would appear that 12% of the population is using one–third of all public resources, state and local governments spend 10 times the amount on education and children’s programs than are spent in programs benefiting elders, including Medicaid.

**Futility and Expensive Costs of Caring for the Dying**

It has become a widespread belief that a majority of health care resources are spent on high technology care for elderly people in their last year of life. The facts show that medical costs in the last year of life for people aged 80 and older are less than for younger people. In 1989, 2,150,466 persons died in the U.S. Of these 29% were younger than 65, 22% were aged 65 to 74, 28% were aged 75 to 84, and 21% were aged 85 and older. In one study of 500 persons who died, 4 people over 80 had only half the hospital costs of those at younger ages, and costs for those age 65 to 79 were only slightly higher than for those under age 65. The beliefs about the costs of caring for the dying come from a series of papers showing that about 30% of Medicare costs are spent on about 6% of people who die. However, only 6% of those who died had costs higher than $15,000, and in all age groups, a high proportion of costs are incurred for a small number of beneficiaries who are either sick enough to be at risk of dying or who are chronically ill. This is not an exclusive old-age phenomenon.

There is also the argument that precious health care resources are squandered on demented elders who would be better off dead and that caring for older people is generally not only expensive, but futile.

Although the exact prevalence of dementia is still to be determined, it probably is present in 10% of people over age 65. It increases in prevalence with age, so that those over 85 estimated to have dementia, ranges between 30% to 50%. Conversely, then from 50% to 70% of people over age 85 are not demented. Even in those who have dementia, with forgetfulness and disorientation as prominent features, the quality of life can be quite acceptable with proper assistance. Those whose lives are more burdensome than pleasurable would be best served by providing care according to their self–determined wishes and advanced directives than by an external application of rationing standards. Although advanced directives, such as living wills, have been developed to further autonomy and privacy, early studies of costs are beginning to show a substantial savings without needing to impose rationing.

If the costs of care is actually spread over an entire age spectrum, it still appears to be intuitive that there would be poorer outcomes of treatment in people of advanced age. Again, we see the value of hard data. In numerous studies of outcomes from surgical procedures and renal dialysis, counter to intuition, chronological age drops out as an independent predictor of results of treatment. Outcomes are more closely tied to comorbidities and functional status. Previous studies on the results of cancer treatment showing poorer outcomes in older patients have now been shown to be flawed by a systematic undertreatment of elders. Although age may be a marker for co–morbidity and poorer functional status, the results of these studies underline the need to assess individuals one–by–one for appropriateness of treatment and caution against an across–the–board age exclusion.

**Overt Rationing**

Despite the lack of data to support age–based rationing of care, it is common to hear or read comments about holding down health–care costs by overtly withholding high–tech, high–cost services for older people. There are no data to support chronological age as an independent criterion. There is also the concern that a limitation of high–tech care will lead to a limitation of all care, the slippery–slope phenomenon. Only a few months ago, British newspapers were focused on the story of a 73–year old man who refused physiotherapy for arthritis. Subsequently, the Royal College of Physicians published its study of equity care for the elderly. They declared, “there is no biological rationale for separating older people from the rest of the human race: They should get the same quality of care as anyone else.” In both the U.S. in the 1960s and in Great Britain until the 1980s there is a history of people over age 45 being excluded from renal dialysis. Subsequently, this age was gradually increased. In the early days of renal dialysis, in both places, with few resources to offer, an age bias was overt. It was assumed that older people would have a reduced life expectancy and derive less overall benefit from treatment. Subsequent information has shown that as a group, older people do have a shorter life expectancy in treatment, but after careful study, the Institute of Medicine Committee for the Study of the Medicare ERSD (End–Stage Renal Disease) Program has specifically rejected age as a criterion for patient acceptance to dialysis, noting that co–morbidities and functional status are the primary predictors of benefits from treatment, not age. Data influencing the decision include, as predicted, that 1–year and 5–year survival of people on dialysis decreases with age. However, this is to be expected, since they note, older people on or off dialysis have a shorter life expectancy than younger people. In addition, the likelihood that intercurrent major medical events will occur is greater in the elderly, leading to a greater prevalence of older people voluntarily choosing to go off dialysis and dying from withdrawal of dialysis. However, whereas there is a reduced life expectancy, studies have shown that older people may value their continued lives on dialysis greater than younger people, with a higher well–being index, more positive feelings, and a greater life satisfaction in general, including being more satisfied with their marriages, family live, savings and investments, and standard of living.

**Covert Rationing**

As carefully as we must defend against unwarranted overt age–based rationing, we must be ever more vigilant against covert rationing. Consider the following actual case: A 75 year–old married man in overall good health except for mild emphysema chooses to be admitted to a long–term care facility with his wife who has severe, crippling arthritis and frail health. They have been married over 50 years and he would rather be admitted to a nursing home to be with her than remain at home alone. In addition, the nursing facility is run by a religious organization and offers the further opportunity to study and to live his faith and culture. While at the facility, he happens upon a friend receiving cardiopulmonary resuscitation. He is frightened by the event, and counseling him presents the opportunity to discuss advance directives. After careful consideration, with lots of questions asked and answered, he decides that his life is of high quality, that he wishes to received medical care.
intensive care if he should ever need it, but without chest compressions. Some time later, he suffers a relatively uncomplicated inferior myocardial infarction and is transferred to the hospital. He is expected to recover fully, but, because of the emphysema and some respiratory fatigue, it is decided to “rest him” for a short while with elective pulmonary intubation. He fully agrees to this plan with the stipulation that if weaning cannot be accomplished easily within a few days, that he not be allowed to remain on the ventilator indefinitely. According to hospital policy, the intensive care unit medical director, who does not know the patient, becomes the attending physician of record. The next day he is visited by his primary physician who finds him extubated, cyanotic, and near death, having been discharged from the intensive care unit. The following explanation is offered the primary physician by the unit resident trainee on duty the previous night who decided, without consultation, to extubate the patient. “Our society cannot afford to keep these elderly nursing home residents alive indefinitely. Besides, he’s a “no code” patient, what’s he doing in an ICU?” The patient died shortly thereafter, leaving a grieving wife who fully expected to have him back with her within a few weeks and a stunned family and primary physician who were not consulted in the ICU decision.

While there are many aspects to criticize about this case, among them the lack of supervision of the unit trainee, the lack of consultation with the family and primary physician, the main factor at work was age discrimination. In-depth discussion with this misinformed and dangerously unsupervised trainee revealed a person who was both lacking in judgment and profoundly influenced by the comments he heard and read about the cost and futility of health care in the elderly.

Covert actions to withdraw care are dangerous, must be anticipated and must result in policies to prevent such errors. Even more dangerous are the more covert, less dramatic, case—by—case decisions that erode options presented to older people. These may either be well—intended, based on the erroneous belief that they will fail to have an acceptable outcome, or related to an excessive concern for costs. There also is a growing concern that the pressure to tightly control costs in managed—care settings will result in the limited marketing of these plans to older people or stay the hand of care once these individuals are enrolled.

Privacy, Self—Determination, and Autonomy versus Utilitarianism

The concerns regarding costs and rationing are usually phrased in the context of the allocation of limited resources among individuals of a group. In cultures where the autonomy and rights of the individual are a strong priority, the discussion of allocation of resources is unsettling. In utilitarianism, the interest of an individual are secondary to the interests of the group. In some cultures, utilitarianism prevails and different decisions are made. Despite the current substantial percentage of the national resources allocated to health care, some would question whether we are near the actual limits of the resources. They raise the “guns vs butter” argument; comments such as “...the cost of stealth bombers” are heard. Given that the resources available for health care do have some reasonable limit and that we will fast approach it, the argument about allocation rages. The issue at hand is to control costs within an acceptable ethical and cultural framework.

There is every reason to believe that self—determination and autonomy can prevail while, at the same time, costs are reduced by focusing on providing the most appropriate care. This requires a careful assessment of individuals, their needs and probable outcomes of care, without financial or other incentives to provide more care. Promoting self—determination and autonomy while containing costs also requires a systematic way to encourage patients to understand and to choose the extent of care they desire, informed by the best available data.

Care should be appropriate, not rationed. Appropriate care requires that decisions to accept or reject care be truly informed with good facts, the tendency to an age bias be recognized and confronted, and advanced directives and health proxies or surrogate decision—makers be explained and recommended for adults of all ages. Health policy must be such that the possibility of overt or covert rationing to people of all ages who are at risk of needing high—cost care be acknowledged and avoided.

References

Psychiatric Assessment of the Suicidal Terminally Ill

George M. Burnell MD*

Terminally ill patients who refuse life-supporting treatments and express a wish to die are often viewed in the same light as suicidal patients who are medically well. Terminally ill patients who are depressed should be treated with antidepressants, but if the wish to die persists, it should be respected.

Introduction
In the last few decades, advances in medical technology have benefited thousands of patients who years ago would not have survived late stages of illness. Unfortunately, these advances have created a new set of problems for the hospital staff, who then must face difficult decisions and choices not always in the best interest of the patient.

For example, patients with terminal illness who are admitted to the hospital for maintenance care or an urgent surgical procedure often present a major challenge to the medical staff when the patient refuses this treatment. The patient’s motives for refusing treatment are often questioned and challenged by the treating team: The patient is using poor judgment or is clinically depressed. Refusal of treatment by the terminally ill can be interpreted as a suicide wish associated with clinical depression and therefore requires careful evaluation. This evaluation is especially important because a patient’s mood disorder can affect cognitive capacity.

In some cases, functional depression does not preclude the need to respect the patient’s autonomy and wish to die by refusing further treatment. However, clinicians generally believe that if the patient is suicidally depressed, treating the depression will eliminate the patient’s wish to die because clinicians tend to view the suicide wish as similar to that in the medically well.

Informed Consent and the Problem of Competency in Medical Settings
In medical settings, legal competence to refuse lifesaving treatment is usually presumed, and the burden of proof rests on the physician to prove otherwise. Sometimes, the need for a given procedure or treatment can seem imperative to the medical team but meets with resistance from the patient. How is the refusal of treatment then to be managed? Is the patient’s competence to make appropriate decisions affected by a mental or affective disorder? Or is it simply that the patient lacks sufficient knowledge to make such a decision? Or further, is the patient making a rational decision in his or her own terms to avoid further suffering in the face of a hopeless and terminal illness?

These questions have become especially important since courts and legislatures across the country have articulated a right to die for seriously ill medical patients. This right has been implemented both through case law and natural death acts. So far, no court has rejected outright the right to die.

The doctrine of informed consent is rooted in the patient’s right to privacy, self-determination, and the promotion of well-being; therefore, no doctor, nurse, or institution should impose treatment on a patient. For patients to exercise informed consent, they must know their diagnosis, the reasons for doing tests and procedures and their risks, the degree of accuracy of the tests (ie, percentages of false-negative or false-positive results), what information will be derived from them, and what kind of treatment is recommended (surgery, radiation, drugs) and its risks and benefits. They must also understand the seriousness of their condition or illness and the purpose of the treatment (curative or palliative).

Degree of Patient’s Understanding
Even when patients seem to understand all the information given, they can still refuse treatment. Further, the way the information is communicated can alter the patient’s feelings and ultimate decision substantially. Another factor in a patient’s ultimate decision for or against treatment is the physician’s ethical bias and moral values expressed during the interview. Further, physicians have different tolerances for and abilities to discuss these issues with patients. For example, they may experience feelings ranging from emotional fatigue, fear of their own death, guilt, insecurity, or anxiety and could have various beliefs about the sanctity of life and the right to die.

The difficulty lies in determining whether the patient has failed to understand the information, whether the patient has been unduly influenced for or against the treatment, or whether the patient’s competence is impaired because of clinical depression. Of course, the patient’s values, religion, and cultural background may have a substantial role in the patient’s understanding and interpretation of the information the physician provides.

Sometimes physicians believe they have to go to extremes to convince a patient to pursue treatment, especially when the patient’s refusal and apparent wish to die are based on an erroneous interpretation of his or her condition. In these cases, the doctor’s persistence in not accepting the patient’s decision could be lifesaving.

The following case illustrates this point: A 45 year old man...
diagnosed with colon cancer told his doctor he wanted nothing done to prolong his life. The doctor, convinced that the man’s cancer was curable, called a renowned surgeon to confirm this, and then, finally, a former patient who had been operated on successfully for a similar type of cancer 10 years earlier. The patient was convinced and finally agreed to the surgery. However, if the patient had not known the doctor for many years, the doctor’s behavior could have been interpreted as harassment.

Competency in Cases of Major Depression

Sometimes treatment refusal by the terminally ill is interpreted as a manifestation of underlying depression affecting the patient’s judgment. According to Appelbaum and Roth, this association is particularly difficult to evaluate because depression can masquerade as a rational, understandable reaction: “That’s just the way I would think if it happened to me.” In other words, patients can offer convincing and rational explanations for the choices they make.

Many clinicians believe the terminally ill patient who refuses treatment because of an underlying depression will later accept that treatment once the depression is treated with antidepressants or electroconvulsive therapy. However, a recent study showed that most patients who make treatment choices through advance directives do not alter their views for as long as two years after writing the directives.

Such consistency is more clearly apparent in acquired immunodeficiency syndrome (AIDS) patients who are terminally ill. These patients present great challenges to physicians because of the challenge of determining whether their refusal of further treatment is a manifestation of suicidal depression or an expression of a well-thought desire to end their suffering. When patients refuse lifesaving treatments, psychiatrists are sometimes called to evaluate and persuade them to change their minds or to treat the depressive illness affecting their judgment.

Sullivan and Youngner investigated the legal and bioethical literature on competence to refuse treatment and the possible impact of depression on treatment refusal. They reported that the patient’s capacity to make medical decisions is impaired because the depression is easily seen as a “reasonable response to a serious illness.”

Moreover, the depression distorts decision-making more subtly than delirium or psychosis. This effect means that patients with major depression retain the capacity to understand the risks and benefits of a medication but may reject its value for personal use. In other words, depressed patients fail to recognize how medical facts and statistics apply to their individual situation.

In addition, the diagnosis of depression provides no definitive evidence that the patient’s medical decision making is impaired. Presence of a major affective disorder may not always influence competence in making lifesaving decisions. The symptoms that satisfy the criteria for clinical depression in the Diagnostic and Statistical Manual (DSM-IV) are not necessarily the same symptoms that impair the ability to make lifesaving treatment decisions. For example, the diagnosis of depression may rely heavily on vegetative symptoms of insomnia and anorexia, which may certainly affect the patient’s quality of life but would not necessarily impair the patient’s competence in making medical decisions. Depressive symptoms affecting the decision-making capacity include distorted (negativistic) assessment of self, world, and future characteristics of depressive thinking.

Other symptoms of depression can also seriously influence competence in making lifesaving decisions. For example, helplessness may result in underestimating the possible effectiveness of treatment of a serious illness. Feelings of guilt-and worthlessness can make the patient believe that suffering and death are deserved and should not be avoided. Anhedonia may make it impossible to visualize a cure and a new life which would make enduring any of the discomforts, pain, or indignity of medical illness worthwhile. Similarly, hopelessness may make visualizing a full life in the future difficult. All these cognitive symptoms can impair the patient’s ability to make appropriate lifesaving treatment decisions even when the patient does not have a full-blown depressive disorder.

Depression in Terminally Ill Patients

A terminally ill patient may not expect much pleasure or realistically anticipate an attractive future given the reality of a terminal illness. Therefore, clinicians must realize that clinically depressed patients with a very poor medical prognosis may express a rational wish to die. “Depression can be diagnosed and treated in patients with serious medical illness. But after optimizing medical and psychiatric treatment and determining that the patient is competent to make medical decisions, it may be appropriate to honor the patient’s desire to die.”

This dilemma is illustrated in the case of a 35-year-old man with HIV who had been diagnosed in 1986, treated with zidovudine since 1989, and had been hospitalized 7 times. In a few weeks before admission for recurrent cytomegalovirus pneumonitis, his condition deteriorated steadily. Intubated when admitted and receiving oxygen by mask, he was gradually losing his sight because of cytomegalovirus retinitis in both eyes. He could not eat and was becoming cadaveric because of severe weight loss. The patient indicated that he did not want treatment of any kind, but maintenance care was nevertheless continued.

A psychiatric consultation revealed a diagnosis of major depression, and the patient showed mild improvement after a course of antidepressants. However, his refusal of further treatment and his desire to die did not change.

AIDS patients in the terminal stage often have few options. They are left with the prospect of a painful and undignified death, stigmatized by society, loneliness and helplessness in the final stages of the illness. In this case, the patient’s Living Will would only have helped stop or withdraw treatment if he had been unconscious. His desire to die was never honored during the final weeks so he endured the last 6 weeks of his life in agony. Further, the patient was too weak to consider suicide, and even then, without a lethal dose of medication, he would not have been able to terminate his life without violence.

Limitations of the Living Will

The Living Will applies only when the patient enters a comatose or persistent vegetative state. Sometimes the Living Will is rescinded verbally during hospital admission, and the patient’s condition waxes and wanes and results in short spans of lucidity. This situation can further challenge the hospital staff, who must then determine what the patient really wants. Generally, adhering to the preferences expressed in the Living Will after a reasonable period of observation and repeated evaluation is best. In addition, maintenance care does not require informed consent.
Suicidal Ideation Versus Rational Request to Die

The diagnosis of depression in the medically ill is very difficult because several factors obscure the diagnostic criteria for depression. The diagnosis is complicated by an illness perceived as terminal and which engenders feelings that further treatment is futile.

The following factors should be considered in making the diagnosis of depression in a medically ill patient:

1) The depressive symptoms are often appropriate and a reaction to the stress of a serious illness, especially a potentially lethal one.

2) Many depressive symptoms are similar to those of the medical illness (fatigue, weakness, weight loss) and can wax and wane as the illness progresses. Diagnostic criteria in the psychiatric nosology have been generally inadequate when applied to depressed, terminally ill patients.

3) Although recognized as a reliable predictor of suicide, hopelessness is not necessarily pathologic in terminally ill patients. A patient’s realistic appraisal of his or her condition and refusal of life-supporting measures may be the last attempt to retain control.

Vegetative signs and symptoms were omitted from the tables because symptoms of fatigue, weakness, insomnia, anorexia, and weight loss can occur in suicidally depressed patients as well as in terminal, depressed patients and therefore have no distinguishing value. (Table 1, 2)

Because of considerable overlap between psychologic and biologic processes in both the suicidally depressed patient and the depressed terminally ill patient, the best features for differentiating between these two groups of patients can be found in the social history, psychologic processes, and, specifically, underlying motives for the yearning for death.

When doubt exists, the depression should be treated with a course of antidepressants and the patient should be reevaluated. If the desire to die by refusing treatment is still present after the depression has lifted, this desire should be respected by stopping all aggressive treatment and maintenance care. The patient’s wishes concerning life and death should take precedence and be respected even if they conflict with those of the staff. At that point, a helpful and wise approach would be to hold a staff meeting to understand the patient’s problem and point of view and to promote consensus among all the caregivers and the family.

Comment

In the hospital setting, refusal of lifesaving treatment or a wish to die is often thought to be associated with major depression. This tendency is also true when the refusal occurs in a terminally ill patient. The best approach in these cases is to obtain a thorough social and psychiatric history. The attending physician may wish to obtain psychiatric consultation to determine not only the competence of the patient but also the basis for refusal of lifesaving treatment.

In cases in which depression seems to have a major role, giving the patient a course of antidepressant medication is wise. However, whenever the desire to die occurs in the absence of clinical depression and is clearly associated with the wish to avoid further suffering and indignity, respecting the patient’s wishes is appropriate. In these cases, when the patient’s wishes are
ignored and aggressive life support is given, paradoxical suicidal ideation and behavior can develop. 14
Clinicians also need to accept that some depression in the terminally ill is resistant to all antidepressant therapy. Knowing when to stop psychiatric treatment is just as important as knowing when to stop medical treatment and let the dying process proceed naturally. Providing relief with a course of benzodiazepine or narcotic agents may be the best treatment to offer to ease the pain and suffering of the terminally ill patient who refuses treatment that might prolong a painful life.

Conclusion
The need to die, as expressed by refusal of further lifesaving treatment in the context of a terminal illness, may or may not be associated with a psychiatric disorder. Clinical depression does occur and should be treated, but terminal patients may persist in refusing treatment and insist on dying. Their striving for a dignified death should be respected and honored. This attitude will help smooth what can be a very rough path for the dying.

Acknowledgment
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References
Medical Decisions at the End-of-Life: Lessons from America*

S.Y. Tan MD, JD

Bioethical issues that deal with medical decisions at the end of life are as interesting as they are contentious. Daily, we confront questions of health care rationing, medical futility, euthanasia, or the use of advanced directives and ethics committees. There is present-day mainstream thinking on these bioethical themes and more important, under-emphasized and controversial aspects of dying in America.

Modern American bioethics originated in 1962 when Dr. Belding Scribner developed the external vascular shunt that made renal dialysis possible. For the first time, patients otherwise doomed to die from renal failure could be treated effectively with hemodialysis. Because there were many more patients than dialysis machines, the University of Washington, where Dr. Scribner worked, was forced to form an Admissions Committee to literally decide who would receive dialysis and live, and who would not and die. The seven anonymous lay members of the Committee—cynically dubbed the God Committee—dutifully selected candidates for the lifesaving procedure. Its methodology and criteria for choosing from among "prostitutes, playboys, and poets" were largely unknown. This was America's first ethics committee at work.

American bioethics has matured much over the past 32 years, spurred in January 1980 by the formation of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The Commission studied medicolegal and ethical aspects of informed consent, brain death, human experimentation, access to care, and mental health. But its best known subject was medical treatment at life's end, which was authoritatively published in 1983 under the title "Deciding to Forgo Life-Sustaining Treatment: Ethical, Medical and Legal issues in Treatment Decisions."

As a discipline, bioethics currently attracts more than 2,000 professionals who are drawn from the fields of medicine, law, theology, and the humanities. Bioethicists belong to societies such as the American Society of Law, Medicine and Ethics, and train at institutions like The Hastings Center in New York and The Kennedy Center for Bioethics in Washington DC. Leading medical publications and specialized ethics journals, eg, The Hastings Center Report, regularly feature scholarly research, analysis, and editorials on a broad array of ethical issues. And at a practical level, about half of all health care facilities across the nation have formed ethics committees to help them solve patient-care moral dilemmas.

American law, more so than philosophy, religion, or medicine, has helped shape the development of American bioethics. Witness the proliferation of case-laws and statutes that attempt to define bioethical boundaries, beginning with the landmark case of In re Quinlan decided in 1976 by the New Jersey Supreme Court. For the first time, a court of law was asked to rule on whether a patient in a persistently vegetative state could refuse mechanical ventilation, even if such refusal resulted in death. Calling it a privacy right that could be exercised on the patient's behalf by her parents, the court ruled that Karen Ann Quinlan's self-determination interest outweighed any real or theoretical opposing interests of her doctors, the hospital, and the State of New Jersey. The decision favored patient autonomy over medical paternalism; more significantly, it injected the law into a clinical arena previously within the exclusive domain of the medical profession.

Subsequent cases before the courts in states like California, Massachusetts, Florida, New York, and Missouri have continued the trend of deciding in favor of the family's wishes to withdraw life-sustaining medical treatment.2 In June 26, 1990, the U.S. Supreme Court decided its first right-to-die case in Cruzan v. Director, Missouri Department of Health.6 Stating that "...a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment..." the court went on to characterize artificial fluids and nutrition as a form of medical treatment that could be refused. The Cruzan court also held that states may promulgate a standard that there be clear and convincing evidence of a patient's wishes before a surrogate decision-maker can authorize the withdrawal of life-sustaining treatment.

Legislation on patient care issues has also been intense in the past two decades. Virtually all states now have statutes on living wills, informed consent, durable powers of attorney, brain death, and assisted suicide. Federal laws also regulate health care decisions; examples are edicts governing the treatment of disabilities including AIDS and anti-dumping laws.

Of all bioethical issues, those that deal with end-of-life treatment decisions in the aged and the incurably ill generate the most debate. This is because they directly confront life-and-death outcomes, as well as issues of self-determination and health care cost.

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Living Wills

Patient self-determination is a bioethical principle of recent vintage, an outgrowth of American laws governing privacy or liberty rights. All competent persons are believed to have a fundamental right to control the decisions relating to their medical care. Autonomy underpins many widely accepted Western medical practices such as informed consent and do-not-resuscitate orders. It empowers the patient with the control of his or her body, even for decisions against medical advice.

When patients become seriously ill, they may become confused, delirious or comatose, and therefore incapable of making decisions regarding their treatment. Yet it is important to know their wishes, since some treatment options are invasive and expensive, and may only prolong the dying process while offering little or no reasonable chance of recovery. Patients may not want such treatment.

A living will is a written document prepared by an individual in order to direct future care in the event of medical decision-making incapacity. It is one way of preserving and respecting the patient’s right of self-determination. All 50 states have statutes that allow individuals to plan in advance for their medical treatment: California was the first with the enactment of its Natural Death Act in 1976. Hawaii passed its Living Will law in 1986, amending it in 1991.

Living wills permit patients to forgo life-sustaining treatment when they become incurably ill and are no longer able to make or communicate their decisions. Patients may specify the refusal of specific measures such as mechanical ventilation, blood transfusions, dialysis or surgery, or they may choose to forgo all life-sustaining treatment. Medical personnel will always continue to provide comfort care to relieve pain and suffering. Written instructions in the form of a living will have two practical effects: They inform health care providers of the patient’s true wishes, and they spare family members the uncertainty and guilt of trying to decide what’s best for the patient. The underlying disease is allowed to run its natural course. “Allowing to die” is therefore different from active euthanasia or mercy killing, where a deliberate act is performed to extinguish life.

A living will is a witnessed legal document that becomes operational when the patient is decisionally incapacitated with a terminal illness. Doctors are legally obligated to abide by the patient’s instructions; it may be revoked at anytime by the patient.

Three aspects of living wills that deserve attention:
- Living will statutes may be unduly restrictive or vague.—For example, “terminally ill” in one jurisdiction was originally defined as death occurring in a “relatively short time.” Physicians may not know what this means and have adopted the definition provided by Medicare: the country’s health plan for senior citizens, which is death occurring within 6 months. In some jurisdictions, persistently vegetative states and severe irreversible neurological damage do not qualify since these are not terminal conditions. Some laws do not address the withholding or withdrawing of intravenous hydration or tube feedings. For example, Hawaii, initially ambivalent about whether these measures constitute “medical treatment,” excluded them from its 1986 law; an amendment in 1987 now permits the discontinuation of artificial hydration and nutrition in terminally ill patients, as well as in those with irreversible neurological conditions that impair decision-making.
- Durable power of attorney (DPA) is superior to a living will.—A DPA for health care decisions confers legal authority regarding medical matters on someone (not necessarily an attorney) who is appointed by the principal (patient). This authority takes effect when the latter is decisionally incapacitated. Appointing a DPA for health care is preferable to executing a living will because the patient now has a trusted surrogate who can faithfully reflect the patient’s wishes known to him or her or are expressed in a concurrent living will. A living will alone is insufficient. It is a static document, made months or years prior, that cannot possibly anticipate every conceivable clinical situation that might arise in the future. For example, the patient may not have considered specific medical measures such as antibiotics, artificial nutrition or temporary dialysis. Or a new treatment may be imminent. Executing both a DPA and a living will gives the patient the best chance of fully exercising his or her self-determination rights when medically incompetent. Together, the proxy-decision maker, the patient (speaking through his or her living will), and the doctor will decide what is best for the patient.
- Educate patients and doctors.—Despite widespread legislation on advance directives, most Americans have yet to execute such a document. The best estimates suggest that less than a quarter of the general population have prepared living wills. Doctors and nurses, who should know better, are no better off. Inadequate public education and inertia in executing a legal document are the likely reasons. Recent federal legislation mandating all hospitals to inform patients of advance directive statutes should prove effective. Called the Patient Self-Determination Act, the law went into effect in December 1991. Yet a study of 302 patients before and after implementation of the Act revealed no difference in patient knowledge. Only 6% were able to identify correctly the meaning and use of both a DPA and a living will, and less than a quarter remembered being given this information. It seems a hospital is not the ideal place to begin the education process.

Living wills should be understandable and easy to prepare. Model forms should be widely available and should incorporate provisions for the appointment of a health care DPA. An effective educational strategy may be to encourage or require physicians to routinely discuss the subject with their patients before they become seriously ill. Special sensitivity is also needed in explaining advance directives to certain ethnic or religious groups. Blacks, for example, may shy away from advance directives for religious reasons or because of a perception of abuse by and distrust of the medical establishment.

Ethics Committees

In the 1960s, some hospitals in the U.S. set up special committees to review decisions regarding abortions, renal dialysis, and human experimentation. Many of the decisions centered around the ethics of autonomy, rationing, or consent, so these early ad hoc groups can be considered the forerunners of our present-day ethics committees. In 1976, a New Jersey court recommended that family and physicians use a hospital ethics committee to resolve cases like In re Quinlan (the right to stop life-sustaining treatment) rather than seek judgment in court. This unusual judicial recommendation, the first of its kind ever, provided the impetus for the creation of ethics committees across the country. The President’s Commission’s report in 1983 further encouraged their formation.
In 1984, the federal government promulgated the Baby Doe rules to prevent the perceived maltreatment of handicapped neonates and infants. The regulations failed to materialize into law, but they led to the proliferation of hospital infant care review committees, which in turn grew into hospital ethics committees.

About half of the 6,000 U.S. hospitals currently have working ethics committees; the percentage is higher in hospitals with more than 200 beds. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) deserves some of the credit for this phenomenal growth. In 1991 JCAHO, which accredits all U.S. health care institutions, wrote into its regulations the requirement that “an organization should have in place a mechanism for the consideration of ethical issues arising in the care of patients and to provide education to caregivers and patients on ethical issues in health care.”

In addition to ethics committees, hospitals are required by federal law to have in place Institutional Review Boards that scrutinize research protocols involving human subjects. Finally, many professional organizations such as the American Academy of Pediatrics, the American College of Physicians, and the American College of Obstetrics and Gynecology have formed committees to establish ethical guidelines and policies for their specialties. The American Medical Association, the country’s leading doctor organization, likewise has such a committee which regularly updates and publishes its position on ethical issues.

What do hospital ethics committees do? Generally, they perform three functions: First, they influence policies on ethical issues governing patient-care. An example is the hospital DNR (do-not-resuscitate) policy. A current policy struggle of ethics committees concerns the formulation of a coherent approach to futile treatment. Second, ethics committees offer consultations to health care providers and families. These clinical consultations frequently involve difficult treatment decisions. Third, hospital ethics committees sponsor teaching programs to educate their staff and the public. The educational function is the least controversial of the three; some have suggested that it should be the only legitimate function of ethics committees.

The roles of the ethics committee should be clearly differentiated from those of hospital legal counsel and its risk manager. Notwithstanding their popularity, hospital ethics committees have come under increasing fire for their lack of fairness, consistency, and effectiveness. It has been said that the main value of ethics committees lies in their process and not necessarily their product. Critics also question the appropriateness of the move to immunize committee members and participants from legal liability.

The most controversial aspect of hospital ethics committees is their role in clinical consultations:

• Who sits on ethics committees?—Most scholars are critical of committees composed mostly of doctors because of the concern that they alone cannot completely represent the patient’s best interests. Doctor-controlled ethics committees are less common today; instead, committees almost universally have multidisciplinary and lay representation. It is important to have lay members, if only because they compel discussions at an everyday understandable level—the same level that is needed to meaningfully inform the patient and family. Nurses and social workers definitely belong on ethics committees, since they spend much time with patients and family, gaining special insight into patient wishes and concerns and family dynamics. Theologians, administrators and philosophers sometimes populate ethics committees; they can provide useful perspectives. One group appears unpopular: Legal counsel. Perhaps it’s a reflection of paranoia over lawsuits and legal pronouncements, or simply the belief that the law sets mandatory standards, whereas ethics is aspirational.

Ethics members may be ignorant of ethical principles and health care matters. A recent article decried the laissez-faire approach to ethics committees, and called for the systematic education and training of committee members in order to achieve standards aimed at raising the level of accountability.

• Who is an ethics consultant?—Suppose a patient refuses a lifesaving blood transfusion. Family members are reluctant or unable to persuade the patient to change his or her mind. The attending physician is reluctant to coerce treatment and calls for an ethics consultation. Who can respond? Only doctors with training in clinical ethics? The chief of the department? What about a non-doctor ethicist or even the entire ethics committee if it can respond quickly enough?

Ethics consultants may review cases on behalf of the institution’s ethics committee on which they serve, or they may offer these specific services without going through a committee. The main advantages of a consultant over a committee are: 1) first-hand direct contact with the patient, family, and health care givers; 2) quick response time; and 3) enhanced accountability. Adding a consultant to an ethics committee, therefore, can be expected to improve its effectiveness in case reviews.

But what training qualifies an individual to be an ethics consultant? There is no U.S. statutory board of bioethics with the authority to certify an individual as a clinical bioethicist. A recent survey asked 154 “ethics consultants” what they would recommend in eight hypothetical variations of the persistent vegetative state. The study revealed wide variations in their recommendations, pointing to the need for standardization. Other studies indicate that the medical fraternity is generally suspicious of non-doctors who make recommendations about their patients. Ethics consultants who are not medical doctors can expect, at least initially, to encounter resistance to their presence on hospital wards.

Finally, should an ethics consultant be paid for services rendered. Currently, most ethics consultations are offered as a hospital service without charge to the patient. Shouldn’t the patient or health care insurance payers reimburse the cost of clinical ethics services just as they do for other clinical consultations?

• Who has access to ethics committees?—Ethics consultations should be patient-oriented rather than physician-oriented. Ideally, patients and their families as well as all health care professionals connected with the case should be able to access the hospital ethics committee. However, in many hospitals, only members of the medical staff have access, and nurses and patients may be excluded. Because an ethical opinion may be sought where disagreement exists among doctors, nurses, and family, ethics committees should have an “Open door” policy to hear all sides of the issue. Patients and others will view committees that restrict access with suspicion, which in turn undermines their credibility and effectiveness.

• Decisions by bureaucracy.—Those bemoaning the increasing bureaucratization of medical decision-making cite ethics committees as one prime example. Dr Mark Siegler, a noted
clinical ethicist, has criticized decisions by committees because they add to the administrative and regulatory burdens on patients, families, and their physicians. Committees usurp the traditional role and responsibilities of the treating physician, replacing him or her with uninvolved moral experts who may have serious conflicts of interest such as minimizing hospital risk or allocating economic resources more efficiently.23

Another pitfall is that committees may paradoxically impair rather than improve decision-making. The phenomenon of “group think” may lead to subconscious pressure on members to reach consensus, and to minimize controversy, risks, and objections.24

Professor George Annas, arguably America’s leading health care lawyer specializing in bioethics, is unenthusiastic about ethics committees for a different reason. He is concerned that a group decision by an ethics committee holds no individual responsible or legally accountable; ethics committees, he believes, should provide “ethical comfort, not ethical cover.”25

Medical Futility

Consider patients in a persistently vegetative state, which is usually caused by prolonged interruption of brain oxygenation. Oblivious to their surroundings, such noncognitive patients stand no reasonable chance of returning to a sapient state. They require supportive treatment, sometimes needing mechanical ventilators to help them breathe. In the 70s and 80s, the issue was whether doctors could insist on treating such patients against the wishes of the family. In America today, the opposite issue confronts medical practitioners—the issue of medical futility.

If it is clear that families can stop treatment, is it also clear they can demand non-beneficial care against the doctor’s medical judgment? Can doctors refuse to provide expensive futile care which neither treats nor palliates? Two recent court cases suggest there may indeed be such a duty to treat under certain circumstances. In the first case, In re Wanglie,26 the New York court upheld the family’s request to continue ventilator support of Helga Wanglie, an 86-year-old woman in a persistently vegetative state who had earlier stated her desire for all life-sustaining treatment. In the second case, In the matter of Baby K27 the U.S. Court of Appeals affirmed a lower Virginia court’s decision to honor a mother’s request that her comatose anencephalic infant (born without a brain) be provided emergency treatment whenever she needed such treatment, instead of being allowed to die.

Because the evolving law appears to favor “pro-life” family decisions, physicians, fearing lawsuits, are understandably reluctant to reject surrogate demands for ineffective therapy. This largely explains the continued use of aggressive futile treatment in hospital wards and intensive care units. Extending, ad absurdum, this putative duty to treat, doctors even go so far as to offer options that are clearly unwarranted, eg, cardiopulmonary resuscitation for the patient with terminal cancer. It’s a misreading of the law of informed consent, and an example of defensive medicine which, by one estimate, adds $276 billion to annual U.S. health costs.28

Might judges be off the mark in their opinions regarding medical futility? The goals of medical practice are to prevent illness, to restore health, to alleviate pain and suffering, and to rehabilitate. These goals are only served by doing what is medically appropriate or indicated. If futile care equals inappropriate care, a family’s misplaced demand for such treatment must necessarily yield to medical judgment. Judges and families should defer legitimate clinical decisions to the medical profession. Doctors are bound by the Hippocratic Oath and are trained to make sound clinical judgments. They define the standard of care, and they should stand by it.29 This is feasible because:

• Medical futility is definable.—Simply put, futile treatment is that which cannot reasonably be expected to improve a patient’s quality of life. Under this definition, comfort care, which relieves suffering, is never futile. On the other hand, cardiopulmonary resuscitation in a comatose terminally ill patient is.

Schneiderman and colleagues29 have proposed several definitions of medical futility that are practical and useful. They believe physicians should differentiate between treatment that merely results in an isolated effect from that which brings about a general benefit to the patient as a whole. Treatment that fails to provide the general benefit, whether or not it achieves a physiological effect, is futile. Treatment that merely preserves permanent unconsciousness or condemns the patient to existence in the intensive care unit can also be considered futile.

Some insist that for treatment to be deemed futile, it must offer zero chance of a favorable outcome. A more practical approach is to acknowledge that absolute certainty is unachievable in medical prognosis and to accept a no-reasonable-possibility standard. Schneiderman et al offer a quantitative definition of medical futility: Less than one chance in 100.

• One way to save medical costs—accept death?—Medical expenses are apt to be particularly high at the end of life. About 30% of all Medicare payments each year are for the beneficiaries who died in that year; about 40% of the medical bill in the last year of life is spent in the last month.30 It has been suggested that a good part of these expenditures may be for futile invasive treatment rather than for comfort and compassionate care, a perversion of high-touch by high-tech.

Because physicians can never be certain whether or when death will occur, some commentators have challenged the view that these end-of-life expenses are unnecessary or wasteful. They calculate that relatively little savings will result even if we take positive steps like advance directives, hospice care, and the elimination of futile treatment.31

Rationing

Most wealthy nations spend 7% to 9% of their GDP on health care. By contrast, the U.S. leads the world by consuming 14%, or nearly $1 trillion. Neonatal care in the intensive care unit can cost upward of $2,000 a day. Major medical procedures such as coronary bypass surgery top $20,000, and organ transplants cost even more: when follow-up care and medications are totaled, the bill exceeds $100,000.

Mired in this milieu of medical megabucks are 37 million Americans, a quarter of them children, who cannot afford health insurance and therefore forgo ready access to health care. Prenatal care is patchy, and many children are not properly vaccinated. These factors largely account for our high infant mortality rate of 9.2 per 1,000. In contrast, Singapore boasts a figure of 5.5, Canada 7.2, and the U.K. 8.4. Our life expectancy, at 75.2 years, trails Canada’s 76.4, Singapore’s 75.7, and the U.K.’s 75.6.32

Even in a crisis of affordability, no caring society can allow its sick to go without medical attention. Ethically we must insist on universal access. Yet America does not wish to surrender its lead in biotechnology, medical innovations and quality care. The
trick is to satisfy these needs within an affordable health care budget, to structure a system that delivers all three: Quality, accessibility, and affordability. Can health care ever be like the good, fast, and cheap McDonald’s hamburger? Or do we believe those who tell us that health care, for better or for worse, can only serve up any two, but never all three?

Enter rationing. Many consider this morally indefensible, forgetting that we already ration care by implicitly limiting the reach of 37 million uninsured Americans. Under one scenario, the new rationing will provide coverage irrespective of the ability to pay, but what is provided will be basic and adequate, not comprehensive. Those who want more will have to pay for the extras themselves. Adequate care does not translate into everything with the slightest hope of medical benefit. As in the family budget, affordability dictates what we might have to do without.

Is providing such a basic package to all, but allowing the individual to buy additional coverage, ethically justifiable? This is two-tiered medicine. It favors the rich, and it is practiced in most countries of the world. We in the U.S. so far have resisted its implementation, but the current health care debate centering on affordability is forcing us to reconsider the issue. Should money buy a second or third opinion, the best available surgeon, a private nurse? Surely there are limits. Should it ever be allowed to buy a kidney?

What will the law say about attempts to limit care in the name of saving money? In America’s litigious society, we can expect lawsuits to proliferate. Newsweek recently described lawsuits as the “weapon of choice” against those who would limit medical services.33 This past year, Nelene Fox successfully sued Health-Net, an HMO, for its denial of a bone-marrow transplant to treat her breast cancer. Ignoring defense evidence that such treatment was experimental, the jury awarded her $89 million in damages.33

Another recent case provides a useful perspective on the subject of rationing. In the summer of 1993, a pair of Siamese twins were born to the Lakebergs. The twin sisters, Amy and Angela, shared a common heart and liver. In an urgent and desperate operation, surgeons in Philadelphia attempted to separate the joined organs. They were prepared to sacrifice Amy for the infinitesimal chance of saving her sister Angela. Unfortunately both died. The cost of the tragedy was estimated at $1.3 million.33

In caring for its poor and its uninsured, Oregon recently set up a list of 696 diagnoses and procedures ranked in order of medical priority. The state legislature funded up to number 565, and excluded items such as heroic treatments for the incurably ill and most types of plastic surgery. Although not without its critics, the courageous and realistic Oregon Plan has received approval from Washington after being previously spurned by the Bush Administration. The nation will be watching closely whether Oregon’s rationing scheme proves to be a workable model of cost-containment in health care delivery.34

* Age as a criterion for rationing.—Several leading philosophers in the U.S. have proposed that age be used as a criterion in the rationing of medical care, reasoning that such limits are justifiable because each citizen would benefit over the course of the individual’s lifetime (every citizen was once young). Thus, age discrimination differs fundamentally from sex or race discrimination since these latter classes would be denied from birth an equitable share of health care resources. Callahan35 in particu-

lar has made the point that citizens should substitute “communalism for individualism,” and accept death at the end of a natural life span both for their own sake and for the sake of others. Extending the logic of his argument, he has called for the cessation of medical research directed at extending life.

The fascination with using age as a criterion follows the dramatic demographics of aging in the U.S. and elsewhere. Currently, those over the age of 65 comprise 12% of America’s population; this figure will rise to 20% by the year 2020. The elderly consume a disproportionate share, almost a third, of health care spending.36-37 And, in contrast to Asian values,38 American attitudes tend to glorify youth and devalue the elderly.

It is not always clear whether these philosophers are talking about limiting routine medical care, intensive care, or futile treatment of the elderly. Few would wish to limit routine, comfort and compassionate care for any patient, young or old. On the other hand, it is easy to argue that medical treatment that extends life devoid of human qualities should not be undertaken. But that argument applies irrespective of age.39

The matter of limiting intensive care for the elderly is probably what’s being contemplated. It deserves closer study. Recent data indicate that the long-term outcomes of hospitalized critically ill elderly patients are remarkably good.40 Compared to a control group (ages 65 to 74), elderly patients 75 years or more did not differ in length of hospital stay, hospital charges, mortality at 1 year, or quality of life. Most were willing to receive intensive care again, if necessary. Such results have prompted a call for re-examining the common assumptions about health care in the elderly.37

Limiting elderly health care is assumed to result in substantial savings. Levinsky has questioned this conventional wisdom,39 high cost hospital admissions account for less than 3.5% of Medicare expenditures; the withholding of all routine medical care from the elderly is believed to be necessary before substantial savings can be achieved. Restricting research that extends the natural life-span has been criticized as naive, since research cannot be compartmentalized (the example is given that penicillin prevents rheumatic fever in the young and extends the lives of the elderly with pneumonia). Finally, Levinsky argues that the noneconomic costs of a national policy to limit health care to the elderly would be substantial, since it is politically unpopular and is likely to exacerbate the tension between the generations.

Euthanasia

More than any other controversy in health care, euthanasia palpably confronts the life-and-death decision. It ranks as one of America’s premier ethical dilemmas, and its most emotional.

Supporters of euthanasia assert an individual has the ultimate right to choose death, and there is no moral difference between allowing a person to die, which is legal, and active euthanasia, which is not.41 They point to the medical profession’s insensitivity toward alleviating pain and suffering at the end-of-life as the raison d’etre in their demand for death control and death with dignity.

Opponents of euthanasia deny such an absolute right to be killed: Allowing the underlying disease to take its course is fundamentally different from an overt act whose purpose is to extinguish life.42 They also argue that life is sacred and that hospice care and better doctor education have resulted in improved comfort measures for the terminally ill.
• The slippery-slope argument.—Many fear that legalizing euthanasia may unintentionally victimize the weaker members of society. What begins as allowing free choice would slide into subtle encouragement to end life; mental coercion and involuntary euthanasia without explicit patient requests lies short steps away. The handicapped, the poor and the aged would be the most vulnerable. A review of MDEL (medical decisions concerning the end of life) in the Netherlands, where euthanasia is condoned, supports this slippery-slope argument.43 The lack of explicit request was found in 1,000 patients who were euthanized in 1990 to 1991. Such abuse concerns led to the narrow 54 to 46 rejection of recent aid-in-dying initiatives in Washington and California.44

The euthanasia assault on the Hippocratic Oath argues ill for American society plagued by family rupture, mindless violence, and increasing discrimination. While claiming to be autonomy-centered, active euthanasia stands to dangerously expand the ethical boundaries of rationing and medical futile.

• The double-effect phenomenon.—Aggressive treatment toward abating pain and suffering at life's end may result in an earlier death for the patient, since medications such as morphine are powerful respiratory depressants. This unintended result of accelerating the dying process is not wholly unanticipated. Doctors, therefore, worry about the wrongfulness of this so-called "double-effect" phenomenon. Physician fear of criminal or civil backlash may be the basis for the dramatic under-use of narcotics (both dose and frequency) to alleviate the suffering of the dying patient. It has been estimated that in as many as 80% of patients, pain is not relieved effectively.45

Bioethicists have universally considered the morally supportable double-effect phenomenon to be fundamentally different from euthanasia or physician-assisted suicide. Their reassurance may not be enough. Laws immunizing physicians from liability in this area may be necessary to gain the confidence and support of an increasingly skeptical profession. A change in physician mind-set toward the double-effect phenomenon will ensure better comfort care in terminally ill patients.

• Is legalized euthanasia likely?—Like the abortion fight culminating in Roe v. Wade46 more than two decades ago, the euthanasia battle is being waged with increasing stridency and cacophony. The country appears intensely interested and evenly divided on this issue. A how-to monograph on suicide entitled Final Exit became a runaway best-seller.47 And a survey of 938 physicians in Washington revealed that a slight majority favored legalizing physician-assisted suicide and euthanasia in at least some situations, although most would be unwilling to participate in these practices themselves.48

The recent court verdict absolving Dr Jack Kevorkian, a pathologist who assisted in the mercy-killing of 18 patients in Michigan, will fuel the national drive to legalize euthanasia. Initial rebuffs at the ballot box in California and Washington notwithstanding, pro-choice advocates can be expected to redouble their efforts to achieve their goal. This November, Oregonians will be voting on an aid-in-dying initiative that sanctions the request for drugs to end life. Liberal Oregon supports legalized rationing, and it is home to The Hemlock Society, the nation's leading right-to-die organization. Early betting favors passage of this initiative. If passed into law, this initial victory for supporters of legalized euthanasia will serve as a powerful catalyst for the passage of similar laws across the country.**

Conclusions

My personal experiences and my reading of the bioethical and medicolegal trends in America lead me to offer the following overview:

1. America should be applauded for its insistence on respect for patient autonomy, but it should be more willing to accommodate physician paternalism. Most of all, it must recognize when autonomy ought to yield to societal values that preserve the common good.

2. Lawyers and the courts are overly intrusive in patient-care matters. Like Damocles' sword, the law hangs over the heads of health care providers, frequently impeding rather than fostering their efforts to look after the best interests of their patients.

3. Doctors must not abdicate their duty and privilege as the patient's ultimate advocate.

4. The health care crisis in America is one of affordability rather than access. To preserve the excellence of our health care system, we simply must restore self-discipline and spend within our health care budget.

5. Equal comprehensive health care for all is an illusion, even if it is politically correct. But we must insist on basic adequate coverage for all, irrespective of age or the ability to pay.

6. Futile treatment confers no benefit on patients, and wastes health care dollars. It should be abandoned.

7. Overall patient and societal benefit should inform and guide the decision to treat, to withhold treatment, and to allocate scarce health care resources.

References


7. Medical Treatment Decisions. Hawaii Revised Statutes, Annotated, Chapter 327D


15. 45 C.F.R. §§46.101-46.117

16. AMA Code of Medical Ethics. Current Opinions with Annotations, 1992,


20. Fox E. Stocking C. Ethics consultants' recommendations for life-prolonging treatment of patients in a persistent vegetative state. JAMA. 1993;270:2572-2582


**On November 8, 1994, voters in Oregon enacted Measure 16 that legalizes the prescribing of medications for terminally ill patients seeking to end their lives.

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Have Physicians Abdicated Their Role?

Steven S. Moser MD

Despite enactment of progressive living will legislation in Hawaii and elsewhere, it is evident that the percentage of patients who have signed living wills has not increased significantly in the ensuing years. The reasons for this are many, but most of the blame can be laid on practicing physicians who have been unable to raise and pursue this delicate subject with their individual patients.1-2

The extensive mandated living will questionnaires required of hospital admitting offices in order to admit patients are more burdensome than helpful: They merely document the existence or nonexistence of a living will, but do not encourage patients to consider signing one, thereby adding to the already onerous paperwork required for admission. Even if they were so encouraged, elderly patients in the throes of life-threatening illnesses are usually in no condition to give the necessary thought required to make this critical determination on short notice in a tumultuous environment.

As a result of the failure of these well-meaned legal attempts to deal with medical futility, we find ourselves still in the dilemma of caring for terminally or catastrophically ill patients of advanced age in intensive care settings. We still spend billions a year of our dwindling medical dollars and resources on patients who should have been allowed to succumb peacefully to overwhelming diseases. Any one of us can walk into our critical units and find them filled with post-resuscitated 70 and 80 year olds on ventilators awaiting bypasses or dialysis or more cardioversions before they die.

Despite the ample literature on medical futility in these settings, it has become almost passe to think about, let alone discuss, this catastrophe of technologically induced agony, which sometimes borders on torture. As physicians, we know that the vast majority of patients will never survive in any meaningful way after our interventions, and yet we seem incapable of doing anything about it. We are all guilty of turning our heads, literally and figuratively.

Instead, our current practice is to rationally "discuss the code status" with the family, striving to explain to them in an even-handed, almost apologetic way, the intricacies of the case, and let them "think about it" and come to a "consensus." We leave what amounts to a clearly clinical decision entirely up to highly stressed family members who are not in any way knowledgeable in this scientifically complex area, let alone psychologically prepared to take on this grave moral responsibility. We do this ostensibly because we are fearful of legal repercussions if we do not offer to do everything to save the patient, even though we know that anything we do will be futile: unless we "cover ourselves," we could be sued.

We must ask whether or not we have abdicated our own field of expertise to lawyers, courts, administrators and the public. We remain silent in this area instead of exerting our considerable power as "experts" in the area of medical futility. It is my contention that the failure of legal means to satisfactorily address this problem throws the ball back into medicine's court. As medical professionals with a solid scientific rationale, we must empower ourselves to become more proactive in our care of the elderly.

Instead of going hat in hand to the family of the 82-year-old woman admitted to us with congestive heart failure and a massive stroke and asking them whether they want us to resuscitate her if her heart stops beating or she stops breathing, why can't we, as knowledgeable and caring physicians, tell them that we are doing everything for her that we can, but strongly suggest to them that in our medical opinion, heroic measures would be fruitless?

We can assure them that we will do everything in our power to prevent them from getting to that stage where such measures would be needed (mention intravenous fluids, antibiotics, blood thinners, oxygen, etc). But mustn't we also go on to say that if she does stop breathing or her heart stops, we do not think, in our clinical judgment (emphasis "in my experience"), that drastic measures such as chest compressions ("their bones are fragile and they almost always break when we do this"), cardioversion ("even if she's in deep coma, this is the one thing that she will feel"), or intubation ("its very uncomfortable for her to have this large tube in her windpipe") or other painful, invasive procedures are medically warranted. "They won't help her in the long run, and they will make the short time that she survives an extremely painful and unpleasant experience just before she dies."

This graphic use of language is not cold, cruel, or manipulative, but is truthful and realistic. We do not need to mince words.

We are painting a vivid picture for the family so they can understand more easily our reasoning for withholding futile and torturous applications of technology, which are not to be confused with medically useful and comfort-inducing therapies we have already told them (and can tell them again) we will give her. Such a proactive presentation sets the stage for the physician to say something like, "...and so with your permission, I'm going to tell the nurses to do everything for her but those very painful and invasive things that I have told you about, and if you have any questions (don't say objections), please let me know." After this presentation, very few family members are going to have the heartlessness or selfishness to demand that their mother or wife be a full code.

It is our prerogative as well as our responsibility to our elderly patients and society to make these decisions: We are the only ones who have the expertise. It is not paternalism, it is professionalism. Just as when we order antibiotics, IVs or dialysis, we are acting on our knowledge and experience to deliver the best care possible, which in this case is primum non nocere. We must start taking control of these clinical situations, for there appears to be no other remedies for the malady of medical futility on the horizon, and as we get better with our technology at suspending death, the problem will get worse.

In the past two years, I have found this proactive approach to obtaining no-code orders to be effective, humane, and acceptable to patients' families in almost all instances, and I have had almost no geriatric intensive care nightmares. The approach
must be individualized in each case and must be practiced, since it initially feels somewhat awkward for us to be speaking in this manner to patients’ families. However, it is medically and ethically correct, and I find it a much more satisfying form of medical practice than performing as some sort of medical technician in the service of a legal system that has failed to solve the question of medical futility.

References

Ethical Issues—Physicians and Managed Care

Stephen J. Wallach MD

Health care delivery, a long-standing cottage industry, has undergone change during the past five years. Large for-profit corporations have gained increasing market share in various parts of the country and Hawaii is not immune to this phenomenon. The payers of health care, business, labor and government have determined that costs have been escalating and management is absolutely essential for economic survival. As health care costs have risen and calls for more cost-conscious health care have been made, health insurers increasingly have adopted principles of managed care. There is no assurance that high levels of quality will be maintained. Some managed care programs have developed so that profit is the only motive and physicians have been forced to ratchet-down services. Some corporate heads have made large personal profits while decreasing patient care and physician reimbursement. Insurance companies have purchased physician practices or entered into very restrictive managed care contracts with physicians. A tremendous threat exists to the sanctity of the doctor-patient relationship.

Hawaii has a unique system because of the Pre-paid Health Insurance Act. Managed care has been in Hawaii for a long time. The competition between managed care and traditional fee for service has maintained high quality, and costs have been controlled, but the rise of medical inflation has not. Hawaii has large populations of Medicaid, Medicare, state and county employees, federal employees, hotel workers, large businesses, and labor unions. These large groups can be shifted into more restrictive managed care with relative ease. There is a concern that Hawaii will attract a ruthless Mainland-type of company seeking large market shares, significant penetration of the marketplace, and will be concerned only with the bottom line of profits without concern for quality of care.

Managed care plans use a number of techniques, some are directed at subscribers, some at physicians, by creating economies of scale, by coordinating care among physicians and hospitals, mandating the use of guidelines or parameters of care and establishing advanced information systems that provide an improved basis on which to measure quality and efficiency.

Managed care plans can constrain the costs of participating physicians’ practices in several ways. The plan could restrict physicians from performing certain procedures, or from ordering certain medications or diagnostic tests. Managed care plans use programs of utilization review to detect what they consider unnecessarily costly practice patterns. Sometimes these programs become harassing, intimidating, and deceptive. They can encourage physicians to make cost-conscious treatment decisions through the use of financial incentives. Some plans pay bonuses to physicians, with the amount of the bonus increasing as the plan’s expenditures for patient care decrease.

While efforts to contain costs are critical and many of the approaches of managed care have an impact, managed care can compromise the quality and integrity of the patient-physician relationship and reduce the quality of care received by patients. In particular, by creating conflicting loyalties for the physician, some of the managed care techniques can undermine the physician’s fundamental obligation to serve as a patient advocate. Moreover, managed care can withhold appropriate diagnostic procedures or treatment modalities from the patient.

The Patient-Physician Relationship

The foundation of the doctor-patient relationship is based on the trust that physicians are dedicated first and foremost to serving the needs of their patients. It is trust that enables patients to communicate private information and to place their health and their lives in the hands of physicians. Patients trust that physicians will do everything in their power to help them. No other segment of the health system is charged with the responsibility of advocating for patients, and no other segment can be expected to reasonably assume the responsibility conscientiously. Physicians who care for patients directly are in the best position to know patients’ interests and can advocate within the health care system for patients’ needs.

Ethical Concerns

Ethical concerns with managed care arise because of at least two conflicting loyalties for the physician. First, physicians are expected to balance the interests of their patients with the interests of other patients. Second, managed care can place the needs of patients in conflict with the financial interests of the physicians. Managed care plans use bonuses and fee withholding to make physicians cost conscious. As a result, when physicians are deciding whether to order a test, they will recognize that it could have an adverse effect on their incomes.

Conflicts Among Patients

Some cost containment can be achieved by eliminating waste and improving efficiency. Cost containment is being achieved by limiting the availability of tests or procedures that offer only small or uncertain benefit, or that provide a likely benefit but at great expense. Because managed care plans generally work
within a limited budget and increasingly are for-profit companies that compete to report favorable results to shareholders, the cost of service will influence whether the service is offered to patients who might benefit from it. Allocation rules are developed by plans to deal with this issue.

Managed care plans can make these allocation decisions in a number of ways: By developing guidelines that determine for a physician when the service should be offered, by instructing physicians to provide medically necessary care, and delegating to the physicians the allocation decisions, or by some combination of allocation guidelines, physician discretion, and oversight.

**Ethical Problems with Bedside Rationing**

Physicians make cost benefit judgments every day as a part of their professional responsibility in treating patients. It is unethical to knowingly provide unnecessary care or to be wasteful in providing needed care. It has been demonstrated that even in an exclusively fee-for-service system, physicians overall respond to credible information about the effectiveness of their practices.

Allocation judgments about costs and services that approach a rationing decision or denial of a procedure that benefits a patient are not part of the physician’s traditional role and, indeed, conflict with it. Although physicians have traditionally served as de facto gatekeepers to the health care system, overseeing the public’s use of medical care, the cost primacy environment of managed care significantly complicates this.

The primary care physician’s role in managed care illustrates the ethical problems associated with bedside rationing. The physician gatekeeper determines whether the patient will be granted further access to the health care system, including referrals to specialists and diagnostic tests. At the same time, the physician is required by rules and encouraged by incentives, to be aware of the overall financial limitations of the managed care entity for which he or she works. These competing concerns mean that a patient’s further treatment depends not only on the physician’s judgment about the legitimacy of the present medical need but also on the relative weight of that need in comparison with the organizational need to serve all patients and to control costs.

The physician is obligated to provide or recommend treatment when he or she believes that the treatment will materially benefit the patient, not to withhold treatment to preserve the plan’s resources. It is imperative that physicians contribute their expertise to developing guidelines and advocating for the consideration of differences among patients.

**Organization of Managed Care Structures**

The American Medical Association recommends that managed care organizations establish a medical staff structure much like every hospital in the United States. The governing board of a managed care organization should have physician members as representatives of participating physicians. According to the Stark Law this cannot be more than 20% of the composition. There should be a medical board, completely comprised of physicians, responsible for review of quality of care, credentialing of physicians, and review of restriction of patient services. The governing board would be ultimately responsible for the activities of the managed care organization, but participating physicians would have formal mechanisms for input and responsibilities on crucial medical practice issues.

**Patient’s Role**

In addition to the physician’s role in making rationing decisions, there is an equally critical role for patients. The decision-making process should include some mechanism for taking into account the preferences and values of the people most directly affected. Accurate and full disclosure is most important.

Once guidelines and criteria are developed at the policy level, physicians are free to make clinical decisions based on those guidelines and criteria. In addition to the development of appropriate procedures for making allocation decisions, there are other steps that must be taken to protect patient welfare when the allocation procedures are implemented. With full understanding of the limitations affecting their treatment, patients will have the opportunity to make alternative arrangements for care that is not available in their health plan.

There are two important ways in which financial incentives to limit care compromise the physician’s loyalty to patient care.

First, physicians have an incentive to cut corners in their patient care by temporizing too long, eschewing extra diagnostic tests, or refraining from an expensive referral. Second, even in the absence of actual patient harm, the incentives may erode patient trust as patients wonder whether they are receiving all necessary care or are being denied care because of the physician’s pecuniary concerns. Physicians should not participate in any plan that requires care below minimum professional standards.

**Appeals Process**

It is critical for managed care plans to have a well-structured appeals process through which physicians and patients can challenge the denial of a particular diagnostic test or therapeutic procedure. Such a process should afford the physician an opportunity to advocate on the patient’s behalf before the plan’s medical board or governing board. Managed care plans as institutions have an ethical responsibility to allow patients to challenge treatment decisions that directly affect their health and well-being.

**Patients’ Interests**

Physicians must place patients’ interests ahead of their own interests, including financial remuneration. Financial conflicts are inherent in the practice of medicine, regardless of the system of...
delivery. Generally physicians have been able to maintain their duty to patient welfare despite those conflicts. However, incentives to limit care are more problematic than measures to provide care.

**Quality of Care**

The most effective way to eliminate inappropriate conflicts is to create the use of financial incentives based on quality rather than quantity of services. Reimbursement that serves to promote a standard of appropriate behavior helps to maintain goals of professionalism.

Judgments about the quality of a physician’s practice should reflect several measures.

1. It is essential to consider objective outcomes data, including data about mortality and morbidity, corrected for case load and severity.
2. Because outcomes are often beyond a physician’s control, it is important to consider the degree to which the physician adheres to practice guidelines or other standards of care.
3. Patient satisfaction should be considered.
   
Because measurements of quality are still in the rudimentary stages of development, it is important to ensure that other safeguards are in place to prevent abuse from incentives based on quantity of care. Reasonable limits should be placed on the extent to which a physician’s ordering of services can affect his or her income. For example quantitative financial incentives should be calculated for groups of physicians rather than individuals.

**Public Participation**

Public participation in formulating benefits packages may resolve concerns of limited autonomy. Legislation reasonably protecting patients’ rights to be informed and to choose, and protecting physician’s rights to remain professionals, is also essential. Patients can exercise their autonomy by participating in the decisions of their health plan or in government processes that may restrict their choices or their benefits. In addition, patients have a responsibility to learn as much as they can about the choices of plans, including the exact nature of different benefit packages and their limitations. Patients have a responsibility to make sure they know and understand the terms of their own health plan.

**Patient Autonomy and Responsibility**

Patient autonomy does not guarantee the right to have all treatment choices funded. Some limits on personal freedom are inevitable in a society that tries to provide all of its members with adequate health care. Patient autonomy entails patient responsibility, including a responsibility to abide by societal decisions to conserve health care and to make an individual effort to use resources wisely and lead a healthy life-style.

**Patient Advocacy**

As patient advocates, physicians continue to have duties of disclosure and informed consent. They must ensure that all treatment alternatives regardless of cost are disclosed. They must also ensure that the managed care organization has fulfilled its obligation to disclose the terms of the benefits packages including all limitations and restrictions.

While physicians must remain patient advocates, patients do not have an unlimited claim to physicians’ obligation to provide health care. Physicians should not manipulate or game the system in order to answer patients’ demands. Any broad allocation guidelines should be established at the policy-making level so that physicians are not asked to engage in ad hoc bedside rationing.

There are ethical dilemmas that arise from managed care; safeguards must be built into the structure of the plan for the protection of the physician, patient, hospital and plan. The physician-patient relationship must be nurtured and preserved.

**References**


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**Classified Notices**

**Position Available**

**Kaiser Permanente, Hawaii's oldest and well estab. managed care organization, is now expanding on the Big Island of Hawaii with clinics in Hilo and Wainea. Excellent opportunities available for BC/BE internist, pediatrician, ob/gyn, and several family practitioners. Also recruiting for internist at Maili Clinic on Oahu.** Enjoy the advantages of group practice and concentrate on patient care w/out the business hassles. Applicant must have commitment to quality care. Competitive salary, comprehensive benefits package, malpractice coverage and profit sharing. Join us in Caring For Hawai'i's People Like Family. Send CV to Joy Caminos, Kaiser Permanente Medical Group, 3280 Moanalua Road, Honolulu, HI 96819 or FAX (808) 834-3994. An Equal Opportunity Employer.

**Office Space**

**Sports medicine and orthopedic surgical practice.**—Willing to share office space at Queen's POB 1 and Pali Momi POB. Complete staff, managerial system, radiology, and physical therapy space available. Call Diane Pong, 536-4992, M-W-F 808-524-3721 T-Th. Office for rent or lease. 1520 Lilua St., 937 sq. ft., Ideal 11o 2 doctors, x-ray, lab and pharmacy in bldg. Call Dennis 538-6622. Kuakini medical plaza office space for sublease and share terms negotiable. Call 524-5225 or 833-5722.

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Life in These Parts

Shakespeare wrote: "All the world’s a stage." His counterparts today write: "All the world’s a bed."

(Paul Harvey on KHVN, March 1, 1995)

Talk radio celebrity Dr Laura Schlesinger listed such varied women’s syndromes as PMS (Premenstrual syndrome); PCS (Post-coital syndrome); GCS (Glass-ceiling syndrome); TSS (Toilet-seat syndrome). "And these afflictions are growing at an astronomical rate. Without a more positive attitude, more and more syndromes will appear. Heaven forbid."

(KHVN, March 9, 1995)

The Governor’s QUEST Idea and Its Detractors

When Governor Ben Cayetano suggested that the state Health QUEST plan be opened to state employees and retirees as well as private physicians, businessmen cried foul. Andrew Don, HMA past president and current member of the Governor’s Advisory Committee on Health QUEST said Cayetano’s proposal was "really jumping the gun." Philip Hellreich, legislative chair of the Hawaii Federation of Physicians and Dentists, described the proposal as "awful." But HMSA Vice President for Community Affairs Fred Fortin thinks it’s an idea worth exploring. So did Chris Pablo, manager of public, government and community affairs at Kaiser Permanente, who believes fee for service does not necessarily assure quality.

Andrew Don said, "Why didn’t they come to talk to HMA and the physicians before proposing it. The whole nation jumped when Clinton tried to do this and it didn’t work."

Philip Hellreich said the quality of health care under Cayetano’s QUEST managed care plan will diminish because there will be a financial incentive not to make referrals to specialists.

Medical Claims Conciliation Panel

Toby Bailin, Executive Officer for MCCP, was the featured speaker at a KMC medical staff meeting on March 10. We gleaned the following gems from her delightful, yet educational session on malpractice claims.

Failure to diagnose cancer.—The bulk of malpractice claims revolves around the failure to diagnose cancer early, especially breast cancer. "The American public knows that mammograms diagnose early breast cancer."

Side effects of medications.—Attorneys consider the PDR as their Bible. Even strange side effects (occurring less than 1% of the time) can lead to malpractice suits, eg, convulsions.

Documentation.—"This has nothing to do with the practice of medicine. The greatest tool for a lawyer is documentation. So protect yourselves. Please document!"

Other tips.—"Lots of bad medicine will not be sued if you have a good personality. Being friendly may save months of litigation." A chiropractor’s friendly relationship with a patient saved a surgeon from suit when he left an instrument in the patient’s belly. "Beware when a young person dies," eg, from melanoma or accident, et al, for malpractice suits tend to result.

Humorous cases.—A woman sued when the physician left an electrical device during a Pap test.

Toby Bailin (who is neither lawyer nor physician) briefly summarized cases she has seen in her five years with the MCCP.

Medical practice claims by specialty:

Allergy, neurology and rheumatology: No cases
Cardiology: complications of coumadin-monitoring and angioplasty
Cardiovascular surgery: surgical complications
Dermatology: drug reactions and missed melanoma
ENT: patient died after T&A
Emergency physicians: Prolated retina in accident victim.
FP & GP: Failure to refer; missed cancer
Internal Medicine: missed cancer; drug complications
Neurosurgery: No cases recently; wrong side of brain explored
Pediatics: SIDs cases
Psychiatry: sexual misconduct; a paranoid patient sued because he was medicated
Pathology: missed cancer diagnosis
Urologist: penile implant went wrong
Hospital: elderly patient fell enroute to the bathroom; injection caused numbness near the site.

We thank Toby Bailin for the highly informative session. She invited physicians to volunteer for the MCCP hearings as paid panelists. The MCCP is completely confident and does not view the cases as a stigma against any health care provider. The health care providers covered are physicians, osteopaths, and podiatrists.

The MCCP has no jurisdiction over chiropractors, dentists, oral surgeons, psychologists and nursing homes.—HNY.

Rules to Live By from Shay Bintiff

1. Never judge a day by the weather.
2. The best things in life aren’t things.
3. Tell the truth—there is less to remember.
4. Speak softly and wear a loud shirt.
5. Loosen up—the unaimed arrow never misses.
6. He who dies with the most toys still dies.
7. Age is relative—when you’re over the hill, you pick up speed.
8. There are two ways to get rich—you can make more or you can require less.
9. What you look like doesn’t matter—beauty is internal.
10. No rain—no rainbows.

(From Changing Hawaii by Diane Yukihiro Chang)

Sun Protection

Norm Goldstein offers his opinion on sun protection: (The Shoch Letter—The Voice of the Clinical Dermatologist Vol 45, Number 1 Jan '95 excerpts therefrom).

"Here in paradise we have a rainbow of skins from the whitest white to the blackest black and everything in between. We have had the opportunity to evaluate four different lines of ultraviolet protective garments. While most do offer good protection, the Sun Protection line is the only one regulated and produced under FDA Medical Device Regulations. Solumbra has been extensively tested in vitro and in vivo, and withstands 100 launderings, extended exposure to UV, and still offers effective protection. I have a wide-brimmed hat (gift from the company) and also wear it on occasion. My political campaign motto: Goldstein for Governor—Hat in Hawaii! Aloha."

Condensed Excerpts from Stitches (Medical Humor, Journal of) Jan 1995

Religious Conviction

During a Monday morning clinic at the student health center, a young, single student came in inquiring about the "morning-after pill." She told me that her partner’s condom had torn during intercourse. Completing her history, I found there were no contraindications for the sought-after pill. However, I’d also ascertained that she was already on the birth control pill and, in fact, she’d just finished her period. When I explained to the young woman that the morning-after pill was unnecessary, she thanked me and started to leave. As she reached the door, she turned back toward me and said, "Whew, I’m glad. I don’t really believe in it anyway—I’m Roman Catholic!" (Jeff White in St John’s)


(A retired public school teacher in Missouri) Examples of “Youngsterisms”—beguiling ideas kids toss around as effortlessly as fries. (More than 30 years of teaching has convinced me of this):

“Digestion is best done on an empty stomach.”

“Chickenpox comes from petting you-know-what.”

“Gymnastics exercises our outsides while genetics exercises our insides.”

“There are cavities all through our bodies, but don’t worry unless they get in our teeth.”
"Health is just keeping well while hygiene is being clean about it."

"If you want to stay healthy, it is important to get your share of sleep and air."

"When people run around in circles, we no longer call them crazy. We call them joggers."

"Ancestors are important. Without them you probably would not have had a father or mother. Everyone ought to have an ancestor."

"Inside each ear they have found hammers, anvils and stirrups. So the ears have a good excuse to ache sometimes."

"Trunks are where we put our valuables. The human trunk has such valuables as stomachs and hearts."

"A local anesthetic is medicine given to you in your home town."

"An anecdote is a medicine we all have to take."

"One of the most painful of the minor injuries is the homesgrown toenail."

"If anybody gets hit in the jocular vein, it can be fatal."

"Infantigo is one of the diseases of infancy."

"Rats carry the blue-bonnet plague."

"Tooth-in-mouth disease is something orators get."

Laughter is the Best Medicine

A friend of mine in the accounting department of a small firm locates and pulls ledgers cards for posting. Her job title is simply puller. One day her daughter reported that her second grade class had been discussing their parents’ occupations. "Mommy," she said proudly, "the teacher was more interested in your job than anyone else’s." My friend asked why. "I don’t know," chirped the tot. "All I said was you were a pusher."

Jane Wesley

Conference Notes

Marcus Conant, Clinical Professor of Dermatology, UCSF Medical Center, lectured on "Dermatological Manifestations of HIV as Prognosticators of Disease Progression" at the Aug 14, 1994 QMC-UH Friday morning conference.

Introductory Comments

re Therapy: We need combined rather than mono-therapy.

re Vaccine: Chimps are protected. Asia has an 8-fold increase in HIV.

re Science: A. Cox looked at cell (Viral D).

How to Approach HIV

a. Early intervention
b. Combined therapy
c. Immune-stimulating drugs

re International HIV Convention in Yokohama Disappointment, no vision, no international agenda on how to conquer HIV.

Problem: How to get FDA to allow combination therapy.

HIV Mortality

<table>
<thead>
<tr>
<th>Year</th>
<th>Results</th>
</tr>
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<tbody>
<tr>
<td>1986</td>
<td>50%-60%</td>
</tr>
<tr>
<td>1987</td>
<td>40%-50%</td>
</tr>
<tr>
<td>1993</td>
<td>5%-10%</td>
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*Kaposi *Pneumocystis carinii pneumonia

Reasons for increased survival:

a. Natural selection
b. Prophylaxis
c. Aggressive management
d. Patient empowerment
e. Antiviral therapy

Clinical Manifestations of HIV

1. Seborrhoeic dermatitis
2. Onychomycosis
3. Acne
4. Bullous impetigo
5. Herpes zoster
6. Candida
7. Molluscum contagiosum
8. Oral leukoplaikia
9. Pruritus ani
10. Kaposi’s sarcoma
11. Eosinophilic folliculitis
12. Basilar angio

Dermatologic Prognosticators of Disease Progress

1. Seborrhoeic dermatitis
2. Onycholysis
3. Herpes zoster
4. Acne vulgaris
5. Bullous impetigo
6. Hairy leukoplaikia
7. Monilia
8. Pruritus ani
9. Bacterial folliculitis
10. Molluscum contagiosum
11. Drug eruptions
12. Recalcitrant Herpes simplex

Vaccine: (3B=U.S. strain) Only 70% effective (no application to Japan, Kansas City, etc, but of practical use in San Francisco, with the highest incidence of HIV, eg. 3 AIDS deaths per day and 3 new HIV+ cases per day.)

How to approach a patient with Herpes zoster: "Herpes zoster usually occurs in the 60s and 70s. It is usually associated with a depressed immune system from infection, stress, etc. Do you think we should test for HIV?"

Potpourri

A famed but particularly succinct psychiatrist was invited to speak on sex at an international conclave of psychiatrists. The amphitheater was packed. A hush fell over the crowd as he strode to the podium. He adjusted his glasses, sipped a bit of water; he then looked up and said in a firm, clear voice, "Gentlemen, it gives me great pleasure and sat down."

(From Playboy Party Jokes)

Mental Health in General Practice

A Questionnaire (Adapted from Prime-MD, Primary Care Evaluation of Mental Disorders, copyright Pfizer, Inc.)

During the last month, have you often been bothered by (answer yes or no):

1. Stomach pain?
2. Back pain?
3. Pain in your arms, legs or joints (knees, hips, etc)?
4. Menstrual pain or problems?
5. Pain or problems during sexual intercourse?
6. Headaches?
7. Chest pains?
8. Dizziness?
9. Fainting spells?
10. Feeling your heart pound or race?
11. Shortness of breath?
12. Constipation, loose bowels or diarrhea?
13. Nausea, gas or indigestion?
14. Feeling tired or having low energy?
15. Trouble sleeping?
16. Thought that you have a serious undiagnosed disease?
17. Your eating being out of control?
18. Have little interest or pleasure in doing things?
19. Feeling down, depressed or hopeless?
20. Feeling nervous, anxious or on edge?
21. Worrying about a lot of different things?

During the Past Month

22. Have you had an anxiety attack (suddenly feeling fear or panic)?
23. Have you thought you should cut down on your drinking of alcohol?
24. Has anyone complained about your drinking?
25. Have you felt guilty or upset about your drinking?
26. Was there ever a single day in which you had five or more drinks of beer, wine or liquor?

Overall would you say your health is Excellent? Very Good? Good? Fair? Poor?

JAMA reports:

"There’s a movement afoot to get primary-care physicians to recognize psychiatric disorders better:

a. Because most people with mental disorders never consult a psychiatrist.

b. And because as many as one in five patients who sees an internist or family physician suffers from a psychiatric disorder, but the problem is routinely not diagnosed or treated."

There are Two Little Magic Words

There are two little magic words
That will open every door with ease.

One little word is thanks
And the other little word is please.

You’d be surprised
What these two little words can do.
They worked like a charm for me,
And they’ll work like a charm for you.

Author Unknown

Thank you, Grazie, Dankeschon, Gracias, Merci, Asante, Kansha suru, Spasibo.

From A Book Of Thanks by Helen Steiner Rice

We welcome any jokes or anecdotes from your friends or colleagues for possible publication in the News and Notes section of the Hawaii Medical Journal.—HY
Overdoing things is always harmful, especially when it comes to efficiency.
And then there were three. The original cataract PPO project selected six sites: one in Arizona, two in Texas, and three in Ohio. The goal is to save Medicare funds by bundling fees and negotiating a discounted price for cataract surgery. Innova Eye Medical Services of Cleveland is the third participant to drop out. The reasons given are that the anticipated increase in volume did not take place, and HCFA regulations on documentation, billing and promotion, proved oppressive. The plan originated with Gail Wilensky PhD, during the Bush administration, when the idea of bundling CABG procedures and cataract surgery seemed ripe for packaging. According to HCFA, the CABG project has accrued significant savings, but the same cannot be said for cataract surgery. The original plan, which was to be extended into “centers of excellence” by the Clinton plan, simply does not pertain to cataract surgery. The obvious truth is that prices for cataract surgery have been ratcheted down so low there is no longer much space for saving.

When economy dominates medical care, it can kill you.
The essence of managed care is that the plan will provide the most economical care without compromising quality. An illustration of the danger to patients in such distorted therapeutic ethics is embodied by the current lawsuit involving Copley Pharmaceutical’s generic albuterol, which was substituted for the brand name anti-asthmatic, Proventil. It is alleged that a 10 year old who did well on Proventil became ill and died while on the generic. Many patients claim to have thrived on Proventil, but degenerated on albuterol. Copley has admitted finding bacterial contamination in their product and recalled the drug in January 1994. Of course, Copley’s lawyers claim there is no proof that anyone has died from the drug, but told the court that the number of adverse-reaction reports may exceed 10,000! The FDA protocol called for three ingredients to kill bacteria, but Copley conceded that it never used two of the three. And that’s managed care folks!

There are some people, if they don’t know, you can’t tell ‘em.
A 64 year old diabetic was known to have high blood pressure, macular degeneration, and surgical aphakia. She suddenly lost vision in the right eye and visited her ophthalmologist. Examination of the optic fundus revealed a large pre-retinal hemorrhage involving the macula with vision limited to hand motion at one foot; the fellow eye retained vision of the 20/70-. The doctor obtained a fluorescein angiogram, explained the nature of the problem to the patient, and referred her to a retinal specialist. The latter surgeon also discussed the condition and possible complications before performing laser therapy on the left eye. Because the first physician had obtained a release, the retinal specialist did not document his explanation or obtain written consent. Mistake! Informed consent means the doctor who actually performs the procedure is primarily responsible for adequacy of the informed consent. When the patient developed a similar hemorrhage in the fellow eye three days after the laser procedure, the patient claimed that she was not aware such a thing could happen.

Don’t overestimate the decency of the human race.
Shortly before dawn on a nearly deserted highway, a cardiologist was speeding to the hospital intensive care unit to implant a pacemaker in a patient who’s heart rate had dropped to 20 beats a minute. An alert traffic officer arrested the doctor and cited him for driving 80 mph in a 55 mph zone. When the emergency was verified, the officer allowed the doctor to proceed, but issued the speeding ticket just the same. In court, the doctor admitted to the violation, but claimed that his haste was warranted, saying, “Conduct that is otherwise an offense may be justified by reason of necessity.” The judge didn’t buy that argument, fined the physician, and awarded two points against his license. The superior court and appellate court both supported the judge. The doctor has spent $5,000 in legal fees, but remains undaunted. “Some colleagues think I’m a fool, but I believe I’m right, and I’m willing to fight for my principles.” Bonus to the doctor is that the case attracted wide attention, and his practice and professional respect have been enhanced.

The Bureaucracy never sleeps.
The Clinton health plan, sponsored by Hillary and Ira Magaziner, crashed on the rocks of an unresponsive Congress, but health care reform continues at the state level. Hawaii has Health QUEST, but that program is trivial compared to the sweeping legislation that established Minnesota Care. The bills delegated broad rule-making authority to the Commissioner of Health, and promised universal access, cost reduction, and a 2% tax on medical care providers. Moreover, the legislation created a virtual monopoly for HMOs by placing stringent regulations on traditional indemnity insurance plans. Prudent, travelers Life, CHUB Life, and Nationwide have stopped selling insurance to small Minnesota companies. Health care delivery has suffered. The Mayo Clinic cut 450 jobs as a cost-cutting measure, and Minnesota has lost 500 doctors in the past two years.

Happiness makes up in height for what it lacks in length.
The Midwinter Seminar promoted by the Hawaii Ophthalmological Society was a great success. Outstanding faculty, fascinating clinical material, excellent hotel facilities and meals, generous and satisfied sponsors, and a concise but comfortable format. Accolades are due to John Drouilhet and his strong program team.

Addenda
• In 1945, there were 42 employees paying into the Social Security system for every one retiree. In 1995, the ratio is 3 to 1, and that fact alone is why Congress must address entitlements.
• A wedding is just like a funeral except that you can smell your own flowers.

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