Patient Self-Determination Act Regulations Provoke Comments

The interim final regulations for the implementation of the Patient Self Determination Act drew over 85 comments from such diverse groups as the American Hospital Association, the American Bar Association, the Prudential Health Care Plan, the American Health Care Association, and Choice in Dying. The interim final regulations were issued by the Health Care Financing Administration (HCFA) on March 6, 1992, and became effective April 6, 1992. Public comments were accepted by HCFA until May 5, 1992.

The range and diversity of comments received by HCFA reflect the very diverse organizational structures and services of the health care agencies (i.e., hospitals, nursing facilities, home health providers, hospice providers, and prepaid health plans) included under the law. Many of the agencies responded to HCFA's inquiry about what would be a reasonable period of time to require health care agencies to update written materials that are given to patients so as to incorporate changes in state law. Suggestions ranged from 30 days to one year, varying often by the type of agency. The American Bar Association recommended that, because written materials on advance directives used by providers are based upon the descriptions of the law developed by or through the state, HCFA should consider a two-step time period -- a deadline on states to revise the state description of the law, followed by a second deadline on providers to revise their own materials.

Health maintenance organizations responded with a number of concerns.
NETWORK NEWS

Baltimore Area Ethics Committee Network

The first Baltimore Area Ethics Committee Network meeting was held on May 6, 1992. Approximately a dozen institutions were represented at the meeting. Those in attendance agreed that the Network should meet every other month and that a different institution should host each meeting. Individuals present were interested in learning how ethics committees at other institutions are organized and operated. In response, the second Network meeting was scheduled for July 7th at 4:30 p.m. at the University of Maryland Medical System. The topic for the meeting was "How Our Ethics Committees are Organized and Operate."

Those who attended the meeting participated in a round table discussion of such questions as: (1) how many members are on your ethics committee?; (2) does your committee include community representatives? ethicists? a lawyer?; (3) do members of your committee have special training in ethics?; (4) who does your committee report to?; (5) has your committee developed any policies? on what topics?; (6) has your committee done any case consultation in the past year?; (7) procedurally, how does your committee conduct its case consultation?; (8) does your committee make a recommendation? outline various options? or assist the parties reach an agreement? and (9) what educational efforts of hospital staff, if any, has your committee engaged in?

If you would like more information about the Network call (410) 328-7191.

Washington Metropolitan Bioethics Network

In May, the Washington Center for Aging Services hosted the Washington Metropolitan Bioethics Network meeting. The topic was "Cultural Issues and Ethical Dilemmas in Long Term and Acute Care." Panelists discussed such topics as organ donation in the black community, attitudes of patients and providers of long term care services in Britain and the United States, cultural backgrounds of nurses aides and nursing assistants in long term care settings, and perspectives of Seventh Day Adventist patients in non-denominational health care institutions.

The June meeting of the Network was held at the Visiting Nurse Association of Northern Virginia. The topic was "Suicide Assisted by Friends: Is it Compassionate?" Kathryn Arnow, the program coordinator, describes the meeting in an upcoming issue of the Newsletter.

The next meeting of the Network is scheduled for July 28th from 4:00 - 6:00 p.m. at Medlantic Manor, 6000 New Hampshire Avenue, N.W., Washington, D.C. The topic will be "Evaluating Ethics Committees: How do you know if your committee is doing a good job?"

The August meeting will be held on Saturday, August 15th at NIH. The meeting will include a theatrical performance of Kurt Vonnegut's "Fortitude" a play dealing with life-sustaining treatment. The performance will be followed by a discussion on the use of media and literature to teach medical ethics. For more information about these meetings or about the Washington Metropolitan Bioethics Network contact Joan Lewis at (202) 682-1581.

West Virginia Network

After five years of informally sharing policies, 22 hospitals and nursing homes in West Virginia officially formed the West Virginia Network of Ethics Committees last year. The Network is funded by $500 annual membership dues and receives faculty and staff support from West Virginia University.

"In organizing the network, we promised a newsletter three times a year, two major annual conferences, an 800-number telephone hot line for information and advice to anyone in the state on advance directives, a speakers bureau, an annotated bibliography of health ethics, assistance in starting or strengthening an ethics committee, and two day-long network forums each year where members get together and discuss difficult cases and policies," explained Alvin Moss, M.D., one of the network organizers and an associate professor of

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State News

Comprehensive Legislation on Life Sustaining Medical Treatment Drafted in Maryland

A major effort to draft comprehensive legislation on the subject of life-sustaining medical treatment continues in Maryland. Acting under the auspices of a committee appointed by the Conference of the Circuit Court Judges, a five-member drafting sub-committee (Judge John Carroll Byrnes of the Circuit Court for Baltimore City; Walter McQuie, of the Maryland Disability Law Center; Jack Schwartz, Chief Counsel for opinions and advice in the Attorney General's Office; Howard Sollins, of Ober, Kaler, Grimes & Shriver; and Dr. George Taler, of University of Maryland Hospital) prepared and distributed for comment a 55-page draft of legislation.

The proposal contains many significant features, including the following:

* The Living Will Law would be amended to encompass not only patients in a terminal condition but also in a "condition of permanent unconsciousness" - that is, persistent vegetative state patients. The Living Will law would also be clarified to allow declarants to state a decision about artificially supplied foods and fluids.

* Powers of Attorney for health care decisions would be authorized and their use spelled out.

* The surrogate decision-making law would be broadened to allow family members and close friends of an incapacitated patient not only to consent to treatment, as under current law, but also to decline treatment on behalf of the patient. Surrogates would be permitted under some circumstances to consent to termination of life-sustaining procedures on behalf of the incapacitated patient in a terminal condition or a condition of permanent unconsciousness.

* The guardianship law would be amended to contain substituted judgement and best interest standards for judicial decisionmaking about life-sustaining procedures.

Physicians would be expressly authorized to refrain from providing "medically futile" treatment, although the exact scope of this authority remains unresolved.

Influencing all of the particular provisions of the draft is an overall approach to the subject that decisionmaking autonomy, while of paramount concern, is not the exclusive policy consideration; that the four traditional state interests - preservation of life, prevention of suicide, protection of innocent third parties, and preservation of the ethical integrity of the health care professions - merit both express legislative recognition and practical application; and that, as a political matter, a bill that does not reflect a balanced approach and that does not have a broad range of support cannot be enacted. The search for consensus leads to certain provisions in the draft that have provoked controversy, including a special procedure if an individual is the sole caretaker of a minor child is to forgo life-sustaining procedures, special procedures if a feeding tube is to be withheld or withdrawn, and a variety of safeguards intended to ensure that those who might be specially vulnerable are protected.

On June 24, the committee of the Conference of Circuit Court Judges, chaired by Judge G.R. Hovey Johnson, endorsed the portion of the draft dealing with guardianships and encouraged the drafting subcommittee to continue its work on a comprehensive bill in light of the many comments received. In addition, Maryland Attorney General J. Joseph Curran, Jr. has indicated a willingness to build on the work of the committee with the goal of presenting a consensus bill to the General Assembly for the 1993 Session.

Maryland Courts Consider Two Termination of Treatment Cases

The Maryland Court of Appeals, the state's highest court, recently agreed to review the case of Deanna Mack v. Ronald E. Mack, the state's first reported judicial opinion on the termination of life support, during the September, 1992 term. The case involves 30-year-old Ronald W. Mack, who has been in a persistent vegetative state for nine years. His wife, Deanna Mack, is appealing a Baltimore County Circuit Court decision that refused to recognize a Florida court decree appointing her legal guardian of her husband, and that denied her petition to discontinue her husband's artificial nutrition and hydration. The circuit court found that Mrs. Mack failed to prove by clear and convincing evidence that her husband would wish to discontinue life support. The court declared in the decision that this was the appropriate evidentiary standard in Maryland for terminating medical treatment. (Ronald Mack's father opposed the request for termination of life support, and the circuit court appointed him personal guardian for his son.) The Attorney General of Maryland has been invited by the Court to file an amicus brief and to present oral argument in the case, according to one of the appellant's attorneys, Rachel A. Wohl. "The court has probably taken this unusual step because this is an important issue of first impression in Maryland and because the Attorney General has issued two opinions on withdrawal of life support," she explained.

Mrs. Mack, the appellant, is arguing that the trial court erred in not giving full faith and credit to the guardianship of Ronald Mack awarded to Deanna Mack by the Florida court; and that the trial court also erred by deviating from Maryland's statutory priority of appointing a spouse as guardian without good cause. "We think the circuit court decision sends the wrong message to the people of Maryland. This decision will cause families to fear that if they petition the courts for withdrawal of life support from a loved one, the court might take away their guardianship," Ms. Wohl said.

The appellant also is challenging the establishment of the clear and convincing evidence standard as the evidentiary standard to be met in Maryland for termination of life support. But even if such a standard is applied, appellant argued that evidence of Ronald Mack's views sufficient to meet the clear and convincing evidence standard were presented at trial.

The appellant also challenges the trial court's decision that an objective best interest test is inappropriate in this case because the patient is unable to feel pain. Appellants argue that two factors unrelated to physical pain should have been considered by the court: Ronald...
Mack’s right to be remembered with dignity and his desire not to cause his wife and children to suffer.

Christopher Brown, Esquire, a prominent Baltimore lawyer and law professor who is the primary attorney for Deanna Mack, stated that, “The most significant question in this case is whether the Court of Appeals will set such a stringent standard of proof to terminate the treatment of individuals in a persistent vegetative state that it will be nearly impossible for persons to meet it. This is especially true for young persons in accidents, or for the mentally retarded, who have not had time to thoughtfully express their views about the options of life support in a persistent vegetative state.”

In another case, In the Matter of Stacy Sahm, the Circuit Court for Baltimore County ruled on March 30, 1992 that life sustaining treatment could be withdrawn from a 29-year-old woman in a persistent vegetative state. Judge Leonard S. Jacobson’s decision was contingent on the patient, Stacy Sahm, remaining in a persistent vegetative state for an uninterrupted three-month period. This allows sufficient clinical observation for a diagnosis of permanent unconsciousness with a high degree of medical certainty, according to an American Academy of Neurology position cited in the opinion. Mrs. Sahm died before the three months elapsed, however.

The case arose when Mrs. Sahm, a patient at Greater Baltimore Medical Center, suffered cardiac arrest a few days after childbirth and sustained 21 minutes of severe hyperfusion/hypoxia, during which her brain was deprived of oxygen. Medical experts testified that as a result, Mrs. Sahm was in a persistent vegetative state, that there was no reasonable expectation that she would recover from her injury, and that the perpetuation of life sustaining medical treatment served no valid purpose and therefore should be discontinued. Mrs. Sahm’s husband sought to be appointed her guardian and petitioned for authority to order the withdrawal of all life sustaining treatment being administered by her doctors.

In reaching his decision, Judge Jacobson relied on the U.S. Supreme Court decision in Cruzan v. Director, Missouri Department of Health, and two opinions by the Maryland Attorney General. Following testimony by Mrs. Sahm’s family, the court ruled that petitioner had shown, by clear and convincing evidence, that Mrs. Sahm would not desire life sustaining medical treatment in a persistent vegetative state in the absence of a reasonable expectation of recovery. The court appointed Brian Sahm guardian of his wife and vested him with the authority to order the cessation of all life sustaining treatment, contingent upon the passage of the three-month period.

D.C. Hospitals Embark On “Futility” Journey

The Washington Hospital Center’s Bioethics Program sponsored a Spring Appreciation Dinner in honor of the efforts of the Bioethics Committee. The celebration included a presentation on “Futility” by Dr. Stuart Youngner, M.D., Associate Professor of Medicine and Director of the Biomedical Ethics Program at the University Hospitals of Cleveland. Commentary and discussion were provided by Dr. Edmund Howe, M.D., Associate Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences. The following is a brief summary of their remarks.

Dr. Youngner introduced the concept of futility by noting its relatively brief but interesting history in the medical ethics literature. Except for a broad reference in the President’s Commission Report in the early 1980’s, the writing on futility has been confined to the previous five or six years. Youngner noted that futility discussions usually center around end-of-life decisions and the question of withholding or withdrawing life-sustaining treatment for persons in ICU settings as well as those who may be in long-term care facilities with such conditions as PVS. He cited four frequently argued moral justifications for decisions to terminate life support therapy which have appeared in the literature: a) patient autonomy; b) quality of life judgements, based on the benefit/burden proportionality standard; c) the notion of “physiological futility,” where a treatment simply would have no possibility of working; and d) cost-containment issues, especially in view of growing societal concerns about scarce resources.

Youngner noted that often the impetus for claiming a treatment is futile is a concern about cost, but he urges that there be a clear demarcation between rationing and futility claims. In somewhat broad strokes, Youngner reflected on some of the larger societal issues that have a bearing on our understanding of futility. He acknowledged that the "going for it" mentality that comprises much of American thinking will have to be reexamined. That is, we will need to constrain the prevailing belief that even the slightest probability that something will work is sufficient for most Americans to “go for it.” This belief is related to the notion of patients demanding that “everything be done” in terms of medical intervention, a view that Youngner warns will lead us into great difficulty.

He offered two distinctions to support his view that some patient choices will need to be constrained. The first is that there is a distinction between the right of a competent patient to refuse life-sustaining treatment (a negative right), and the right of the competent patient to demand whatever treatment he desires (a positive right). The former is derived from a constitutional right to privacy as well as a common law rule that allows recovery for battery. By contrast, a positive right means that one is entitled to something from another.

Youngner questions whether there exists a right to demand medical treatment in the United States. He argues that since there does not appear to be a right to vaccinations, and other preventative health measures, a right to extremely expensive treatment that may have a low probability of success is unlikely.

This distinction is important for Youngner’s overall notion that the way to understand the meaning of futility is in terms of physiological effects. That is, if a treatment has no possibility of working to correct the physiological Cont. on page 5
problem, then it is futile. For instance, if CPR could not get one’s heart to restart, then it would not succeed physiologically as a medical intervention. He says that patients do not have a right to demand or expect treatment that will not work.

Furthermore, physicians should not ask the patient or family if “they want us to do everything?” This gives the patient the wrong message. He says to do so may well undermine patient autonomy rather than promote it. He also claims that it simply is not good medical practice to give patients treatments that are not medically indicated; the doctor seeing a patient in an outpatient clinic being seen for a cold who requests a CT scan would not typically honor such a request. This is so because health care professionals have standards which guide their practice and society requires that they use their skills and knowledge responsibly.

However, Youngner acknowledges that determinations of futility are not usually so objective in nature. He acknowledges the impact of subjectivity on such judgements, particularly in terms of the patient’s evaluation of what risk is worth taking. He introduces a second distinction which is closely related to this point. He says some treatments are clearly beneficial in that they work quite well, but that others are only marginally beneficial.

Those treatments that are only marginally beneficial may be legitimate to request. Youngner admits to not being sure how to develop standards regarding this and says he feels comfortable with saying that many ICU’s are full of people who shouldn’t be there. He is somewhat wary of efforts to build consensus standards on these matters where the element of subjectivity is so high; the risk he sees in developing standards is that reliance on standards may have the consequence of further reducing patient and doctor communication. He ended his remarks with reflection on larger societal questions of value and the difficult choices we may soon have to make.

Dr. Howe’s remarks centered around four concrete cases that helped to bring the clinical and moral issues of the futility debate to light. He said that determinations of futility have effects on physicians, patients, staff, and society. In acknowledging several different meanings of the word “futility,” Dr. Howe supported the view advanced by Dr. Robert Veatch, that all treatment decisions are fundamentally questions of value.

He commented on some of the larger patient-physician relationship concerns that the futility debate highlights. One of these is the growing problem that many patients and physicians interact as strangers and do not have enduring knowledge of each other’s values. He also introduced the topic of extended autonomy, where the right of a patient to accept or refuse medical treatment could be understood as promoting the value of “family autonomy.”

There was general discussion from the audience on some of the difficulties that clinicians encounter in their practice and of the need to get more conceptually clear on just what we mean by “futility.”

In closing, Janicemarie Vinicky, Director of the Bioethics Program at the Washington Hospital Center, announced that plans are underway to have a consensus statement prepared by cooperating hospitals in the D.C. area to address at an institutional level the issue of futility and to formulate regional policy on this difficult topic.

submitted by Michelle Carter, PhD

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee in the region and how the committee resolved it. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.

Case Consultation in a Virginia Hospital

PRESENTATION:

E.A., a 67-year-old, unmarried Hispanic female, presented with extensive advanced breast cancer manifested by a necrotic lemon-sized mass in her left breast which had eroded through the skin. Subsequent studies revealed evidence of wide-spread bone metastases as well as local extension into the chest wall and lung cavity. She acknowledged her discovery of this mass approximately nine months earlier but did not seek medical attention, fearing that it was a tumor. She was brought to the hospital at this time because of uncontrolled bleeding from the tumor and an offensive odor which troubled her family more than herself. The patient’s failure to seek earlier medical attention was also partly due to strong religious convictions and the feeling that God would “take care of everything.” Palliative surgery was offered but rejected, chemotherapy was rejected, local topical measures were applied to suppress bleeding, and transfusions were administered to replace blood loss. The patient returned home to the care of her family, still expecting divine intervention. She was brought back to the hospital three months later, virtually moribund, profoundly wasted, with a tumor which had now grown to the size of a grapefruit. The family now requested that “everything be done” and specifically, that nutritional support be provided.

ETHICS COMMITTEE CONSULTATION PROCESS:

The admitting physician (a surgeon) requested an ethics consultation. He felt that the therapy, earlier rejected, was never potentially curative but only

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Case Consultation
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difficult to determine and is clearly not determined only by the medical team. For this patient and her family, therapy (in this case, nutritional support) which prolonged her life even a few days was not considered futile. It was felt that such nutritional support should be provided. However, it was felt that this should be provided enterally via a feeding tube and that provision of nutrition by either gastrostomy placement or via a parenteral route would be “disproportionate” and could reasonably be withheld. The recommendation was that enteral feeding via a feeding tube be initiated at the family’s request.

**OUTCOME:**

Enteral feeding was initiated, and the patient expired three days later.

Case Discussion: A Bioethicist’s Perspective

This case presentation raises a number of questions from the perspective of planning for the care of patients. Was end of life decision-making explored with the patient or family at the first admission? If no dialogue occurred, then an important opportunity may have been lost. A clear advance directive from the patient might have relieved the family from the stress of deciding the course of treatment for a dying, no longer competent, relative. The intent of the Patient Self-Determination Act is to promote planning for end of life decisions before a crisis occurs or the patient has become incompetent.

The case presentation makes no mention of planning for medical care after discharge from the hospital following the first admission. What form of comfort care and support was made available to the patient? Was hospice care considered? Was the patient suffering during the second admission to the hospital? The patient was receiving pain medication. Was this adequate to relieve suffering? Suffering is always relevant to planning for the care of patients. If I were a member of the ethics committee which reviewed this case, I would want to know whether artificial nutrition would prolong the suffering of this terminally ill patient.

Planning for the care of patients is not simply a matter of deciding what to do to patients; rather, it is a process of working with patients (and family or other surrogates in the case of incompetent patients) to determine what is best for the patient. The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research endorsed “shared decision-making” between clinicians and patients. Shared decision-making depends, in part, on developing a shared understanding of the patient’s condition and options for treatment. It is not clear what the family meant by the request that “everything be done” for the patient. Does “everything” include merely prolonging the process of dying, particularly if the patient is suffering? The concerns and motivations of the family would seem to be worthy of exploration. The patient had neglected to seek medical intervention until it was too late, and she refused palliative treatment recommended by her attending physician. Is it possible that the family feared that the patient was going to be abandoned by the medical team in view of the patient’s history of neglect and refusal of treatment? Was the decision to “do everything” motivated by a desire to compensate for the patient having done nothing earlier when medical intervention might have made a significant difference? Attention to psychodynamic factors in this case might have enhanced dialogue between clinicians and the family and thus led to a shared understanding and decision on continued care for the patient.

Requests or demands for aggressive treatment of incompetent patients based ostensibly on religious convictions pose perplexing problems for clinicians and ethicists. Were the religious considerations of the patient and family addressed adequately in the planning for the care of this patient? The case presentation mentions that a

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clergyman participated in the meeting of the ethics consultation team with the patient’s sister. What role did this person play? The case presentation states, “It was suggested tactfully that perhaps God would have intervened earlier if able to do so.” Was this tactful? Might it not have been preferable to suggest to the family that God does not stand in need of medical intervention to work His will? Perhaps sensitive intervention by clergy might have helped resolve the conflict between the family and the physicians, thus obviating the need for ethics consultation.

The ethics committee wisely refrained from regarding “futility” as a decisive consideration in this case. Whether a course of treatment is futile depends on the purposes that those involved in a case desire to achieve. Given the imminence of death for this patient with advanced breast cancer, artificial nutrition might be considered medically futile, since there is no reasonable chance of restoring health. But if the goal of the patient or surrogate is to maintain life, then artificial nutrition may not be futile. Who decides the goals of treatment? The principle of shared decision-making recognizes that treatment decisions are not to be determined unilaterally by clinicians, since they involve nonmedical values. The foregoing of feeding for terminally ill patients remains controversial. Withholding of nutrition in this case, against the “substituted judgment” of a surrogate decision-maker, would be unjustifiable unless it was reliably considered to prolong unrelievable suffering.

submitted by Franklin Miller, PhD

Case Discussion: The Views of An Attorney: The Case of “E.A.” and the applicability of Virginia’s Health Care Decisions Act of 1992

E.A. is presented as a woman who has clearly ignored the dire implications of her advancing breast cancer. However, the facts provided do not indicate whether the physicians who carried out the initial diagnostic tests and observed her “lemon-sized mass” talked openly and straightforwardly with E.A. about the likely course of her disease. Equally important, it is not clear whether the physicians explored either her fears or her beliefs at that time. Evidently, E.A. had postponed seeking medical attention for nine months partly because of her religious beliefs and partly out of fear that she really had a malignancy. The presence of both indicate considerable ambivalence on the part of E.A. towards her illness. The failure to examine the basis for E.A.’s refusal earlier on raises questions about the validity of her refusal -- whether it was truly an informed one.

At the point where E.A. is brought in literally at death’s door, and her family demands “aggressive nutritional support...” there does not appear to be a sound basis on which to assume that everyone concerned is speaking the same language. Given E.A.’s condition, and her imminent death, and given the uncertain quality of previous communication and resultant understanding between family members and the medical team, the request to continue some level of nutritional support does not seem unreasonable or unethical, despite the family’s obvious lack of appreciation of the inevitable outcome. Yet, under Virginia’s new Health Care Decisions Act (HCDA), if the treating physician felt strongly that any form of continued support, however minimal and for however short a time, would violate his or her ethical norms, he or she would be permitted to refuse to provide it, even in the face of family opposition. The physician would then be obligated to make a “reasonable effort” to find another physician who might see things differently and be willing to provide enteral feeding.

Under Virginia law, the family is presumed to be representing the patient’s wishes in good faith and to be acting in the patient’s best interests unless there is evidence to the contrary. E.A.’s sister appears to be advocating a course that is consistent with her sister’s previous behavior. Although the patient’s prior decisions seem not to have been adequately explored, it is too late to do so now. The kind of therapy being requested is not so burdensome as to be harmful to the patient, and unlikely to be continued for long enough to raise the issue of wasted resources. Since an argument can be made for continuing a low level of nutritional maintenance via enteral feeding, out of compassion for the family more than out of any claim to real benefit to the patient, it is likely that another physician could be found to provide this to the patient should E.A.’s present treating physician refuse to do so.

It is important to note at the outset that the new Virginia statute does not create any new rights or any new law. It is an explicit recognition of the fact that neither law nor ethics has ever required physicians to provide therapies, perform surgeries or prescribe medications that were believed by the physician to be of no medical benefit to the particular patient. The Virginia statute refers to "medically unnecessary" care not "futile" care. The definition in either case is somewhat murky and the two terms are often used interchangeably. The term "unnecessary" is further elaborated in the statute to mean any "treatment that the physician determines to be medically or ethically inappropriate." The determination is a subjective one; it is not intended to be measurable by objective standards. By advancing a subjective standard, the statute acknowledges that physicians, Cont. on page 8
The Views of An Attorney
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like patients and their surrogates, are moral agents and are engaged in making value-laden judgments. As some scholars have noted, even supposedly “objective” criteria for futility, such as the physiologic futility standards, can never be value-free.

The notion of physician-determined futility suggests that the statute invites a return to unilateral and paternalistic decision-making. This is not the case. The statute is an effort to accommodate the values of both physician and patient without requiring either to violate a personal or professional code.

Physicians who refuse to provide treatment for this reason must also make a “reasonable effort” to transfer the patient to another physician if the physician’s refusal contradicts either a written advance directive or a recognized surrogate decision maker. This provision, while vague in its use of the term “reasonable effort,” is a compromise reached with those who opposed the notion of allowing physicians the option of refusing to comply with demands for treatment believed by the physician to be ethically unsound or not clinically indicated. By not specifying what constitutes a “reasonable effort” to transfer, the drafters intended to allow a case by case determination. Since there is no requirement to continue treatment while pursuing the transfer, the efforts must be made in a timely and prompt manner. If no one can be found after a “reasonable” search, it is very likely that the treatment is widely regarded as useless – i.e. “medically and ethically inappropriate” – and the family would be unable to obtain it.

The ethics committee in this case appears to have concluded first, that futility cannot be determined solely by the medical team and second, that in any case, nutritional support for E.A. was not futile because it might prolong her life for a few days. Under the HCDA, however, any treating physician could, indeed, decide that artificial nutrition and hydration in any form, is futile for a particular patient, refuse to initiate or continue it, and make a reasonable effort to transfer the patient to another physician.

The ethics committee’s conclusion -- that enteral feeding be provided -- seems entirely reasonable, given that the patient has been in the hospital only two days, is unlikely to live long, and that the family appears quite unable to grasp the gravity of E.A.’s situation at the present time. Unless there is evidence now or in the future that such feeding caused discomfort for E.A., it is a minimal intervention, apparently consistent with the patient’s wishes, and comforting to her family. All such considerations and decisions would be consistent with Virginia’s Health Care Decisions Act. Also consistent would be the original physician’s refusal to comply. In this case, transfer to another physician who feels ethically comfortable with the requested feeding seems not to pose any difficulty.

In spite of the clarity of the statute, the question of potential liability may arise. Some physicians who believe that they are being asked to provide something medically and ethically inappropriate will be unwilling to refuse to provide it in the face of intractable demands from a patient’s family because they fear being sued by the family. There are two immunity provisions in the Virginia statute: one provides immunity from civil or criminal liability for the person authorizing withdrawal, withholding or provision of treatment pursuant to an advance directive or a surrogate’s decision, and the second provides immunity from liability for alleged lack of consent.

The question of immunity for a subjective determination of ethical or medical inappropriateness is both impossible and unnecessary. Impossible because a family member can almost always file a claim, even though it is unfounded. Unnecessary because if the physician’s determination is really wide of the mark, or even slightly idiosyncratic, another physician will be found to supply the requested treatment and the family will therefore have no grounds to sue; the patient has not been abandoned. If the physician’s assessment of futility is so widely shared that no other physician can be found to whom the patient can be transferred, this would be interpreted by judge and jury as evidence of accurate and sound judgment on the part of the first physician.

submitted by Margot L. White, J.D.


PSDA Regulations
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For instance, the Prudential Health Care Plan of the Mid-Atlantic (PHCP) pointed out that for HMOs the interim regulations refer to those who must receive the required information as individuals, enrollees and members, not subscribers (the persons who actually enroll in the plan) or subscriber’s enrolled adult dependents which are HMO categories of individuals. Given that the regulations do not address a family unit with more than one adult enrollee, the PHCP recommended that the regulations require that information be provided to the person who subscribed to the Plan, on behalf of the family unit, for use by all adult members. The PHCP also requested verification that the requirement to provide these materials is at initial enrollment only and that "at the time of enrollment" be interpreted broadly enough to include enclosing these materials with the initial membership materials sent upon receipt of the application.

PHCP also recommended that the interim final rules require only that organizations make reasonable efforts to acquire information about the existence of advance directives. PHCP argues that the current requirement to document whether or not an advance directive exists creates difficult issues: policies to
actively pursue members in order to acquire this information will be difficult, time consuming, expensive and can be expected to cause undue concern among members; and there is no guarantee that an advance directive will not be executed in the future without the organization's knowledge.

Other compliance problems for group-practice model HMOs were raised by Ochsner Health Plan (OHP), a 90,000-member group practice model health maintenance organization in Louisiana. OHP believes the regulation requiring that HMOs pointedly ask each and every enrollee whether they have executed an advance directive to be intrusive and not supported by the language of the PSDA. In addition, OHP maintains that such affirmative choices on advance directives should be announced to those providers in the best position to act on such a choice: a primary care physician, a hospital's nursing staff, or a nursing home medical staff. OHP stated, "A decision on advance directives announced to a group practice or Individual Practice Association (IPA) model HMO makes little sense because the HMO is not in a position to act on such information. Group practice and IPA model HMOs...do not actually provide health services....or maintain medical records...." OHP recommended that the final regulations reflect the fact that many HMOs do not produce or maintain medical records and have no authority to make entries on medical records. OHP also requested that HMOs be required to distribute information on advance directives only to subscriber members who will be deemed to pass such information along to dependent members of the HMO.

Concerns about the applicability of the PSDA to individual personal care service providers were raised by the American Bar Association's Commission on Legal Problems of the Elderly. Noting that individual personal care attendants are often unskilled or semi-skilled workers who perform non-medical functions, the ABA Commission suggested that HCFA "either permit the delegation of PSDA respon-

sibilities to program case managers/supervisors in programs...that utilize individual personal care workers or alternatively rely on the fact that the PSDA obligations apply only to providers of medical care so that individual personal care providers would not be subject to the PSDA mandate."

The American Hospital Association submitted a number of recommendations including the need to make clear in the regulations that providers should have discretion to decide when to provide information on advance directives when the patient's mental and physical status are in question. AHA also recommended that the regulations specify that physicians themselves, not hospitals, directly discuss with their patients their own policies with respect to implementation of advance directives and explain any conscientious objections they have. The AHA pointed out the practical difficulties for hospitals, often with hundreds of physicians on staff, to be responsible for describing each physician's position on advance directives.

The American Nurses Association recommended that nurses be included in the group of health care professionals, listed in HCFA's public information document, that adult individuals can talk to before deciding whether they want an advance directive. The ANA also asked what mechanisms would be built into the regulations to ensure periodic reassessment of patient competency so that formerly incompetent patients will be given the opportunity to initiate an advance directive.

Choice in Dying, a national advocacy organization with 155,000 members, noting that verification of provider compliance will be accomplished in part by response to complaints, pointed out that there is no information anywhere in the interim final rule or the preamble regarding the complaint-making process. Nor is there a requirement that accredited hospitals provide adult individuals covered by the PSDA with information concerning the complaint-making process.

Concerns were also raised about the written materials that agencies are required to provide under the statute. For instance, the American Bar Association noted that the interim regulations give states the option of either requiring all Medicaid providers to use the state-developed description of state law, or alternately of allowing providers to incorporate the state information generally into the provider's own package of materials. The ABA argues that states need to have a process in place to evaluate and pre-approve the provider's particular version of the description of the law to avoid inaccuracies and inconsistencies. The ABA makes an even stronger recommendation: "Realistically, because of the additional expenditure of resources and time required to review individual provider materials, HCFA should actively encourage states to use a single, uniform state description."

In contrast, Choice in Dying argues that nothing in the PSDA provides or implies that the states have any authority to dictate the content of information disseminated by providers to covered individuals. Choice in Dying, therefore, maintains that language that permits states to dictate content must be eliminated from the regulations.

The ABA also recommended strengthening the non-discrimination mandate of the PSDA. Noting that many providers are making advance directive forms available to individuals as part of their resource materials, the ABA raised concerns that this policy, while not discriminatory on its face, can have a coercive effect on patients. The ABA stresses that admission is not the proper point at which "to proselytize, either directly or indirectly," and proposed a PSDA rule which states, "...expressly direct providers not to give or [have patients] execute advance directive forms routinely at the point of admission." The only caveat to this principle, the ABA stated, is if an individual actually requests to execute an advance directive at admission.

Thomas Hoyer, a division director with HCFA's Bureau of Policy

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PSDA Regulations
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Development, stated, "Following a thorough analysis of the comments we have received, we expect to issue final regulations in the future responding to the comments and making any changes that are necessary."

Network News
West Virginia Network
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medicine at West Virginia University Medical School's Center for Health Ethics and Law.

In addition, this summer the network will conduct its first intensive course in bioethics at the Canaan Valley Resort and Conference Center in Davis, West Virginia. The two and a half-day conference will educate people who currently serve or who plan to serve on ethics committees or be an ethics resource person. The conference topics include informed consent and treatment refusal, realistic expectations for ethics committees, decision-making capacity, and effective ethics consultation.

The conference is full, which shows the growth in interest and enthusiasm for issues in ethics and medicine, according to Dr. Moss. "We're finding in West Virginia that not all hospitals and nursing homes chose to have ethics committees but many that don't are identifying individuals in the institution to serve as resource people for ethical issues," he said. "We are trying to be a resource for all of those involved in health care ethics."

The network will cosponsor a Pediatrics Ethics Conference in Charleston, West Virginia, with the West Virginia Business and Professional Ethics Project on October 28, 1992. Dr. Norman Fost, a professor of pediatrics at the University of Wisconsin will be the featured speaker. Also, the first annual Dr. Wilhelm Albrink Memorial Lectureship will be held on November 6, 1992 at the Health Sciences Center in Morgantown. Dr. Albert Jonsen, professor of ethics in medicine and chairman of the Department of Medical History and Ethics at the University of Washington, will speak on "Fighting in the Fortress of Medicine: The Ethical Conflict Between the Personal and the Institutional."

Dr. Moss is excited about the future of the West Virginia Network, given the "very strong response and support during the first year." He said the network expects an increase in membership next year and is exploring new services, such as an electronic bulletin board and other electronic services. For more information, contact Dr. Moss at the Center for Health, Ethics and Law, Health Sciences Center, Morgantown, WV 26506.

Letter to the Editor
May 7, 1992

Dear Editor:

This is in response to your request for comments in your Spring 1992 Newsletter on whether the patient or surrogate should be told about the physician’s unilateral decision to withhold or withdraw treatment which is futile. I am the long term care ombudsman for the Prince George's County Bureau of Aging and so have a direct concern for protecting the rights of nursing home residents.

I suggest the answer to the question you raise becomes clearer if we recognize that a physician serves the patient not only as a medical performer but also as a medical advisor. All physicians have an advisory responsibility within their specialty areas and the attending physician has an overall advisory role (in some cases advising the patient may indeed be the only role which he fulfills).

As a medical performer the physician may have the right to refuse to perform a procedure which he believes is of no medical benefit even if requested to do so by the patient. However, I think in saying this we are talking about the doctor’s professional decision not to perform the service and not about the patient’s decision not to have the service performed.

As the patient’s medical advisor, the physician, I believe, has a professional duty to inform the patient of the facts which led to the physician’s judgment. The patient can then make his own decision as to whether to accept the non-performance of the procedure or to look elsewhere for someone who will perform the procedure. There are simply too many differences among health professionals on matters of professional judgment to say that just because one physician believes a procedure is futile, all other physicians will agree—or that the physician may simply assume that all other physicians will agree.

One of the most hopeful signs I have seen in the evolution of the physician-patient relationship is the growing recognition, especially by younger physicians, that their role is not to make all the medical decisions but rather to inform the patient of the factors and risks involved in various courses of treatment so that the patient can make an informed decision. A physician may not be comfortable telling the patient that if he wants a procedure performed he will have to look for another physician because the physician thinks the procedure would be futile. Comfortable or not, the physician, I believe, owes the patient this information as part of his professional duty.

Thank you for the opportunity to comment on this issue.

Alfred E. Shpiegelman, Esq.
Ombudsman
Prince Georges County
Government
Department of Family Services
Bureau of Aging
CALENDAR OF EVENTS

JULY

July 19 - 23
Conference: The Third International Conference on Health Law and Ethics, sponsored by the American Society of Law & Medicine, Royal York Hotel, Toronto, Canada. For information call (512) 341-8131.

July 23rd
Panel Discussion: Non-English Speaking Patients, Ethical and Legal Issues. NIH, Lipset Ampitheater (Bldg. 10), 2:00 p.m. - 3:30 p.m. Contact: NIH Bioethics Office (301) 496-2429.

July 26 - 31
Conference: Ethics Practice & Teaching, co-sponsored by The Hastings Center and the Association for Practical and Professional Ethics. Colorado-College, Colorado Springs, CO. Contact: The Poynter Center (812) 855-0261.

July 28th
Washington Metropolitan Area Bioethics Network Meeting, 4:00 - 6:00 p.m., Medlantic Manor at Lamond Riggs Nursing Home, 6000 New Hampshire Avenue, N.W., Washington, D.C. Contact: Joan Lewis (202) 682-1581.

AUGUST

August 15th
Washington Metropolitan Area Bioethics Network Meeting, 9:30 - 11:30 a.m., National Institutes of Health, Bethesda, Maryland. Contact: Joan Lewis (202) 682-1581.

August 17th - 28th
The Center for Biomedical Ethics at the University of Virginia will sponsor a two-week clinical training program for individuals sponsored by an institution. Contact: Edward M. Spencer, M.D., Director of Outreach, at the Center (804) 982-3758.

SEPTEMBER

September 18th
Kennedy Institute of Ethics, Annual Members’ Symposium, 9:30 a.m. - 10:00 p.m., Leavry Conference Center, Georgetown University. Contact: Irene A. McDonald (202) 687-8099.

September 23rd
Baltimore Area Ethics Committee Network Meeting, Francis Scott Key Hospital. For exact time and location, contact Henry Silverman (410) 328-6250.
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