American Society of Anesthesiologists

Committee on Ethics

Syllabus on Ethics

Informed Consent

Committee on Ethics of the American Society of Anesthesiologists

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PREFACE

The cataclysmic transformation of the practice of medicine has reflected the accelerated rate of change in both its own scientific foundation and the conglomerate nature and values of the heterogeneous society it serves. This baleful upheaval has, with increasing frequency, confronted physicians with complex ethical and moral dilemmas that impact not only our professional lives -- and by extension those of our patients -- but also our personal lives. Indeed, it has become necessary to respond to these challenges in an informed and effective manner based on an expanded awareness and knowledge of biomedical ethics.

The Accreditation for Graduate Medical Education (ACGME) acknowledged that a variety of factors -- the ascendency of patient rights, the technical advancements in medical care, the extension of both extremes of our patients' life span, the ever-expanding costs of providing care within a setting of limited national resources, to name a few -- are bringing an enlarging list of ethical dilemmas to the arena of clinical practice. In order to empower physicians-in-training to better understand and manage the perplexing ethical problems inherent to our profession, the ACGME mandated that all accredited residency programs provide an education in the ethics of the practice of medicine.

A survey of residency programs conducted by the ASA Committee on Ethics in the spring of 1996 revealed that many programs were experiencing some difficulty in incorporating the teaching of medical ethics into their residency curriculums. Most programs were providing sporadic lectures, but few claimed to have an organized approach to teaching the relevant issues. Indeed, a majority of respondents indicated that they welcomed assistance in establishing an ethics curriculum for our specialty.

In response to these exigencies, the ASA Committee on Ethics undertook the daunting task of creating a model curriculum for teaching ethics. The linchpin of this project is the publication of a yearly Syllabus on Ethics. Each Syllabus will concentrate on one fundamental area of bioethics relevant to the anesthesiologist. The contents will include anesthesia-specific educational material: informational background, references and guided case studies. There also will be articles that address the challenges that faculty encounter in the teaching of ethics to residents.

We offer the Syllabus with the suggestion that it can serve as a valuable resource for faculty. Furthermore, our committee stands readily available, upon request, as personal resources for assisting faculty in orchestrating the teaching of ethics. We are also open to feedback and suggestions for improving this and any future Syllabus.
Bioethics occupies the interface of the absolutism of ethical theory and the relativism of clinical medicine. However, in the final reckoning, the hallowed and time-honored patient-physician relationship, now housed in a relentlessly dehumanizing milieu of hostile influences, is the ultimate context in which most clinical decisions and actions are made. It is in this noble relationship of trust and caring that the physician's moral obligation to serve as the patient's protector and advocate must emerge as the primary focus of ethics in anesthesiology.

Stephen H. Jackson, M.D.
Chair, ASA Committee on Ethics
INTRODUCTION

This Syllabus contains a presentation discussing implementation of a bioethics curriculum and four modules for teaching discrete aspects of informed consent.

"Implementation of an Ethics Curriculum: Getting Started" describes Gail Van Norman's experiences at the University of Washington Department of Anesthesiology. This article provides a blueprint for designing a consummate bioethics program for anesthesiology residents.

The first module, "Introduction to Informed Consent," provides a broad overview that can serve as a basis for understanding the succeeding three modules. The second module, "Who Speaks for the Patient," focuses on assessing patient competence and the use of proxy decision-makers. The third and fourth modules, "Special Issues in the Care of Children" and "Informed Consent for Jehovah's Witnesses," center on the special challenges of informed consent for these two populations of patients.

Each module contains the following elements:

**Summary review:** A discussion of the pertinent issues designed for use as both a background source for instructors and a handout for residents.

**Annotated bibliography:** A guide for readers to selected references. Highly suggested references are bolded.

**Cases:** Bioethics education is best accomplished by a mixture of didactic education and case conferences. To facilitate case-based teaching, each author offers case presentations (formatted to facilitate reproduction) that have proven didactic success. Each case also includes instructor's notes that may be used to guide the discussion. We anticipate that the examples provided will encourage faculty to develop their own teaching cases.

**Special teaching method:** Residents tend to find nontraditional instructional methodology both practical and stimulating. Each module therefore includes a nontraditional vehicle for teaching bioethics.

The Syllabus is designed to be used creatively and flexibly according to the specific demands of your department. For example, presentation of a module can begin with a didactic lecture, with future sessions centering on case conferences and special teaching methods to clarify key points. Another option would be to distribute the summary review and to focus the teaching session on the case conferences. Departments may also choose to teach a specific module to CA-1s, another to CA-2s, etc.

The Syllabus on Ethics and certain references are available on the Wood Library-Museum of Anesthesiology Web site at http://www.asahq.org/wlm/. References that are not on the Web site are available by request from the Wood Library-Museum of Anesthesiology.
We, the contributors to the syllabus, stand willingly available as a resource for teaching faculty seeking advice and assistance in developing a bioethics curriculum.

David B. Waisel, M.D.
Editor Starting a Bioethics Library

We are often asked what books or journals should be in a bioethics library for residents. This short list contains what we advise to be readily accessible for anesthesiology faculty and residents. Additional materials are available from the Wood Library-Museum of Anesthesiology.

Bioethics Textbooks


Medical-Legal Textbooks


Journals

Many journals have articles pertaining to bioethics, most notably *The New England Journal of Medicine* and *Annals of Internal Medicine*. The two journals listed below, however, are the most practical and widely read journals of bioethics and should be available to residents.

*The Hastings Center Report*

*The Journal of Clinical Ethics*

Ethical Guidelines of Medical Organizations


Notable Reviews

CONTENTS

Special Paper. Implementation of an Ethics Curriculum: Getting Started
Gail A. Van Norman, M.D.

Module A. Introduction to Informed Consent
David B. Waisel, M.D.

Gail A. Van Norman, M.D.

Module C. Informed Consent: Special Issues in the Care of Children
Robert D. Truog, M.D.

Module D. Informed Consent for Jehovah's Witnesses
David M. Rothenberg, M.D.

Editor:
David B. Waisel, M.D.
Attending Anesthesiologist
Wilford Hall Medical Center
San Antonio, Texas

Consulting Editor:
Gail A. Van Norman, M.D.
Acting Assistant Professor of Anesthesiology
Department of Anesthesiology
University of Washington
Seattle, Washington

Contributors:
Robert D. Truog, M.D.
Director, Multidisciplinary Intensive Care Unit, Children's Hospital, Boston
Associate Professor of Anesthesiology and Pediatrics, Harvard Medical School
Boston, Massachusetts

David M. Rothenberg, M.D.
Associate Professor of Anesthesiology
Director, Division Anesthesia-Critical Care
Department of Anesthesiology
Rush-Presbyterian-St. Luke's Medical Center
Chicago, Illinois

IMPLEMENTATION OF AN ETHICS CURRICULUM: GETTING STARTED

The doctor-patient relationship, regardless of the specialty, goes beyond the practice of technological skills, and is inter-woven with moral values involving respect and trust, rights and duties, truthfulness, confidentiality, integrity and fairness.1 The practice of medicine is suffused with moral value -- the act
of "doing good" -- and the education of practitioners of medical arts therefore requires more than the
development of technical skills. Medical education is, and should be, intimately entwined with the moral
development of its graduates. Education in the ethics of medical practice is integral to the creation of a
"physician," as versus the training of a techni-cian. In support of this concept, in 1996, the Accreditation
Council for Graduate Medical Education mandated ethics education as a part of every residency
curriculum.2

Building a curriculum program that encom-passes medical ethics is an exciting, if not challenging, task.
The broad goals of ethics education as they apply to the clinical practice of anesthesiology present
opportunities for creative academic faculty in search of a "niche" in a truly "leading edge" area of
residency education and medical education research.

How an ethics curriculum is implemented de-pends on each department's environment, receptivity and
needs as well as the goals of ethics education. How ethics should be taught, and who should teach it,
flow from the educational ends we wish to meet.

I. What Should Be the Goals of Ethics Education in Residency?

While it is agreed that ethics should be a part of any residency curriculum,3-11 the goals of teaching
ethics are not entirely settled. The reasons for the recent groundswell of interest in the ethical
dimensions of medicine are complex and not entirely obvious. The idea that technological advances in
medicine have led to an increase in the number and complexity of ethical problems in medicine may be
more perception than fact, since even such "modern" ethical issues in medicine as abortion and
euthanasia have foundations in distant historical debate.12 The social readiness in the United States in
the 1950s and 1960s to question authority, together with per-ceptions that medicine has become driven
by technology and technical values, may have set the stage for the re-examination of the moral values in
medicine.13 Recognition that caring for patients involves more than addressing the technical aspects of
disease may have lead to a search for answers in ethical terms. In the words of L.R. Kass, " if healing the
sick is always the heart of the physician's business, and if, as I suspect, the essential features of the
healing relation between the physician and the ill have not been, indeed cannot be, altered by
technological advance or societal change, then medicine must remain (at its core) what it always has
been -- a very special profession."14

Ethics education has been promoted on an assumption that certain moral behavior is expected and
desirable among all physicians, both in their collegial interactions as well as their treatment of patients.
Furthermore, ethics education has been promoted on the assumption that certain undesirable practices
and personal traits have evolved in the medical environment, which a consciously directed moral
education can correct.15 Promoters of formal clinical ethics education therefore assume that past ills and
future mistakes in medical practice will be remedied, and that education in ethics will promote moral
behavior.4,5,6,7,16 Detractors point out that "evil" can and has occurred, even in the face of appropriate
education, and that there is little evidence that the moral development of physicians is changed through
education.7 Prov-ing that education changes behavior, however, is difficult for even more traditional
areas of medical education. It is unclear, for example, that education in biochemistry has any affect on
the decisions, behavior or competency of physicians. Yet biochemistry is considered a basic aspect of
medical education.

Discussion of moral development and moral character as a vital part of becoming a physician creates a
sense of queasiness among many doctors, who may be nervous that anyone can become the victim of
moral finger-pointing, and who believe that in ethics there are, or should be, "no right answers." Physicians
skewered on the horns of a moral dilemma in practice, however, suffer acutely themselves, and are helped little by the pronouncement that "there is no right answer." Clinicians desire solutions to
moral problems involving patient care, just as they seek viable treatments for physical diseases and symptoms.

Should ethics education be a way of directing and fostering moral development of physicians or should it provide tools for "solving" certain types of clinical ethical problems or both? We can teach clinical problem analysis and potential "short-term" solutions to certain types of problems, but appropriate moral development of physicians might build a health care environment in which ethical problems, because they are seldom dilemmas in the true sense, become less and less frequent.

At the University of Washington Department of Anesthesiology, we have a three-year curriculum program devoted to the teaching of clinical ethics in anesthesia practice. Four faculty members are primarily interested in the presentation of ethical issues and curriculum development, and the program is now three years old. While the structure is basically the same from year to year, our view of the program remains fluid, and our ethics curriculum is still evolving. It is helpful, however, to look at one program's goals and approach in ethics education and how we have tried to meet those goals.

II. Teaching Ethics in Multiple Formats

In our program, we believe that individual students may learn best in different formats, and so we have three forums in which clinical ethical problem solving is discussed: a case-based lecture series dealing with basic ethical issues in anesthesia practice, a regular presentation of ethical issues at our departmental morbidity and mortality conference, and a yearly evening ethics forum involving members of the community as well as experts from other medical departments.

Case-Based Lectures in Clinical Ethical Problem-Solving. Our program began with the simple goal of presenting common ethical problems encountered in anesthesia practice to our residents in order to familiarize them with one approach to resolving ethical dilemmas. We used a method of clinical-ethical case analysis described by Jonsen, in which a case is presented with four questions to answer:

1) What are the medical indications for the procedure?
2) What are the quality of life features of the case? That is, what will the patient's quality of life be with and without the procedure?
3) What are the patient preferences?
4) What contextual features contribute to the case? That is, are there familial, financial or legal pressures to act? What about schedule conflicts, just distribution of scarce resources, political pressures?

Each case is discussed, and the answers to each of these four questions are developed by the residents, who are then asked to formulate a "resolution" to the problem and discuss how their resolution addresses the various ethical principles that may be in conflict.

Question #1, for example, represents the ethical principles of beneficence (doing good) and nonmaleficence (avoiding harm) from the physician's perspective. An answer to question #1 must include a discussion of the medical alternatives available to the patient and their respective benefits and harms. Question #2 represents the principles of beneficence and nonmaleficence again, but from the perspective of the patient. Question #3 represents the ethical principle of respect for patient autonomy. In question #3, residents must consider features that may affect the patient's self-determination, such as whether the patient is competent and whether they are making a voluntary decision. Question #4 represents issues of justice. Are the physicians or patients being subjected to unfair pressure? Are resources being allocated justly?

Residents have two lecture hours per year devoted to medical ethics teaching in the first two years of residency and a two-hour seminar in the senior year. Each lecture begins with an illustrative case, which
is "analyzed" as the lecture develops, and then didactic material is presented. Sample case development can be found beginning on page B-10.

The first year's lectures are devoted to basic and common problems in anesthesia practice like informed consent issues and do-not-resuscitate orders in the operating room. In the second year, somewhat more complex issues such as proxy decision-making are explored. In the third year, a two-hour seminar is devoted to a medical ethical topic of broader implications, usually utilizing a topic in the news that year. Topics have included understanding definitions of brain death, ethical issues in organ trans-plantation and rationing health care.

*Morbidity and Mortality Conference.* Our department has a weekly conference discussing interesting or illustrative cases from recent schedules at each of our department hospitals. Three or four times a year, a collection of cases involving ethical issues is used as the conference focus. In this way, the general faculty are involved in the education process regarding clinical ethical dilemmas. The case format described above is used to initiate discussion.

*Annual Evening Ethics Forum.* Our residency program includes monthly evening "specials" for residents, in which dinner is provided and a two- to three-hour program is presented on a variety of topics, ranging from management of the difficult airway to substance abuse. One "special" per year is devoted to ethical issues in medicine and anesthesia practice. In this forum, a panel of experts is convened to have a moderated round-table discussion about two medical cases involving ethical issues. We try to utilize both community experts and visiting pro-fessors. A typical panel consists of an anesthesiologist, an ethicist, an attorney, a theologian, a media representative and a second medical expert representing the specialty involved in the case. Each panelist is given the case scenarios to be discussed in advance, together with a list of questions to consider that might be addressed by the case moderator during the evening. The panelists are also given "bare bones" medical facts for the case, and some relevant references and articles of interest from both the medical and lay literature are presented. Since the issues of focus are ethical and not medical, medical features of the case are de-emphasized in the discussion.

Each case is moderated by a faculty member familiar with the ethical features which we wish to use as teaching points. A tentative case "development" is composed and rehearsed in advance by the moderator, who then presents the scenario to the panel and asks each panelist in turn to respond to various issues in the case.

The result is a "real-time case," with reactions from experts who might in real life function in an advisory capacity to the physicians involved. Our aim is to provide residents with a broader perspective on medical ethical issues; one which included the perspectives of other medical specialties, nonphysician ethicists, legal experts and spiritual or theological experts. Preparation for the evening is intense, but the results have received praise from the residents and panelists alike. It's also fun.

We found, as many other clinical educators have, that case-based discussions appear to elicit the most interest and participation from both faculty and residents.15,17,19-25 This is likely due to its similarity to other aspects of residency education, in which the diagnosis and treatment of disease is learned by "doing cases" and discussing anecdotal scenarios. The use of real cases emphasizes the relevance of recognizing and developing an approach to ethical problems for use in everyday practice. While we sometimes use cases from sources other than the University, we feel that the best discussions are generated if the residents admit to difficult situations they themselves have experienced and how they handled them.

Promotion of these discussions requires that we emphasize and guard against any negative repercussions to residents who bring problems to light. Cases that are brought to us privately by residents are often
used for group and departmental case discussions. In all cases, the residents involved are forewarned, and case details are changed to "protect the innocent."

Case discussion also require an atmosphere of "sympathetic listening." We find that tough ethical dilemmas, like tough medical decisions, are often painful and elicit dramatic emotions in the participants. It is not uncommon for residents or faculty discussing difficult dilemmas to exhibit guilt, anger, frustration and sorrow.

III. Experience Expands the Goals of Ethics Teaching

As we have gained some experience in clinical ethics education, our goals have broadened from that of simple case discussion. We now have at least five goals in ethics education.

Goal 1: We hypothesize that residents have trouble recognizing ethical problems as such, and tend to view them as issues of authority and "turf." One goal of ethics education should be to help residents and faculty appropriately identify true ethical conflicts and distinguish them from other types of conflicts. We want residents to recognize that not all conflicts are ethical conflicts and that not all ethical conflicts can be reduced to issues of authority and territory.

Examples of issues we have seen include:

"The patient won't do what I want them to." Residents may be distracted from practicing respect for patient autonomy by the affront of having the patient question their "authority."

"The surgeon is telling me what to do with my patient." Rather than explore whether in fact the surgeon might be correct in what they want to do, the resident is caught up in a "turf war" and is prevented from focusing on patient care by an argument with another physician regarding propriety over the patient.

"I don't agree with my attending about what should be done." Residents may recognize an ethical conflict, but feel prevented from exploring the dilemma out of fear of reprisals from an authority to which they are subordinate. While recognition of authority is important in medical education, residents should be encouraged to appropriately speak up when faced with ethical conflicts, to follow the principle of "primum non tacere ," (first, do not be silent) as discussed by Dwyer.19

"A colleague is behaving in an unethical/obnoxious/inappropriate manner." Residents may react to each type of behavior similarly, despite the fact that they represent different conflicts which require different responses. Disrespectful behavior from a colleague does not equate with unethical care of a patient.

Goal 2: Identification of ethical problems is only the beginning in developing an approach to clinical ethical problems. In analyzing real cases using a simple format, we hope to develop habits that will help a resident approach ethical problems in a constructive manner.

By having a formal approach to ethical problems we ensure that:

a) All aspects of a problem are considered.

b) Conflicting features of the case are identified.

c) The true nature of the conflict can be recognized, whether it is ethical, emotional, authoritative or otherwise in nature.

d) An appropriate approach to the identified conflict can be formulated.

Goal 3: We want to expose residents to the ethical conflicts they are likely to see in practice. By anticipating some of the common ethical problems in anesthesiology, residents can develop an approach...
prior to encountering difficulty, much the same as we ask residents to have a defined approach to the
difficulty airway.

Issues we want residents to consider are:
  a) Do-not-resuscitate orders in the operating room
  b) Informed consent
  c) Proxy consent for medical care
  d) Brain death (ethical issues and diagnosis)
  e) Organ procurement/ transplantation issues
  f) Physician aid-in-dying and euthanasia

Goal 4: In addition to ethical issues common to anesthesia practice, we believe that anesthesia residents
have an obligation as medical practitioners and, as knowledgeable members of society, to have an
awareness of broader ethical issues facing medicine.

Issues that we examine include:
  a) Managed care
  b) Economic credentialing
  c) Allocation of scarce resources
  d) Professionalism and contractual issues of employment
  e) Research and publication ethics

Goal 5: We believe that language is an essential part of education. Language contributes to the
solution of problems through precise and respectful communication during conflicts. Language also
shapes the way we think and how we act. Finally, appropriate use of language may prevent problems
and can facilitate problem-solving.

The development of good language skills involves four key aspects: knowledge, respect, practice and
example. We try to promote the development of language as a tool in residency in the following ways:
  a) We discourage faculty and residents from using disrespectful language in any communication
     involving patients and colleagues.
  b) We encourage the use of precise language and appropriate medical and ethical termi-nology in both
     written and oral communi-cation.
  c) We encourage residents to present cases at departmental conferences as a way of developing comfort
     with public communication.

IV. Ethics Faculty

As in any educational program, the goals of ethics education direct the program development. While
formal ethics education for faculty who teach ethics is ideal, more often a program starts with the simple
belief on the part of one or more faculty members that the teaching goal is important enough to gain
their interest and attention. Many physicians teaching clinical ethics started on the strength of their
interest in the topic and problems and have relied on self-education. For faculty members interested in
ethics education and in teaching ethics, several courses are offered in the United States each year that
can help educators get started. A list of basic texts is also recommended in the Syllabus (page iii), and
members of the American Society of Anesthesiologists Committee on Ethics are willingly available
as resources for educators.

REFERENCES

INTRODUCTION TO INFORMED CONSENT

The last 40 years have brought about an increased respect for the rights of the individual. One way medicine has acknowledged this movement has been in the growth and development of informed consent. Obtaining assent, the agreement of a patient to have a procedure, has changed to obtaining consent, the autonomous, informed authorization by a patient to have a procedure. This was put in specific relief by three court cases: Salgo, Natanson and Canterbury. Residents should be familiar with
these cases as they are the legal articulations of the goals of informed consent.

In 1957, Salgo brought forth the requirement of informed consent. Salgo became paraplegic following translumbar aortography. He had not been informed of the risks of the procedure. The court introduced the concept of informed consent by requiring the physician to explain the risks, benefits and alternatives of the procedure to the patient.

In 1960, Natanson began to define what information should be told to the patient to fulfill the requirement of informed consent. Natanson had severe radiation burns following the use of cobalt radiotherapy, a new tech-nology. Although some disclosure had taken place, the court held that the disclosure had been inadequate. This case introduced the professional practice standard, which requires dis-closure to the extent that other physicians in the community would make under similar circum-stances.

In 1972, Canterbury refined what should be disclosed. Canterbury became quadriplegic following a laminectomy. He sued, claiming he should have been informed about the low but finite likelihood of such a significant risk. Although the surgeons did fulfill the professional practice standard, the court held that the disclosure was insufficient, and promulgated the reasonable person standard, which requires a physician to disclose the information that the hypothetical reasonable patient would consider important to make a decision.

**What Is Informed Consent?** The obligation to respect a patient's right to self-determination is commonly referred to as the principle of respect for autonomy. In anesthesiology, this principle is honored by the process of the patient and the anesthesiologist deciding on a plan and the patient's authorization of the anesthesiologist to perform that plan. The process of obtaining informed consent is often considered in two senses: the legal sense and the ethical sense.

The legal sense of informed consent requires the fulfilling of a process as defined by the local institution. This often takes the form of writing a note in the chart or having a patient sign a document. Anesthesiologists should be aware that completing the institutional requirements does not necessarily achieve the goals of informed consent. Patients may, for example, sign forms they do not understand. The institutional requirement, however, does provide a useful reminder to the provider to obtain informed consent, and its completion is evidence that some discussion about risks has taken place.

Mechanically fulfilling the legal sense of informed consent, however, rarely satisfies the ethical requirements incumbent upon a physician. A physician shows respect for a patient's right to self-determination by nurturing the patient's ability to achieve as much autonomy as possible in decision-making. To abrogate this expression of autonomy is to treat the patient as less than a person. To achieve the ethical sense of informed consent, then, the anesthesiologist must seek to maximize the ability of the patient to make substantially autonomous decisions. By steadfastly pursuing this goal, the anesthesiologist is not only more likely to fulfill the ethical requirements of in-formed consent but also to decrease liability ex-posure. Beauchamp and Childress have divided the process of informed consent into elements that provide a pathway toward achieving the ethical spirit of informed consent.

**Process of Informed Consent**

Threshold Elements
Competence and Decision-making Capacity
Voluntariness

Informational Elements
Disclosure
Recommendation
Understanding

Consent Elements
Decision
Autonomous authorization

Threshold Elements

*Competence and Decision-making Capacity.* The term competent means that a patient is legally capable of consenting to a medical procedure. Every adult patient is assumed to be competent to consent to medical procedures, unless ruled otherwise by a judge. Decision-making capacity, on the other hand, refers to the ability of a person to make a specific decision at a specific time. A patient's capacity to make decisions may vary.

Anesthesiologists encounter patients with limited decision-making capacity in at least three fundamental situations (see *Who Speaks for the Patient*, page B-1, and *Special Issues in the Care of Children*, page C-1).

1. The patient without legal decision-making authority, such as a minor or a legally incompetent patient. Anesthesiologists should encourage these patients to make decisions and participate in their care as much as possible. For example, an 8-year-old may be able to choose whether to have an intravenous or inhalation induction but not whether to have the operation.

2. The patient whose decision-making capacity is temporarily altered as from preoperative sedation or pain medication. Recognize, too, that the level of impairment varies depending on the medication, the tolerance of the patient to the medication and the decision to be made. Indeed, some patients have improved decision-making capacity when pain is decreased (consider at which time the parturient receiving a labor epidural may be most capable of making an informed decision).

3. The patient who appears to have a preexisting impairment in decision-making capacity.

Anesthesiologists have an obligation to consider a patient's decision-making capacity and are encouraged to seek help when needed in making this determination. Evidence of adequate decision-making capacity includes the ability to understand the situation, to comprehend the relevant information and to express a preference based on rational, internally consistent reasoning. For example, it may be rational for patients to refuse a spinal because they are frightened of a needle being inserted in their back. Even if their anesthesiologists believe a regional anesthetic would be of lesser risk than a general anesthetic, patients may choose the general anesthetic because they value certain attributes (no needle in the back, being "totally out") more than they value minimizing risk. Physician disagreement with a patient's choice does not necessarily constitute inadequate decision-making capacity. Patients are allowed to make what anesthesiologists perceive to be poor decisions. Anesthesiologists, however, do not necessarily have to provide care if they believe the patient's choice is inappropriate or likely to result in harm (see *informed refusal*, page A-4).

*Voluntariness.* Physicians should only perform procedures on patients who are acting of their own accord. This issue comes into play most prominently when determining what to do with a patient who may have limited decision-making capacity (see *Who Speaks for the Patient*, page B-1). Anesthesiologists should also recognize that they may hinder the ability of a patient to act voluntarily if information is presented to a patient in an inappropriate way. For example, an anesthesiologist should not try to influence the patient's choice by presenting misleading information or by "playing down" certain risks. Censoring the information provided does not permit a patient to make a voluntary decision.

Informational Elements
Disclosure. Most localities use either the professional practice standard or the reasonable person standard to determine the information that needs to be disclosed. A third standard, the subjective person standard, defines perhaps the ideal disclosure but is difficult to use as a legal standard.

1. Professional practice standard. The extent of disclosure is dictated by the practices of the local physician community. The difficulty with this standard is that this level of disclosure may be found to be insufficient to fulfill both ethical and legal requirements. Further, having physicians determine what should be disclosed ignores the fundamental desire to have the patient be at the center of decision-making.

2. Reasonable person standard. Disclosure should be to the extent that would satisfy the hypothetical reasonable person. The difficulty with this standard is that it is unclear what the reasonable patient may want. For example, younger patients may prefer more information than older patients. Gender and other demographic data are not necessarily predictive of what a patient may desire for disclosure. Moreover, it does not require the caregiver to individualize the informed consent process.

3. Subjective person standard. The disclosure is tailored to the particular patient's wants and needs. However, determining to what extent a patient wants disclosure can be problematic. This is also difficult to use as a legal standard because part of determining liability for insufficient informed consent is causality, or the requirement that the patient would have chosen a different option with knowledge of the additional information. If a court were to employ a subjective person standard, patients could always claim they would have made a different decision.

A problem with all three standards is that they do not articulate exactly what a patient should be told. One solution is to mention risks that cause a temporary complication 10 percent of the time and a more permanent complication 0.5 percent of the time, and then ask the patient if they want to know about less common and more severe risks. This allows the patient to retain some control of the informed consent process. Anesthesiologists should routinely include in disclosures the specific risks and benefits of each anesthetic option, the complications of instrumentation of the airway, the risks and benefits of invasive monitoring, the presentation and use of a fallback plan, and the basis for the anesthesiologist's recommendation. For example, a recommendation might be widely accepted and based on high-quality multicenter studies, or it might be controversial and based on personal opinion. Anesthesiologists should also inform the patient whether an individual or an anesthesia care team will be providing anesthesia services, and, if the latter, the names and roles of the team members.

The most common theory of suit relating to informed consent is negligence. Negligence means that the anesthesiologist did not provide sufficient disclosure to permit a patient to make an informed decision.

Materiality and causality are the legal requirements used to ascertain if the information given was sufficient. Materiality determines whether the information met the local standard of care, which is usually either the professional practice standard or the reasonable person standard. Causality determines whether the additional information would have affected the patient's decision. Because patients can always say they would have made a different choice, most courts determine causality by deciding if the hypothetical reasonable person would have used that additional information to choose differently. The court can, however, consider factors specific to the patient and situation. For example, a patient must have time to consider and ask questions about the information. Disclosing risks as the patient is wheeled into the operating room is unlikely to be considered adequate.

Recommendation. Some have taken the idea of respect for autonomy out of context and mistakenly believed that the anesthesiologist must present the options without offering an opinion. This is wrong. Anesthesiologists are, in fact, obligated to offer an opinion as to which options are preferable and the advantages and disadvantages of each option. By explaining the underpinnings of their opinions,
anesthesiolo-gists allow the patient not only to receive the benefit of their expertise but also to understand the reason for the recommendation. Patients can then decide for themselves which benefits best fit their priorities.

When making a recommendation, anesthesiologists must be careful to do so in an ethically appropriate manner. The use of persuasion, the act of presenting information to the patient to buttress a recommendation, is appropriate and indeed required. Manipulation, however, which can be defined as inappropriately causing a certain behavior, is ethically unacceptable. For example, an anesthesiologist may manipulate a patient by not offering general anesthesia for an operation because of a desire to minimize operating room time or a desire to gain experience with regional anesthesia. This is inappropriate. Coercion, the act of threatening a patient with a plausible punishment so the patient will act in a certain way, is clearly prohibited.

Understanding. Patients need to understand the risks and benefits of the proposed procedures, the recommendation made and why that recommendation was made. It is difficult to determine if a patient fully understands the informed consent discussion, and, indeed, many patients may not. For instance, in one study, 27 percent of postoperative surgical patients did not know which organ had been operated upon, and 44 percent did not know the nature of the procedure (Byrne and others, 1988). Only 55 percent of cancer patients could list one of the major complications for chemotherapy within one day of signing the consent forms (Cassileth and others, 1980). Preprinted risk-specific consent forms do not necessarily help retention of risks (Clark and others, 1991). Decision-makers have even signed consent forms that they acknowledge they do not understand (Waisel and Truog, 1995).

This information should not cause the anesthesiologist to abandon the informed consent process. Instead, this information should spur the anesthesiologist 1) to focus on important information without cluttering the discussion with lists of risks and 2) to attempt to thoroughly educate patients according to their individual needs. By doing this, anesthesiologists may more adequately achieve the goal of substantial self-determination.

Consent Elements

Decision. Following the above process, the patient needs to decide on an anesthetic technique. A patient may decide that none of the techniques offered by the anesthesiologist is acceptable or may decide that he or she prefers a technique that the anesthesiologist does not consider acceptable. This brings forth the concept of informed refusal and whether an anesthesiologist must do whatever a patient wants. For example, consider a patient who is eight-hours postpartum and wishes to have general anesthesia for her tubal ligation. She hears about the risks and benefits for regional anesthesia, appears to understand them and chooses, as is her right, general anesthesia over regional anesthesia. Is the anesthesiologist obligated, then, to do the case?

The answer, for the most part, is no. In nonemergent situations, anesthesiologists are not ethically obligated to provide care that they believe is inappropriate. It would behoove the anesthesiologist to discuss his or her concerns with the patient, so as to help the patient understand the risks she would be taking. Indeed, in situations requiring informed refusal, the anesthesiologist should give additional information about the ramifications of the patient's choice. In the example cited above, this woman should be educated about a greater likelihood of difficulties with airway management and an increased risk of aspiration before accepting her preference for general anesthesia. Her reasons for preferring general anesthesia should be ascertained to see if they are based on fact or if the goals she prefers can be achieved in another way. For example, she may be frightened of a spinal headache because she incorrectly thinks that it always follows a spinal and does not resolve for a month. If she understood that spinal headaches occur less frequently, resolve more quickly and even are treatable, she may then choose a spinal anesthetic for her tubal ligation.
Autonomous authorization. The informed consent process concludes with the patient intentionally authorizing the anesthesiologist to perform a specific procedure. This authorization is the expression of the patient's self-determination and therefore is the basis of informed consent.

Some mistakenly hold that the elements of informed consent can never be fully achieved: no patient can ever be fully autonomous, fully informed or fully free from pressure. This incorrect thinking arises from an unrealistic belief that informed consent must be total. Anesthesiologists should disregard this impossible standard and prioritize the goal of achieving a substantial level of informed consent.

Other Issues
Same-day surgery and the preoperative evaluation clinic. Changes over the past few years have made the process of an anesthesiologist obtaining informed consent from a patient more problematic. One significant example is the growth of same-day surgery and the preoperative evaluation clinic. The anesthesiologist who performs the preoperative evaluation and obtains informed consent may not be the anesthesiologist providing anesthesia. A patient may not meet the anesthesiologist or undergo an informed consent discussion until minutes before the surgery, and a rushed atmosphere may render the process meaningless. Anesthesiologists need to be aware of these problems and take organizational, institutional and personal steps to decrease their impact on the informed consent process.

Emergency situations. The requirements for obtaining informed consent in emergency situations are less strict. Informed consent for emergency care is based on the assumption that patients want life-sustaining treatment. Anesthesiologists should provide as much information as is practical. In emergencies, anesthesiologists are for the most part expected to provide care for a patient whom they otherwise might have refused care on an elective basis.

Ethics consultation services. The process of obtaining informed consent can put the anesthesiologist in the difficult situation of recognizing that there is an ethical dilemma that he or she is unable to resolve. Institutional ethics committees and their consultation services provide experience and expertise in helping to resolve such dilemmas.

Summary. Anesthesiologists get informed consent; they do not give informed consent. By viewing informed consent through this prism, the anesthesiologist will remember that the locus of decision-making lies with the patient, and the process of obtaining informed consent is best driven by the desire to fully satisfy the patient’s needs.

ANOTATED BIBLIOGRAPHY

Informed Consent:

Reference #1 is an ASA guideline that provides the blueprint for ethical behavior for the anesthesiologist. References #2-#4 thoroughly cover the ethical and legal aspects of informed consent.

University Press; 1994.

Legal Aspects of Informed Consent:


Disclosure Issues:


Understanding of Informed Consent:


Production Pressure:

http://www.asahq.org/wlm/Ethics.html 10/20/03

**Informed Refusal:**

*The earlier references discuss the ethical issues of informed refusal; this reference discusses the legal aspect of it.*


**Cases Cited:**


**Case 1**

**A Standard Preoperative Discussion**

You are asked to provide a preoperative anesthetic evaluation for a 32-year-old man who is scheduled to have arthroscopy of the knee. He is otherwise healthy. The procedure can be performed under local anesthesia with sedation, regional anesthesia or general anesthesia.

1) How do you greet the patient? Do you have to tell him you are a resident?

2) The first thing the patient says is "I want to go to sleep for this, Doc." Can you restrict your discussion of anesthetic options to general anesthesia?

3) What do you need to tell him about each technique? How do you determine what you need to tell the patient? Give specific examples of a disclosure that meets reasonable person standards for local anesthesia with sedation, regional anesthesia and general anesthesia.

4) If a resident wants to do an epidural (for experience), can he or she talk the patient into it? What is the difference among persuasion, manipulation and coercion?

5) What do you need to write down? Why? Does documenting the informed consent discussion give legal protection?

6) How should the interview conclude?

**Case 1, Instructor's Notes**
1) Patients have a right to know to whom they are talking. An introduction should not only include a name, but also the physician's service, level (e.g., resident, attending), role, and if that person will be doing the anesthesia.

2) It is not necessarily in the patient's best interest for the anesthesiologist to readily acquiesce to a possibly uninformed request. An integral part of informed consent is that the patient make a knowledgeable decision. The patient may be requesting general anesthesia because of a lack of information. For example, the orthopedic surgeon may have told the patient that general anesthesia is better. Or, this patient may have had a relative who had a bad experience with regional anesthesia. It is worth probing these experiences and explaining to the patient why this situation may be different.

3) Anesthesiologists need to forthrightly offer the advantages and disadvantages of each technique. Some patients may be more frightened of a needlestick in the back than they would of some operative discomfort, and so they may prefer a local. Others may want no pain at all. What is important is to interact with the patient so you can help him determine the best technique for himself.

4) The resident can certainly mention the advantages of the epidural (as long as the disadvantages are also presented), but the resident should in no way misrepresent these advantages and disadvantages to manipulate the patient into accepting epidural anesthesia. Patients and their caregivers may not share the same values. As such, the patient should be the one to decide which values should predominate.

5) There are several purposes for institutional requirements for informed consent:
   a) It is a reminder to caregivers of the necessity to obtain informed consent (anesthesiologists should think in terms of "getting" informed consent rather than "giving" informed consent; the former puts the focus on the patient, the latter on the physician).
   b) It documents that a discussion did take place and that there was an exchange of information.
   c) It may prompt patients to ask questions, especially if they read a written document.

6) The interview should conclude with the patient authorizing the anesthesiologist to perform a specific anesthetic. Residents should understand that the absence of an objection is not equivalent to an authorization. Even non-verbal patients can signify authorization with hand or head motions.

Case 2

**Informed Refusal: General Anesthesia for a Cataract?**

A 68-year-old woman with severe chronic obstructive pulmonary disease wishes to have general anesthesia for cataract surgery. As her anesthesiologist, you feel that local anesthesia with sedation poses less risk than general anesthesia. She can lie flat comfortably for the time needed for this procedure.

1) Are you obligated to present the other options?

2) How would you present the risks of general anesthesia without manipulating her (i.e., scaring her) into accepting local anesthesia with sedation? Can you "push" the patient into accepting local anesthesia with sedation?
3) If the patient continues to prefer general anesthesia, must you provide it for her? Is it coercive to tell her that she may need to return on a different day for a different anesthesiologist if she desires general anesthesia?

4) May you give her intravenous sedation so she "calms down" and is more willing to accept local anesthesia with sedation?

Case 2, Instructor's Notes

1) Yes, you are obligated to present the other anesthetic options. In fact, part of the concept of informed refusal is the idea that a patient should have substantial knowledge about a technique before rejecting it. Therefore, it is appropriate and necessary for the anesthesiologist to educate the patient about the risks and benefits of both general anesthesia and local anesthesia with sedation; otherwise, she would not be making an informed choice. Persuasion is a justifiable technique for educating patients. Coercion is not. Properly informing this woman about options may help her consider a technique previously rejected out of misinformation. Indeed, the anesthesiologist should try to determine why the patient prefers general anesthesia and specifically address her fears while reassuring her about the safety and comfort of local anesthesia with sedation. The patient may still prefer general anesthesia for her cataract operation after the anesthesiologist has attempted to make her fully informed. This is the concept of informed refusal.

2) This is indeed a difficult question. Frightening a patient into accepting local anesthesia with sedation is neither ethically nor medically appropriate. On the other hand, the anesthesiologist has an obligation to forthrightly inform the patient. The anesthesiologist must then, in a calm manner, inform the patient factually why local anesthesia may be safer than general anesthesia. For example, the anesthesiologist could say, "I am not saying that general anesthesia is unsafe. In my opinion, however, it does give you a higher likelihood of having postoperative trouble. With your COPD, I am concerned that you might have some difficulty with your breathing after I remove the breathing tube from you. So, obviously, if I can avoid putting a breathing tube in you, I think you could avoid having complications related to a breathing tube, such as ."

3) In nonemergent circumstances, physicians are not obligated to provide care that they feel is not in their patients' best interest. This fundamentally arises from the ethical tenet "First, do no harm." But, clinicians should be reticent to make this claim and should only do so in the truest of circumstances. This right to refuse to provide care is ripe for abuse because physicians can easily use this virtuous claim as a pretense not to provide care.

4) This brings forth a distinction between the appropriate use of sedation to calm an anxious-but-willing patient and the inappropriate use of sedation to manipulate a patient's decision-making. If she desired local anesthesia with sedation, but she requests to be "fortified" with sedation, that is appropriate. Part of anesthetic care is providing anxiolysis. But sedating a competent patient in order to reverse a previous decision is wholly unethical.

Case 3
**Your Informed Consent Process**

Each department may have its unique system difficulties in the process of obtaining informed consent. Residents should evaluate their system and propose methods of improvement.

1) What system problems are currently present? How do these problems affect patient care and the obtaining of informed consent?

2) What are potential solutions?

3) What is production pressure? What are sources of production pressure? Does your current system reflect the impact of production pressure?

4) How can production pressure affect the ability and desire to enact potential solutions?

**Case 3, Instructor's Notes**

1) Problems may include:

a) In the preoperative anesthetic clinic, the person obtaining informed consent does not administer the anesthetic.
   - no opportunity to develop relationship
   - inability to finalize anesthetic plans until the day of surgery
   - patient confusion over who is caregiver

b) Obtaining informed consent the day of surgery may limit the value of the discussion.
   - no opportunity for the patient to think about anesthetic options
   - no opportunity to minimize anxiety about anesthesia
   - the requirement to obtain informed consent from a patient who may be anxious about the surgery and therefore distracted
   - pressure to rush the informed consent process to minimize delays in the operating room schedule
   - limited value of informed consent discussion (e.g., patient has already made all arrangements and the informed consent discussion has become a formality)

2) Potential solutions may include:

a) The anesthesiologist can have a telephone discussion with the patient the night before surgery.

b) Preoperative discussions and other care can be better coordinated for the more complex patients.

3, 4) Production pressure is "the internal or external pressure on the anesthetist to keep the operating room schedule moving along " (Gaba, Fish and Howard, 1994). Production pressures may cause anesthesiologists to deliberately "cut corners" or to make unintentional errors out of haste. Internal pressures include the desires to avoid delaying surgery, avoid litigation, get along with surgeons and
work when fatigued. External pressures include exhortations from surgeons to proceed with cases instead of canceling them, hasten anesthetic procedures and alter usual techniques. Anesthesiologists may feel pressure from administrators to reduce turnover time and limit the use of expensive drugs. External pressure may also come from colleagues, consultants and the patients and their families (Gaba, Howard and Jump, 1994).

"No one sets out to create a system that poses undue risks [n]onetheless, in the absence of frequent overt negative outcomes, safety concerns may be eroded by the other increasing pressures. We are concerned that to appear competitive, to attract patients or to negotiate agreements with surgeons and managed care organizations, both hospitals and anesthesiologists may be tempted to make excessive claims of productivity, cost efficiency and safety that cannot be met realistically. In an era of pro-gressively greater constraints on costs of care and growing intensity of competition, there will be increased pressure to increase production at the expense of safety." (Gaba, Howard and Jump, 1994)

Special Teaching Technique

Role-playing

Residents may better understand the informed consent process by role-playing specific problems. The resident assigned as the patient is given the scenario, and the resident assigned as the physician is given a bullet (e.g., 40-year-old male for anterior cruciate reconstruction) and conducts a preoperative interview. The other residents critique the interview at its conclusion. Another option is to have all the residents pair off in groups of four, with two residents role-playing and two residents offering suggestions back and forth.

Scenarios:
1) A healthy but belligerent 40-year-old who will be having an anterior cruciate reconstruction tells you, "I'll talk to you now, but I want an attending to do my anesthesia." You are in a teaching institution and attendings rarely if ever directly administer anesthesia care. (Consider the differences in this case if the hospital were a small community hospital or a large VA hospital, or if the surgery were more complex or even life-threatening.)

2) You are called to the emergency room to preoperatively evaluate a 90-year-old woman with acute peripheral vascular occlusion. The surgeon says she will lose her leg if they do not operate immediately. She has decided she doesn't want the procedure. However, all her family members do want her to get the procedure and have told the surgeon to proceed. The surgeon has agreed to proceed. (A third and fourth student can play a family member and surgeon, respectively.)

3) A 55-year-old ASA III for suprarenal aortic aneurysm repair does not want to hear about the anesthesia. He repeats over and over, "Do what you need to do." When you bring up an epidural for postoperative pain relief, he says, "Look, I don't care. I'd really rather watch the football game," and he turns to the television.

4) A 35-year-old woman presents for laparos-copy for infertility. She has been waiting a long time for this procedure, and it took quite a bit of juggling to make all the proper arrangements. Unfortunately, she has come down with a severe cold, including wheezing on auscultation of the lungs and a productive cough with yellow sputum. She tells you she wants to go through with the procedure "no matter what." (Consider changing the case by giving the patient a more or less severe upper respiratory infection or by varying how long the patient must wait until being able to reschedule the procedure.)
WHO SPEAKS FOR THE PATIENT?

Ethical Principles in Assessing Patient Competence and Appropriate Use of Proxy Decision-Makers in the Practice of Anesthesiology

Why Do We Need Proxy Decision-Making? Respect for patient autonomy requires that competent adults be allowed to determine what happens to them. In the 1960s and 1970s, concern arose that increasingly expensive and invasive medical therapies might not be accomplishing ends consistent with the personal goals and values of the patients they served. Issues of medical futility were raised with regard to certain interventions such as cardiopulmonary resuscitation, which in many medical settings had been proven essentially futile, as well as other interventions such as chemotherapy, which were perceived in some circumstances to be cruel.

Active patient participation in decisions about their medical care is paramount because of the ethical principle of respect for patient autonomy as well as the legal requirement for informed consent. When patients are unable to participate fully in the informed consent process, ethical principles and legal precedents have established that their wishes can be carried out through the actions of proxy decision-makers.

The case of Joseph Saikewicz. Joseph was a 67-year-old institutionalized man with an estimated IQ of 10 and a mental age of about two and a half years. He communicated with gestures and grunts and responded only to gestures or physical contact. He appeared disoriented in unfamiliar physical surroundings and did not appear aware of common dangers. In 1976, he was diagnosed as having acute myelogenous leukemia. In about 30 percent to 50 percent of cases of this type of leukemia, chemotherapy brought about a temporary remission, usually lasting two to 13 months. Results were poorer for those over age 60. Belchertown State School petitioned the court to appoint a guardian to make the decisions about his care and treatment. The court-appointed guardian found that Joseph's disease was incurable, that chemotherapy had significant adverse affects and discomfort, and that the patient could not understand the treatment or its resulting pain. It was concluded that not treating Joseph "would be in his best interests." The Supreme Court of Massachusetts upheld the decision. Joseph died five months after diagnosis (Beauchamp and Childress, 1994).

The matter of Karen Ann Quinlan. In April, 1975, the then 22-year-old Karen was brought to the hospital in a coma of unexplained etiology and from which she never recovered. After several months, her parents requested that she be removed from mechanical ventilation. They did this after consultation with their church and with church support in the assertion that the ventilator constituted extraordinary support, and that to return her to her "natural state," even if it resulted in death, was morally correct. The hospital refused.

By any criteria, Karen was not brain-dead, and disconnecting her from the ventilator violated the medical ethics edict to "do no harm." The Quinlans petitioned the Superior Court of New Jersey for Karen's father to be appointed guardian for the express purpose of removing her from the ventilator. The petition was refused, and the Quinlans appealed to the State Supreme Court. The court returned a verdict in March 1976 in favor of the Quinlans. The doctors, however, refused to disconnect her from the ventilator, and after two months, Karen was weaned from the ventilator and transferred to another facility. She survived another nine years.

Paul Armstrong, attorney for the Quinlan family, based his arguments in the decision of the U.S.
Supreme Court in 1965 in *Griswold v. Connecticut* (guaranteeing the right of access to contraception) and *Roe v. Wade*. Evidence was presented that the Quinlans were merely trying to carry out the actions Karen would have wanted but was no longer able to express. The doctors argued that courts have no business interfering with physicians' medical judgments. The court decision included several interesting points. While doctors argued that medical values and judgment should be determinative, the court asserted that "judges should not be prevented from deciding matters clearly justifiable, nor preclude a re-examination by the Court as to underlying human values and rights."

To the argument that judges lacked the expertise to overrule a professional decision based on prevailing medical practice and standards, the court asserted, in essence, that what doctors said in court and what they did in practice were two different things. The court questioned whether there was, indeed, an internal consistency to the decisions of doctors. The court pointed out that there was a "widening ambiguity" to the actions of physicians in not providing advanced life support or resuscitation to the hopelessly ill. The court accused doctors of using "judicious neglect" by writing "in pencil on a patient's chart the foreboding initials DNR." While doctors distinguished between sins of omission and sins of commission, the court found that "the thread of logic in such distinctions may be elusive to the nonmedical mind," because the end was the same -- the patient died.

Finally, the court accused doctors of being un-willing in Karen Ann Quinlan's case to do what they did as a matter of course in other cases because of fear of malpractice suits or criminal prosecution. Doctors, in other words, were accused of acting out of self-interest and not in the interests of their patients. The court took as its duty to "find a way to free physicians, in the pursuit of their healing vocation, from possible contamination by self-interest or self-protection."

**Assumptions Behind Proxy Decision-making.** Historically, proxy decision-making was based on three assumptions:

1) That the incompetent patient's right to refuse medical care may be exercised through a proxy decision-maker.

2) That, knowing the patient's wishes, the proxy will make the decision that the incompetent patient would make if competent. The proxy decision-maker would "don the mantle," of the patient (so-called substituted judgment).

3) That, in the absence of proxy decision-makers, doctors might act less out of interest for the patient then out of self-interest to avoid litigation.

The proxy decision-maker often would be a family member who would be best acquainted with the patient's values and views of medical care and the entire life "context" of the patient. Further, the family has a unique attachment to the patient, and the family is more likely to "treat the patient as a person, rather than a symbol of a cause." (Emanuel and Emanuel, 1992)

**Objections to Proxy Decision-making.**

1) In the absence of specific directions, the proxy decision is at best an approximation of the patient's wishes.

2) The interpretation of the proxy decision-maker is subject to the biases, values and psychological agendas of the person making the decision.

3) Incompetent patients can be both emotional and financial burdens, and proxy decision-makers may have a potential conflict of interest that can distort their beliefs and testimony about what the patient would have wanted.

4) Making life or death decision for someone is psychologically stressful; surveys show that people are more hesitant to terminate care for relatives than for themselves.
Research on proxy decision-making shows that proxies and patients infrequently discuss issues and values surrounding the use and withdrawal of life-sustaining technologies. Moreover, the majority of patients say they have not discussed their preferences regarding cardiopulmonary resuscitation with a family member or physician (table 1).

**TABLE 1: Percents of Patients Having Prior Discussions With Families and Doctors About Life-Sustaining Interventions**

<table>
<thead>
<tr>
<th>Discussed with Family</th>
<th>Discussed with Doctors Number of Subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>16% 7% 705</td>
<td>45% 11% 756</td>
</tr>
<tr>
<td>55% 6% 1529</td>
<td>NA 23% 1198</td>
</tr>
</tbody>
</table>

Research indicates that family members are unreliable at assessing a patient's quality of life. Epstein found "highly significant" discrepancies between patients and proxies in the assessment of the patients' emotional health and satisfaction (Epstein and others, 1989). Finally, studies have shown that proxies cannot accurately predict patients' preferences for life-sustaining interventions (table 2).

**TABLE 2: Agreement Between Patient and Proxy About the Use of CPR**

<table>
<thead>
<tr>
<th>Patients' Medical Condition</th>
<th>Percent Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kappa Statistic</td>
<td></td>
</tr>
<tr>
<td>Number of Pairs</td>
<td></td>
</tr>
<tr>
<td>Currently healthy</td>
<td>88% 0.30 575</td>
</tr>
<tr>
<td>Dementia</td>
<td>68% 0.27 575</td>
</tr>
<tr>
<td>Currently healthy</td>
<td>90% 0.35 908</td>
</tr>
<tr>
<td>Incapacitating stroke</td>
<td>53% 0.08 908</td>
</tr>
</tbody>
</table>

**Mechanisms for Proxy Decision-making.**
1) Living will (advance directive): A competent patient's statement of his or her wishes for end-of-life care, executed in front of qualified witnesses.

2) Durable power of attorney: A mechanism for the competent patient to designate a proxy decision-maker should the patient become incompetent. This is designed to follow the principle of substituted judgment.

3) Legal hierarchy: Most states have a hierarchy through which a legal surrogate is assigned if one has not been designated by the patient. In Washington state, for example, the hierarchy in descending order is as follows:
- Legal Guardian
- Recipient of Durable Power of Attorney
- Spouse
- Adult Children (provided that their decision is unanimous)
- Parents
- Siblings (provided that their decision is unanimous)

_We strongly suggest that you become familiar with the law in the state in which you practice._

**Medical Decisions Which a Surrogate May NOT Make.** The laws vary from state to state, but certain therapies may NOT be agreed to by any surrogate and can only be carried out under court order if the patient is incompetent to consent. In Washington state, for example, psychotherapy and electroconvulsive therapy cannot be consented to by a surrogate. In Massachusetts, sterilization of a minor or mentally handicapped person requires a court order and cannot be carried out with parental consent alone.

_Don't Forget the Role of the Anesthesiologist!_ Courts have found anesthesiologists liable for harm that comes to the patient while under anesthetia. Anesthesiologists have been held responsible if unwanted medical therapies are performed on the unconscious patient.

**When Is a Patient Unable to Make Decisions About Therapy?**

1) The patient is unconscious and will not regain consciousness before a medical decision must be made. Decisions involving patient competency should be weighed against the urgency of the treatment under consideration.

2) The patient is conscious but legally incompetent. If the patient is suspected to be incompetent but has not been so declared by a judge, the anesthesiologist needs to seek appropriate help to make such a determination.

3) The patient is conscious but immature. The patient may be either too young or too immature to formulate and express preferences, to understand implications of therapy and disease or to place decisions in perspective (see _Special Issues in the Care of Children_, page C-1).

**Assessing Patient Competence.** Situations in which patients are actually adjudged to be unable to make medical decisions for themselves are very limited, but situations in which doctors have serious concerns about the abilities of patients to make decisions are a common occurrence. Anesthesiologists are called upon to assess the capabilities of their patients to make medical decisions under suboptimal circumstances: the preoperative anesthetic assessment of a patient often takes place only moments before surgery or in a noisy and hectic environment (such as in the active throes of labor) with the physician and patient coming together as virtual, if not actual, strangers. The preoperative interaction may be further handicapped by the anxieties of the patient and physician, by the effects of preoperative medications and by impediments to communications such as language differences or physical impairments of communication. The situation may be further compounded by the urgent need for
surgery. In the setting of the intensive care unit, actions such as the withdrawal of ventilator support -- or even the termination of nutritional support -- can lead us to ask basic questions about the moral and ethical foundations of what we do as well as about who can and should make such soul-wrenching decisions on behalf of patients who can no longer decide or express their decisions for themselves.

When questions arise about a patient's ability to make medical decisions, what can the anesthesiologist do to clarify whether the patient can act as his or her own decision-maker or whether a surrogate decision-maker should provide informed consent?

A patient can be competent to do certain tasks but not others. Different tasks require different competencies. A patient who may be confused about what day of the week it is, for example, may nevertheless possess the skills needed to consent to medical care.

In general, tests of competency to consent to care require that the patient be able to understand the nature of the condition requiring treatment, the proposed treatment, the likely risks and benefits of the treatment, available alternative therapies and the necessity that a decision be made. The patient is not held to a level of understanding approaching expertise but should be able to understand to the degree that it affects their quality of life. Decisions made by patients in opposition to established medical advice do NOT constitute proof of incompetence! Decisions made in the face of unusual belief systems, if consistent, do NOT constitute proof of mental illness!

Mr. A, a 60-year-old man with severe peripheral vascular disease, presents for placement of a jejunostomy feeding tube because of inability to eat following a below-the-knee amputation. He has had multiple cerebrovascular accidents with right hemiparesis and expressive aphasia. Because of difficulty swallowing, he has problems with chronic aspiration and has been hospitalized multiple times for treatment of pneumonia. During the current hospital admission, he has refused medications and has "given up" trying to eat. He indicates with difficulty that he "only wants to die." He refuses to discuss anesthesia, beyond saying that he does not want surgery and wants to die. Is he competent to refuse therapy?

In studies of hospitalized patients referred to psychiatric consultation for independent evaluations of competency to give informed consent or to refuse medical therapy, patients like Mr. A were far more likely to be referred for evaluation of competence because of refusal to accept medical therapy than because of other evidence of impaired mental capacity. Refusal of therapy or diagnostic procedures or threats to leave against medical advice constituted up to 70 percent of such referrals (Weinstock and others, 1984). Yet, of patients refusing therapy who were formally evaluated, only about half were found to be incompetent. Patients were more likely to be found incompetent if they were trying to terminate care against medical advice or carried the diagnosis of organic brain syndrome or chronic alcohol abuse. Patients with psychiatric diagnoses such as depression or schizophrenia, or patients who were refusing only some part of medical therapy or diagnostic procedures were unlikely to be found incompetent to make medical decisions.

Patients who agreed to therapy represented a smaller percentage of referrals for competency evaluations (17 percent versus 26 percent) than patients who refused treatment, and they were more likely, if evaluated, to be judged competent (57 percent versus 100 percent) (see Competence in annotated bibliography).

While this finding may reflect an actual association of consent for care with competence, the authors speculated that refusal of therapy is merely more likely to trigger suspicion by physicians that patients are incompetent, reflecting a bias against patients who refuse medical care. Such suspicion could represent a reflection of anger or frustration on the part of physicians struggling to care for difficult
patients and also raises concerns that physicians judge the competency of patients to make decisions based on their perception of the quality of the decisions the patients make.

There are two problems with this approach. First, any judgment about the quality of patient decision-making interjects the physician's biases, personal values and perceptions about quality of life above those of the patient, effectively usurping patient autonomy. Second, such judgments entail a false assumption that all competent decisions are necessarily "good" decisions. Respect for patient autonomy requires a difficult surrender to the precept that competent patients, once informed, have a right to make their own decisions, even if they are "bad" decisions. If physicians are allowed to intervene whenever they disagree with a patient's choice, doctors will once again assume a paternal role with their patients, one that has been consistently rejected in favor of the moral as well as legal rights of patients to behave independently and determine for themselves what will be done to them.

In summary, evaluation of the need for a proxy decision-maker in a conscious patient rests in determining if the patient is able to receive and understand information necessary to make a decision about medical care. Psychiatric evaluation may be helpful when it is not obvious that the patient has the necessary skills. The patient's decision itself, whether it is to proceed with or to forego medical care, should not be the determining factor in referring a patient for psychiatric evaluation or in a finding of incompetence.

Patients with mental impairments are likely to be competent to make medical decisions, whether the impairment is dementia, mental illness or mental retardation. Characteristics associated with incompetence include chronic alcohol abuse and diagnosis of organic brain syndrome. Psychiatric diagnoses are unlikely to be associated with an inability to give informed consent or informed refusal. Finally, consent to medical care should not be taken as evidence of competence to make medical decisions in a patient who is otherwise obviously impaired.

**Assessing Surrogate Competence.** "Health care professionals remain moral agents, with a responsibility to safeguard the patient's interests and preferences (where known) by monitoring the quality of surrogate decision-making" (Beauchamp and Childress, 1994). Family conflicts of interest that threaten a patient's previous wishes, as well as proxy incompetence, inadequate information or emotional instability, all may disqualify even a close family member from acting as a surrogate decision-maker.

**When Might Competence Be Questionable in a Conscious Patient?**

*Can laboring women give informed consent?* Arguments have been given that laboring women are not competent to make decisions because pain obscures their ability to hear and understand the risks and benefits of procedures. Courts have used cooperation for epidural placement in the face of pain as an indicator of the ability to set aside physical discomfort to accomplish a goal and as an implied acceptance of the procedure and risks. While it has been shown in multiple studies and settings that many patients, including laboring women, have little memory of the informed consent process, this lack of memory to the obtaining of consent has not generally been an accepted argument that consent was not obtained. Proxy decision-makers are appropriate only when laboring women show other signs of not being competent to make decisions, such as a past history of mental incompetence, severe mental illness, obvious organic brain syndromes such as encephalopathy associated with pregnancy-induced hypertension, or unconsciousness.

*Is the premedicated patient incompetent?* Premedicated patients are not automatically incompetent. A patient who is in pain, for example, may be more able to listen to a risk discussion once the pain is treated. The patient may actually regain competency as a result of medication. Patient competence is judged by the nature and quality of the discussion that occurs, irrespective of whether or not the patient
has been given medication.

Withholding pain medication from a patient who is in acute distress for the purpose of obtaining consent is not only potentially cruel but also may coerce the patient to consent to unwanted care in order to get relief of pain. To quote Stanley Rosenbaum, Professor of Anesthesiology, Medicine and Surgery at Yale University, "Any will can be broken if you torture it long enough." Coercion "entirely compromises autonomy." (Beauchamp and Childress, 1994) Informed consent obtained under such circumstances may be suspect, both from the issues of competency and voluntariness.

Competence should be at least questioned in a somnolent patient or one who is obviously hallucinating.

*Are mentally ill patients incompetent to consent?* Mentally ill patients are not incompetent to make many decisions, unless extremely incapacitated. Depression, unless incapacitating or leading to hallucinations, does not constitute incompetence. Even schizophrenia and other severe mental disorders do not automatically disqualify a patient from making a competent decision. When patients' decisions differ from those of their physicians, it is important not to make the assumption of incompetence. However, professional consultation may be needed to separate issues of patient competency from eccentricity.

*Are mentally retarded patients incompetent?* Competence is highly individual and depends less on absolute IQ than on relative maturity. A patient can have a low IQ, yet still be able to understand and express preferences for medical care.

*What about demented patients?* Competence can wax and wane. Patients can suffer from dementia that impairs memory, for example, but not understanding.

*What about the patient with difficulties communicating?* It is important to sort out whether patients suffer from problems with understanding and reasoning or are merely impaired in their ability to express preferences. Patients who are not fluent in the language of the doctor, or are deaf or suffer from various forms of expressive aphasia are not, therefore, incompetent, even though they may have difficulty expressing themselves. Interpreters, written information and speech and rehabilitation specialists may be of help in particular circumstances. Family members and friends may have a great deal of experience in working with the patient's particular communication problem and are an important resource.

**ANNOTATED BIBLIOGRAPHY**

**Informed Consent:**
   *Beauchamp and Childress have provided a pre-eminent reference for professionals whose roles involve ethical issues in biology and medicine. The text provides understandable explanations of basic biomedical ethical principles and their philosophical foundations. The text is supported by liberal use of historic case illustrations and contains summaries of the cases discussed in this paper. This book is required reading for anyone involved in clinical ethical issues.*

   *This textbook presents a well referenced discussion of clinical ethical dilemmas and a review of basic principles in biomedical ethics as they apply to specific cases. The text is relatively short, and is arranged to provide easy access to pertinent reference material relevant to a given scenario. The case-based approach is easy to understand, and the concepts are presented in an interesting fashion. An excellent basic text for clinicians.*
In this book, Rothman presents a sociologist's narrative of the factors that have affected medical decision-making and medical ethics in the last five decades. This book is a thought-provoking review of the changing doctor-patient and doctor-society relationships. It provides insight about the ethical obligations doctors have toward their patients.

CPR and Medical Futility:
The following set of articles describe the early use of cardiopulmonary resuscitation and the subsequent concerns that it was being inappropriately used in situations which might be deemed medically futile.


Proxy Decision-making:
Reference #1 is an excellent review of the historical and ethical foundations of proxy decision-making. References #2-4 discuss the issues relating to proxy decision-making. References #5-9 examine the correlation of patient's perceptions and decisions with those of proxy decision-makers.


Competence:
References #1, #7 and #9 provide summaries of the issues in assessing competence in impaired patients. References #2, #5 and #8 examine the demography of consults sought in the hospital setting to assess patient com-petence.


http://www.asahq.org/wlm/Ethics.html

10/20/03

Informed Consent for Labor Analgesia:

Miscellaneous and Cited Cases:
An excellent and thoughtful article that connects language and perception with clinical practice. Recommended reading.

An excellent article that outlines a clinically relevant way in which an ethical problem can be organized for discussion. Highly recommended as a teaching and communication tool.


Case 1

Refusing Care

Mr. A, a 60-year-old man with severe peripheral vascular disease, presents for placement of a jejunostomy feeding tube because of inability to eat following a below-the-knee amputation. As a result of multiple cerebrovascular accidents, he has a right hemiparesis and an expressive aphasia. Because of difficulty swallowing, he has problems with chronic aspiration and has been hospitalized multiple times for treatment of pneumonia. During the current hospital admission, he has refused medications and has "given up" trying to eat. He indicates with difficulty that he "only wants to die." He refuses to discuss anesthesia, beyond saying that he does not want surgery and wants to die. Is he competent to refuse therapy?
This case is also designed to illustrate the four questions approach of analyzing an ethical dilemma discussed in Implementation of an Ethics Curriculum: Getting Started, page 1.

1) Use a systematic approach to evaluate and discuss the clinical ethical problems presented in this case.

a) What are the medical indications, risks, benefits and alternatives to the placement of a jejunostomy tube to provide nutrition?
b) What are the quality of life expectations from the alternative choices?
c) What are the patient's preferences?
d) Are there any contextual features that should be considered?

2) What features distinguish competent from incompetent patients? What are resources available to an anesthesiologist to aid in the evaluation of patient competency?

Case 1, Instructor's Notes

I. The Four Questions
In order to discuss the issues in a clinical ethical problem, whether it be in the setting of a learning discussion or in the clinical setting in which the problem must actually be solved, it is important to be able to outline the features of the case in an organized and coherent fashion. Just as clinical progress notes often follow a common format, so should ethical case discussion. In clinical progress notes, we might organize our communication of the issues along a "SOAP" format: Subjective (what the patient tells us), Objective (what we observe in terms of behavior and physical exam), Assessment (how we interpret the subjective and objective information that we have gathered) and Plan (what we intend to do). Jonsen has proposed a method of expressing the features of a clinical ethics case into four categories that will help us to organize and evaluate the problem (Jonsen, 1990). The four categories correspond roughly to the major principles in biomedical ethics: beneficence (the principle of doing good), nonmaleficence (the principle of avoiding harm), respect for patient autonomy (the principle that competent people can decide for themselves what will be done to them) and justice (the principle that people should be treated fairly with regard to what resources are owed to them). The four categories proposed by Jonsen can be expressed in the form of four questions each student should answer about the case under discussion:

1. What are the medical indications, risks and benefits, and alternatives of the treatment being proposed? (Illustrating the principles of beneficence and nonmaleficence from the medical point of view.)

2. What are the quality of life expectations from the alternative choices? (Illustrating the principles of beneficence and nonmaleficence from the point of view of the patient's values.)

3. What are the patient's preferences? (Illustrating the principle of respect for patient autonomy.)

4. Are there any contextual features that should be considered? (Illustrating consideration of the principles of justice.)

Question 1) Medical indications. The medical indications for the proposed procedure are to provide nutrition for the patient, in whom inability to eat combined with complications of attempts at oral nutrition have lead to a search for alternative methods of alimentation. Alternative methods of dealing
with the nutritional issues include:
1) continued attempts at oral nutrition
2) placement of a feeding tube into the jejunum by oral or nasal route
3) gastrostomy
4) jejunostomy
5) hyperalimentation via central venous access

Each has advantages and disadvantages. Continued attempts to use the oral route of nutrition had failed and had the disadvantage of predisposing to the complication of aspiration in this patient. Oral feeding involves "hard work" on the part of the patient, which may be exhausting and discouraging, contributing to depression and the patient's desire to "give up." Feeding tubes by oral or nasal routes have some physical discomfort associated with them and may carry the complication of nasal erosion. In addition, they are visible, and as such may present unacceptable characteristics to patients. Gastrostomy or jejunostomy (with or without feeding tubes) have the disadvantage of being invasive, requiring a surgical procedure with potential complications of anesthesia and surgery, however unlikely they might be. But alimentation is simplified, utilizes the patient's GI tract for nutrition and may be more aesthetic to the patient than a nasogastric tube. Hyperalimentation requires central venous access, with potential complications, and more specialized care in the use of nutritional materials. In addition, nutritional supplies are expensive.

Question 2) Quality of life. Some aspects of the patient's quality of life may improve with better nutritional access. Better access may decrease the number of episodes of aspiration and subsequent hospitalizations for I.V. antibiotics. Better nutrition may provide more energy, ability to fight infection and ability to respond to physical therapy. The patient may feel less depressed and hopeless. Improved nutrition is almost certain to improve this patient's sense of physical well-being and to promote improved survival. Failure to provide adequate nutrition is likely to contribute to the patient's inability to fight infection, lack of energy, listlessness and depression.

Prolongation of this patient's life may or may not be a net benefit to the patient, depending on how he views his potential "best case scenario." It is possible that this patient's functional level is so poor that he sees prolongation of his life as unwanted further suffering.

Question 3) Patient preferences. The patient states that he does not want surgery and wants to die. The right of a competent adult to make such a decision is supported by both ethical principles respecting autonomy and legal precedents stating that "every person of adult years and sound mind has the right to determine what shall be done to them." (Schoendorff v. New York Hospital)

When considering patient statements of their preferences, we have an obligation to patients to facilitate and support their ability to make independent and unencumbered decisions. Is this patient's ability to decide affected by correctable encumbrances? One example of an encumbrance is inadequate information: has the patient had a reasonable opportunity to hear the advantages and disadvantages to the proposed treatment? One study showed that doctors were far less likely to try to discuss end-of-life decisions directly with the patient if the patient was felt to suffer from mental impairment (Uhlmann and others, 1988). Many patients with mild forms of mental impairment are perfectly capable of participating in medical decisions.

Another potential encumbrance for this patient is a physical impairment in the ability to express himself. Patients with expressive aphasia often suffer from some receptive aphasia as well. Are there ways in which we can better determine whether the patient is being given an adequate opportunity to understand and then express his wishes? Is the patient suffering from dementia or other organic brain problems that might call into question his competence to make decisions?
Finally, is the patient depressed, and if so, is depression preventing him from making an unencumbered decision? The mere presence of depression itself does NOT imply incompetence.

What other resources can we use to evaluate the ability of this patient to make decisions? We can ask experts, such as rehabilitation specialists, to help us evaluate the patient's ability to understand options and express decisions. Psychiatric evaluation may help clarify the extent of depression and whether or not it impairs decision-making. Family and friends may be able to tell us if the decision to forego care is consistent with past decisions and whether it is in general agreement with the philosophical context of the patient's life. A primary care doctor may be able to tell us if he or she has had discussions in the past with the patient about care and what the patient's approach has been. A review of past medical records may reveal a previous ex-pression of the patient's wishes regarding medical care and support toward the end of life. In short, many resources exist to help us determine if the patient's decision appears autonomous and consistent with past decisions.

**Question 4) Contextual features.** Contextual features can include any features that might in-fluence the "flavor" of the case.

Legal aspects of such a case may influence a physician's decision. As the court suspected in the case of Karen Ann Quinlan, doctors do in fact base some decisions on fear of litigation and self-interest. It is important to note that self-interest is not an ethical principle and cannot be used to ethically justify an act.

Are medical resources being used fairly? Should expensive care be allotted to a patient who does not wish to live under these conditions?

Are family members exerting influence? Family members may, out of a sense of guilt or helplessness, exert pressure to ignore a patient's wishes to be allowed to die. Alternatively, family members may suffer from conscious or unconscious motivations to support a death-wish.

Are the physicians and other caregivers subject to subconscious motives? Physicians who are overly reluctant to accept a patient's decision may be imposing their own values and anxieties on the patient, including fear of professional failure. Physicians who are overly anxious to accept the patient's decision without determin-ing that it is unencumbered may be responding to suffering that they themselves experience in caring for an ungrateful patient.

Do financial considerations have undue weight in the patient's decision? If the patient is afraid of impoverishing family resources, they may be pressured to relinquish medical options.

Many kinds of "outside" influences may appropriately or inappropriately affect the way in which we respond to a patient's wishes.

**II. Case Development**

Once the initial outline of the case has been carried out, we can now "develop" the case to include specific educational points. Using the syllabus as a resource for answers, a model case development might include the following questions:

*Is Mr. A competent to refuse therapy?*

1) Are there features of the case presentation that suggest problems with Mr. A's competency?
2) What evidence in the case presentation do you have to support his competency?
3) What are the features of "competency?"
4) What does Mr. A's refusal of medical care indicate about his competency?
5) Suppose, instead of multiple cerebrovascular accidents, Mr. A suffered from schizophrenia? Is he more or less likely to be found competent by an expert consultant?

Mr. A's wife appears tearful and confused about the medical issues. She is unwilling to sign a consent form for the surgery, saying that she does not want to go "against" her husband's wishes. His daughter, on the other hand, insists that surgery proceed and, at the request of the surgeon, has signed a consent form. The surgeon reports to you that he or she has obtained a valid consent for the procedure and demands that you proceed.

1) Is the daughter's consent legally valid?
2) What is the legal order of surrogacy in your state?
3) What is the likelihood that Mrs. A has had a direct discussion of these care issues with Mr. A?

You decide not to proceed until the issues are clarified, and you request a competency evaluation for the patient. The consultant returns the opinion that the patient is probably not competent, based on the presence of severe impairment from organic brain disease and both receptive and expressive aphasia. The daughter insists that surgery proceed, and the wife still refuses to sign the consent. Both present conflicting perspectives on "what the patient would want." The surgeon wonders why you are holding up the surgery, since you now know the patient is likely incompetent and the surgeon has a signed consent from a surrogate. What should you do?

It is not uncommon for family members to be in conflict with one another about what should be done in an incompetent patient's medical care. Resources to remember include family counseling, the hospital ethics advisory committee and even the court system, which may go so far as to appoint a guardian ad litem to determine the patient's best interests.

The rest of the story

This case represents a real scenario from clinical practice. The case was halted until a competency evaluation could take place. In fact, problems with communication proved to be the major obstruction to discussion with the patient. With patience and some help from rehabilitation specialists, the patient ultimately agreed to have surgery. His depression has improved.

Case 2

A Change of Surgical Plans

Mrs. C, a 28-year-old Chinese woman who immigrated to the United States at age 25, presents for laparotomy and lysis of adhesions for intermittent pelvic pain. She is otherwise healthy. During preoperative discussion, her language skills appear more than adequate to understand the procedure, risks and potential benefits. Her husband has accompanied her to the hospital, but did not come to the surgery holding area. Her surgeon is native Chinese and is known to take care of many members of the local Asian community. He is being assisted in the surgery by another gynecologist.

During laparotomy, one severely adhered fallopian tube is damaged during attempts to remove the adhesions and is removed. The other fallopian tube appears severely scarred from previous infection. In addition, the patient is found to have several large uterine fibroids. The gynecologist announces his intention to proceed with hysterectomy, on the assumption that the fibroids are the cause of the patient's
postponement of treatment may lead to the patient's death. In the interest of benefiting the patient medically while still respecting her autonomy, it seems appropriate to ask for surrogate consent in the latter case, but not in the former.

*The surgeon returns after a discussion with the husband, in which the husband has consented for hysterectomy. Should you proceed?* Ethical principles behind obtaining consent demand that we support the patient's ability to be informed and to decide what will be done to them. Surrogate consent is no different in principle and is an appropriate substitute for the patient's consent only when the principle of respect for patient autonomy cannot be carried out in a safe manner without it. Since informed consent can be obtained from this patient if we allow her the time to regain consciousness, principles for respect for her autonomy require us to do our best to facilitate her return to consciousness.

*Despite your objection, the surgeon leaves to scrub in order to proceed with hysterectomy. Is there anything you should do?* Anesthesiologists have been held legally liable for injuries done to patients while under general anesthesia. In legal principles, the anesthesiologist is responsible for removing from the patient the ability to protect themselves and, therefore, assumes responsibility to protect the patient from unwanted intrusions. Ethically, anesthesiologists have the same obligations that all physicians carry: to see that the competent patient's wishes about his or her care are carried out.

In a practical vein, it is useful to be aware of the resources present in the operating room when medical, ethical or legal disputes arise. You can request that the surgery be stopped and not aided by nursing staff, until nursing and medical administrators, an ethics advisory committee or hospital legal counsel can be consulted.

The rest of the story

This case is taken from actual practice. The gynecologist left the room to obtain consent, at which point the first assistant expressed his own reluctance to proceed under these circumstances and gratitude to the anesthesiologist for objecting. The husband refused to give consent, and surgery was halted. The patient stated on the following day that she wanted the surgery to relieve pain "so that she could bear children." She stated unequivocally that she would have brought suit if the surgeon had performed a hysterectomy.

**Special Teaching Method**

**Expanded Use of Case Scenarios**

Case-based learning discussions are effective tools for using "real-life" scenarios to illustrate specific teaching points. The use of real cases emphasizes to residents and faculty the reality that ethical problems are common in clinical practice and are virtually certain to arise in the course of "normal" anesthesia care. While faculty and residents become familiar with the "four questions" case discussion format and the flow of case-based learning, the use of a single case illustration is simple and provides "linear" flow that is easy to understand. A single case limits participation to some degree, however, and participation is key to inspiring interest in residents and faculty about the approach and solution to ethical problems.

In addition, an important goal of case-based teaching should be the development of oral presentation skills among residents: clear, concise, knowledgeable and respectful communication can be an important determinant in whether a difficult ethical problem is approached in a constructive or confrontational manner. As Shafer (1995) so aptly pointed out, language and metaphor do not just reflect our
understanding of anesthesia practice, they shape the way we think about it. Constructive and compassionate language skills can help to shape compassionate and constructive practices.

One highly interactive way to use case-based discussions is to find related scenarios that illustrate different points set forth in the learning goals for the discussion. Instead of one case, each of several cases is developed by a separate resident "assigned group," and then presented orally to the entire lecture group for discussion.

An example learning session is described in When Should I Listen to the Patient? (see B-18), which is based on true case scenarios.

When Should I Listen to the Patient?

Is a surrogate decision-maker always appropriate in urgent medical situations?

Goals for Residents:

1) To utilize a systematic approach to the evaluation and discussion of clinical ethical problems by outlining the four major aspects of each case.

   a) medical indications  
   b) quality of life  
   c) patient preferences  
   d) contextual features

2) To communicate clearly and concisely the issues in each case, together with an assessment and a proposed course of action for each scenario.

3) To review ethical principles supporting the use of surrogate decision-makers and the appropriate circumstances in which they should be used.

4) To learn which features may help in deciding whether a patient is competent to consent to or to refuse medical care in an urgent situation.

   a) review the features of competence  
   b) summarize resources available to suggest whether a patient can make certain medical decisions  
   c) develop a list of resources that may be of help in determining competence in urgent clinical situations

The Lecture Plan:

In this lesson, four case scenarios with similar features will be used to illustrate points relevant to the teaching goals set forth in the case. Case preparation ahead of time is necessary, and teaching materials are distributed at least one week in advance to the residents.

The resident group is divided into four "teams," each of which will be responsible for the development of a case to be presented on the lecture day. Each resident is provided with the following materials:

1) The names of the residents on their "team."  
2) Their own case scenario only (four case scenarios are included below for the teacher).
pain and that she is likely infertile anyway.

You inform the surgeon that he does not have consent for hysterectomy and that you object to proceeding, since it does not represent an emergency at this time. You would like the patient to give informed consent. Failing to convince you that his patients "are Chinese and will abide by his best decision, since culturally they rely on their doctors to choose," he then scrubs out, announcing his intention to procure the husband's consent.

Should you accept a surrogate consent for this procedure?

1) Use a systematic approach to evaluate and discuss the clinical ethical problems presented in this case.

a) What are the medical indications, risks, benefits and alternatives to laparotomy for diagnosis and relief of chronic pelvic pain? What are the medical indications, risks, benefits and alternatives to hysterectomy?

b) What are the quality of life expectations from the alternative choices?

c) What are the patient's preferences?

d) Are there any contextual features that should be considered?

2) What is the appropriate use of surrogate consent?

3) Under what circumstances is it inappropriate?

4) What are the anesthesiologist's obligations in acting on behalf of the unconscious patient?

Case 2, Instructor's Notes

I. The Four Questions

Question 1) Medical indications. Medical indications for the original surgery include diagnosis and relief of chronic pelvic pain. Alternative therapies include no therapy (there is no indication that any life or health-threatening process is in play), conservative antibiotic and/or hormonal therapy, with attendant risks of drug reactions, side effects and expense, and other surgical approaches such as laparoscopy with similar risks and benefits to mini-laparotomy.

Medical indications for hysterectomy are for relief of pelvic pain. But the risks-to-benefits ratio is different than that of simple lysis of adhesions. Hysterectomy will result in infertility for this patient, who may not have been informed of this potential result. While severe fallopian tube scarring makes traditional conception unlikely in this woman, she still has options, which include in vitro fertilization, and could still potentially bear children if her uterus is not removed. Alternatives to hysterectomy include hormonal therapy or myomectomy with preservation of the uterus.

Question 2) Quality of Life. Relief of pelvic pain may have far-reaching effects in the patient's life. We don't know, for example, what effect chronic pelvic pain has had in her marriage: chronic illness, sexual dysfunction and/or infertility may have resulted and may, in turn, be magnified by cultural expectations. Her ability to work inside or outside the home may be impaired, and her perception of her quality of life may be poor. Relief of pain may play an important role in her family life as well as in her own physical comfort.
Question 3) Patient Preferences. We know that the patient has agreed to surgery for the diagnosis and relief of pain. What we do not know is whether she would be willing to give up the possibility of having children if she knew the alternatives to hysterectomy.

Question 4) Contextual Features. Strong cultural bias permeates this case, but in ways that are hard to assess without the patient’s input. The gynecologist’s assertion that he can speak for the patient may reflect true cultural norms, but without talking to the patient, we cannot be sure. The husband may also traditionally be able to speak for his wife, but without having the patient’s input, we would be guessing. Fertility is important in many Asian cultures, but might not override the choices of specific couples.

Legal precedents suggest that the patient should be informed about the procedure and asked for her consent, unless the emergent nature of the intervention precludes such a discussion. The patient faces no such emergency, but would face the inconvenience of another surgery and the potential complications of a second procedure and anesthetic.

There are strong influences against interrupting the flow of patient care in the operating room environment, which include inconveniencing operating room personnel, the surgeon, the anesthesiologist and the patient. Marked pressure is likely to be exerted to proceed if the surgeon deems it "necessary" to proceed at this time.

II. Case Development
At the heart of this case is the question, "Should you accept a surrogate consent for this procedure?"

When do you need surrogate consent? When medical therapy is needed and the patient is unable to give consent, surrogate consent can be sought. Patients are unable to give consent when they are too immature (as in the case of many minor children), when they are incompetent or when they are unconscious. But is surrogate consent always appropriate?

Instead of uterine fibroids, the surgeon discovers a large, walled-off abscess in the pelvic gutter, which originates from a large rectal perforation. Resection of this part of the rectum will require a colostomy. The surgeon consults a colorectal colleague, who agrees that the surgery is needed and that rupture of the abscess could result in widespread pelvic and abdominal contamination, infection and, potentially, death. The consultant strongly recommends proceeding with emergent surgery at this time. Is surrogate consent appropriate in this case? While surrogate consent can be sought for unconscious patients, the appropriateness of obtaining surrogate consent for the purpose of medical therapy depends on several factors. How urgent is the need for treatment? How likely is it that the patient can regain consciousness or competency in time to both give consent and benefit from the proposed procedure? Obviously, the more elective the procedure, the more time can and should be allowed to permit patients to decide for themselves.

The ethical principle at stake is respect for patient autonomy. Surrogate consent is at best an approximation of the patient’s wishes and, at worst, an expression of the wishes of the surrogate and not of the patient. Studies show that surrogates often do not know what patients would want, and their judgments correlate poorly with those of patients. Since surrogate consent is imperfect, we should try whenever possible to obtain the patient’s consent directly.

In the case of the patient with uterine fibroids, postponing definitive surgery until the patient can hear about the risks and benefits is not likely to reduce the benefit she would receive from hysterectomy if she decided to proceed. In the case of the patient with a potentially life-threatening abscess,
3) The teaching goals of the session.
4) A letter of expectations for each resident (see B-18).
5) The references used in case development should be supplied so that the resident will spend time working on case development and not on trips to the library.

On lecture day, each resident group presents its findings on the case they were assigned (try to keep each case presentation to 10 minutes). The remaining portion of the lecture time is spent in general discussion of features that distinguish the cases and a summary of the teaching goals.

Note: This type of teaching session requires a tight schedule!

The short cases are designed so that half the page (the Short Case side) can be photocopied and distributed initially and the whole page can be distributed later if desired. Following all four short cases is one page (B-24) with instructor's notes.

Sample Letter

Expectations for Residents

Our discussion of clinical ethical topics on Wednesday will concern the use of surrogate consent for procedures. We will be discussing several recent cases in which questions arose about a patient's refusal of anesthesia services in an urgent medical situation. For the purpose of discussion, you are being asked to work with several other residents to discuss (briefly) one of these cases. All of the materials you need are included in this packet.

On Wednesday, your resident "team" will be asked to present the enclosed case to the rest of the group. Each member of your team should take responsibility for a brief (1-2 minute) presentation of the group's findings in one or more of the following categories:

1) What are the medical indications and risks for the intubation?
2) What are the quality of life issues in the case?
3) What are the patient's preferences, including evidence that supports or questions the patient's ability to make the decision?
4) Is there a surrogate decision-maker involved? If so, who is it, and is that person an appro-priate person to make the decision? What "outside influences" may affect their ability to decide?
5) If there is no surrogate, should there be one? If so, who would be appropriate and why?
6) What are the contextual features of the case not covered in the above questions?
7) You are the anesthesiologist in the scenario! What would you do? Why?

Short Case 1

You are the on-call anesthesia resident in a large teaching hospital. You are called at 3 a.m. for a "stat" intubation in the ICU. When you arrive, you find an 80-year-old woman, sitting bolt upright in bed, in obvious respiratory distress. Vital signs are stable, respiratory rate is 40. The patient suffers from inoperable esophageal carcinoma that has eroded into the trachea. Her respiratory distress has been
increasing throughout the night, and in the past hour, her oxygenation has been worsening. The resident insists that you intubate the patient immediately. When you approach the bedside and start to explain to the patient what you are about to do, she tells you that she has cancer and does not want to be intubated. The medicine resident points to the patient's most recent arterial blood gas, with a PaO2 of 53 on 75% FIO2, and a PaCO2 of 72, and states that the patient has "carbon dioxide narcosis, hypoxemia, and is incompetent to make this decision." The resident demands that you intubate the patient. Is the patient incompetent? What would you do?

The rest of the story

Despite growing demands from the medicine resident to intubate the patient, the anesthesia resident reviewed the chart and discovered the rest of the blood gas. Questioning the medicine resident's assessment of the patient's decompensation, particularly in light of the patient's clarity of communication despite her distress, the anesthesia resident contacted his own attending, who in turn contacted the intensive care attending most familiar with the case (in this case, not the on-call attending). The medicine attending revealed that, while no decision had been reached, the patient had, indeed, expressed doubts in the past about desiring intubation. The patient had no family with which to discuss the issues. After communicating again with the patient, intubation was avoided, comfort measures instituted to relieve respiratory distress, and the patient died approximately 12 hours later.

Short Case 2

You are called to the emergency room to intubate a somnolent patient with respiratory decompensation. On arrival, you find a 42-year-old woman who suffers from severe pulmonary fibrosis and pulmonary hypertension. She is somnolent, with arterial blood gases that show pH 7.28, PaCO2 72, PaO2 49 and HCO3 26. When you approach the bedside and tell her that you are there to "place a breathing tube," she says one word between breaths: "No." The ER doctor requests that you intubate her over her objection, and he barely needs to point out the blood gas, the patient's mental status and her obvious physical distress, since your inclination is to proceed with intubation. But should you? Can you quickly produce any other information to support your inclination?

The rest of the story

This patient was well-known to the medical center, if not to this particular ER doctor. The anesthesia resident inquired about the patient's family, to discover that the patient's husband was en route and expected in the next half hour. The chart had not been reviewed, largely because it consisted of four volumes and was more than eight inches thick, but a quick look at the chart revealed that while there was no previous advance directive, the pulmonologist had documented a recent discussion in clinic about the issues of intubation, in which the patient expressed doubts about wanting intubation. The blood gas indicated acute respiratory decompensation, and the patient's mental status raised questions about her competence. A call was put out to the patient's primary pulmonologist, and the anesthesia resident, with the support of his attending, reassured the patient, who was by now nearly unconscious, and began assisted mask ventilation in the hope that the patient's doctor would call. Preparations were under way to intubate, when the patient's husband arrived and stated unequivocally that the patient had decided to refuse intubation after her discussion with the pulmonologist earlier. He refused surrogate consent for intubation. Comfort measures were instituted, and the patient was transferred to a hospital bed. The pulmonologist was reached and confirmed the husband's assertions. The patient died two hours
later without regaining consciousness.

Short Case 3

You are called to the emergency room to intubate an 80-year-old woman with known COPD who has just been brought in by ambulance. She is unconscious, her respiratory rate is 40, and she appears cyanotic. ABGs on 100% mask reveal pH 7.21, PaCO2 75, PaO2 45, and HCO3 26. She has been hospitalized multiple times. On her last hospitalization two weeks ago, a "do-not-resuscitate" order was entered into the patient's record at the insistence of both her and her husband. The husband is en route.

The rest of the story

In this case, the acuteness of the clinical situation overwhelmed both the anesthesia resident and attending, who asked the advanced ethics question, "Why not intubate in the emergent situation because the patient can always be extubated later if appropriate?" In this acute emergent situation, neither the resident nor attending could think of an ethically compelling reason not to intubate. While this is not an "incorrect" decision, they were about to discover the "downside" of this approach when the husband arrived. He was beside himself when he discovered that his wife had been intubated. He did not understand the doctors' decision, since information in the chart made it clear what the patient's wishes were. He perceived the intubation as cruel and invasive, and disrespectful to his wife's wishes to die with "dignity." It was extremely painful for him to now be faced with the responsibility of telling his wife's care-givers to "take the tube out," and he ultimately expressed feelings of guilt and a sense of direct responsibility for her death. The endotracheal tube was removed in the ER, and she died 30 minutes later.

Short Case 4

An 84-year-old woman with a long-standing history of COPD presents to the ER with severe respiratory distress. ABGs on 100% face mask show pH 7.25, PaCO2 68, PaO2 49, and HCO3 28. The patient is awake and appears alert, but distressed. When you explain that you are going to intubate her, she insists that she does not want to be intubated but refuses to give a reason. Review of her chart fails to disclose any prior DNR or do-not-intubate order, and she has been intubated before. There is no advance directive. She has no family. What should you do?

The rest of the story

In this case, the patient was expressing a wish inconsistent with past medical experience with her. There is evidence that her respiratory decompensation was acute, and elevated PaCO2 might be impairing her judgment. While patients can certainly "change their minds" about medical care, the best evidence we have in an acute situation like this is past behavior. While no one in the ER was familiar with the her pulmonologist was available and had a long-standing relationship with the patient. Her pulmonologist expressed puzzlement about the patient's refusal and came to the ER to see the patient. The patient expressed immediate relief upon seeing a familiar face. When her doctor suggested that "a breathing tube might help," the patient readily agreed to intubation. She was suffering from acute pneumonia, and after intubation and IV antibiotics, she was extubated and ultimately discharged home.
Short Cases, Instructor's Notes

Short Case 1
In this case, other ABG values included a pH of 7.32, and HCO3 of 36. Is this an "acute" decompensation, as presented? Is the patient likely to be suffering from carbon dioxide "narcosis?" Does the patient's interaction suggest "narcosis?" Does she understand the implications of her situation and decision? Does an on-call medicine resident necessarily have the best information about this patient? To whom can you turn to get "better information?" Is there someone we should be rousing from sleep who is more familiar with the patient? Is there any evidence in the chart that this patient has previously expressed the desire not to be intubated? Or to not undertake any other means to prolong life?

Short Case 2
Who is behaving as the patient's surrogate in this case? Can you think of a more appropriate surrogate than the doctor? Where is the patient's family? What is the patient's history? She has known severe pulmonary disease and is not a candidate for lung transplant. Is it possible that intubation as an intervention has been discussed before? Do we know if she has an advance directive? Does the chart indicate a past desire not to be intubated? Can you think of anyone else who might help us here?

Short Case 3
What issues should induce us to proceed with intubation in this patient? Who, or what, is acting as the patient's surrogate in this case? Is the surrogate appropriate?

Advanced ethics question: Why not intubate in the emergent situation, since you can always extubate later if it turns out to be the wrong decision?

Short Case 4
What evidence do we have that this patient's decision-making capacity might be impaired? How can we clarify whether she is competent? Is the evidence to suggest that her refusal today is inconsistent with past behavior? Is there anyone else we can call upon for more information?

INFORMED CONSENT: SPECIAL ISSUES IN THE CARE OF CHILDREN

Discussions on informed consent always begin by pointing out the sea of change that has occurred over the past 40 years in medical decision-making. Earlier generations of physicians made decisions for patients based upon the physicians' perception of the patients' best interests, often with little involvement from the patients themselves. Physicians did not regard this behavior as unethical; indeed, they felt that it would be unethical to place too much of the burden of decision-making upon the patient and family. Consistent with this approach, patients and families were also often "protected" from the harsh realities of unfavorable diagnoses and prognoses.

One of the defining features of the 1960s, however, was a rebellion from authority and a renewed emphasis upon the rights and freedoms of the individual. From the civil rights movement to student protests to consumer activism, citizens demanded greater involvement and control in decisions that
affected them. The patient-physician relationship was not immune from this revolution, and the pursuit of patient autonomy became a defining issue for the bioethics movement.

Philosophically, the foundations for this new approach to the patient-physician relationship could be found in liberal political theory, and its emphasis upon individual rights and freedoms. From the classical works of John Stuart Mill and Immanuel Kant, through the more modern philosophy of John Rawls, priority is given to supporting the autonomy of individuals. This philosophical stance has been reflected in the law. Beginning with the Salgo case in 1957 and progressing through Canterbury in 1972 (see Introduction to Informed Consent), the courts have steadily moved away from allowing physicians the right to decide for their patients and toward the view that the locus of decision-making authority must reside with the patient.

There is a long history in pediatrics of new technologies and ideas being developed in the world of adult medicine and then filtering down to the care of younger patients. This has been true not only in the realm of medicine, but also in the area of ethics. And, just as we have learned that some medications or treatments do not work as well in children as they do in adults, so have we learned that some ethical principles do not work as well in pediatrics as in the rest of medicine. Such is the case with informed consent.

In retrospect, this should not be surprising, since the entire theory of informed consent is based upon the concept of patient autonomy. As the term is used in the philosophical sense, autonomous action requires a very high level of functioning. According to the standards of Kant, for example, many otherwise typical adults would have difficulty qualifying for the label of "autonomous." If this is a high standard for adults, then it is insurmountable for most children. In other words, the very foundations of informed consent are based upon standards that are simply inapplicable in most of pediatrics.

Of course, the same problem is also common among adult patients, since many of them are too ill to participate in their own decision-making to any meaningful extent. Nevertheless, the concept of autonomy can still be applied in these cases, since it is only necessary to determine what the patient would have wanted if only he or she were capable of autonomous functioning. In other words, in these circumstances, the task is to find a surrogate decision-maker who knows the patient well and who can use the principle of substituted judgment to make the decision that the patient would have made if he or she were competent. In this way, the foundational reliance upon the principle of autonomy is maintained.

Unfortunately, this philosophical maneuver is generally not available to pediatricians, since young children have never attained a degree of function that would qualify them as autonomous. It is therefore impossible to say what decision they would make if they were autonomous, since they have never achieved that state or condition. Any discussion of substituted judgment in this situation is a purely fictional activity based only in fantasy. In other words, the attempt to develop a theory of informed consent in pediatrics that is based upon the principles developed for competent adults has been a complete failure and has probably done more to confuse the issues rather than to clarify them.

**Best Interests Standard.** In an attempt to bridge this theoretical gulf, judges and ethicists have turned the concept of best interests to guide decision-making for children and other individuals who have never achieved an autonomous state. This standard is explicitly not based upon a respect for the child's autonomy, but is rather an objective standard designed to aim at what is best for the child overall. Since it is an objective standard, the decisions that are chosen for a child on this basis should be independent of the decision-maker. In other words, this standard presupposes that there is a single "best" decision for the child and that this decision should be the same regardless of whether it is the parents, the caregivers or the state empowered with making the decision.
Of course, in actual practice, it is never this easy. In any interesting case, it is usually quite difficult to determine what is in the child's best interests, and reasonable people will disagree. We are therefore left with the practical problem of deciding how decisions should be made for children. And the answer, of course, not only with medical decisions but with decisions in virtually every facet of life, is to give the parents authority over decision-making for their children.

It is important to realize, however, that this is not the case because we believe that parents "own" their children. Whereas adults may have the absolute right to forego necessary repairs on their automobiles, they do not have the right to forego necessary care for their children. Again, decision-making for children is based upon the child's best interests, and parents have been chosen as the decision-makers in most cases for the practical reasons that 1) someone has to be designated to determine what is in the child's best interests, and 2) there is no reason to think (in most cases) that anyone is better qualified than the child's parents.

As an aside, some have argued that the choice of parents as decision-makers for their children is not as arbitrary as implied here. For example, we know that children are likely to adopt at least some of the values and beliefs of their parents as they grow into adults. This implies that the decisions made by the child's parents are, perhaps, likely to be the same decisions that the child would have made if the child were old enough to have formed his or her own values and beliefs. In addition, some argue that parents should be given more weight in decision-making because they must bear the consequences of the decisions. For example, if a decision is made to discontinue life-support on a child when the prognosis is poor, the parents are the ones who must live with the grief and perhaps guilt of that decision. On the other hand, if the decision is made to continue with life-support and the child survives, the parents are the ones who may need to assume responsibility for caring for a multiply handicapped child. For both of these reasons, therefore, some have argued that the priority given to parents in decision-making is more than just a choice of convenience.

Nevertheless, the fundamental responsibility of parents is to make choices for their children based upon their perception of the child's best interest. For the reasons outlined, we defer to the parents' determination of the child's best interest, unless it falls outside of a range that society deems to be "reasonable." We can think of the acceptable range of treatment choices as falling along a continuum, with a lower bound defined by unacceptable undertreatment of the child, and an upper bound defined by unacceptable overtreatment of the child.

**A Case of Undertreatment: Baby Doe.** How is the acceptable range of choices defined and determined? Not surprisingly, the answer to this is complex and is best illustrated by examples. Perhaps the best case study illustrating undertreatment is the 1982 case of Baby Doe. Baby Doe was born in Bloomington, Indiana, with Down Syndrome and a tracheoesophageal fistula. Based upon their assessment of the child's future, the parents elected not to proceed with surgery, and the baby died of dehydration. At that time, a clear consensus did not exist about the permissible spectrum of treatment for children with Down Syndrome. As the case became public, however, a consensus developed that nontreatment of children with Down Syndrome on the basis of their disability was outside the range of acceptable options. This conclusion was legally and politically enforced through enactment of the so-called Baby Doe Law, more formally known as the 1984 Amendments to the Child Abuse Prevention and Treatment Act. As a result of these ethical, legal and political discussions, children with Down Syndrome now receive treatment for correctable surgical conditions, regardless of the views of the parents.
A Case of Overtreatment: Baby L. The other end of the spectrum has proven even more difficult to define. A well-known example of presumed overtreatment occurred at Children's Hospital in Boston in 1987, and has come to be known as the case of Baby L. This involved a 2-year-old girl with severe birth asphyxia and a history of repeated aspiration pneumonias and cardiorespiratory arrests. Her neurological functioning was at the level of a newborn. During an admission for treatment of yet another aspiration pneumonia, her condition deteriorated and she developed the need for mechanical ventilation. In light of her clinical condition, the director of the intensive care unit felt that this potential escalation of care would be inappropriate and refused authorization to admit her to the ICU. Baby L's mother, on the other hand, insisted that her child's life be sustained by any means available. As discussion of the case moved from the hospital's ethics committee to the courts, a physician at another institution was located who was willing to provide care in accordance with the mother's wishes, and the child was transferred to a different facility.

Since this case, there have been several others where physicians have tried to refuse to provide care they believed to be futile but which was demanded by parents. With rare exception, courts have not been sympathetic to this assessment by physicians, and in most cases the child has continued to be treated against the judgment of the clinicians.

The problem of overtreatment has continued to be a serious and unresolved issue. In response to this problem, a number of hospitals have developed "futility" policies. At least two states have adopted legislation regarding futile care, several medical societies have written guidelines on futility, and the American Medical Association has appointed a task force to address the issue of futile and inappropriate treatment. A better understanding of the "upper bound" of the spectrum of acceptable choices by parent decision-makers must therefore await the outcome of these efforts to define "overtreatment."

Determining Best Interests. In the meantime, what guidelines should be used, by parents or others, in attempting to determine a child's best interest? An excellent framework for deliberating about this issue was outlined by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in their 1983 publication titled, Deciding to Forego Life-extending Treatment. They proposed five considerations by which to assess a child's best interests:

1) The amount of suffering and the potential for relief
2) The severity of dysfunction and the potential for restoration of function
3) The expected duration of life
4) The potential for personal satisfaction and enjoyment of life
5) The possibility of developing a capacity for self-determination

In addition, in an adaptation of work produced by that Commission, ethicist Christine Mitchell has proposed a table for evaluating the different assessments of parents and caregivers regarding a child's best interests (see table).

TABLE: Resolving Conflicts Between Surrogates and Clinicians

SURROGATE EVALUATION

MEDICAL OPINION

"Worth a Try" "Don't Know" "Not Worth It"

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Standard Treatment

Treat
Treat
Do Not Treat/
Optional Review

Uncertainty
Trial of Treatment Trial of Treatment No Treatment
Highly Unlikely
to Work Trial or Transfer
Permissive No Treatment with Review
No Treatment
No Medical Benefit Treatment and Review/
No Treatment and Review
No Treatment No Treatment
Won't Work
No Treatment
and Review No Treatment No Treatment

To summarize up to this point, the task of determining a child's best interests is generally the responsibility of the child's parents, unless their assessment falls outside of a range held acceptable by society (as expressed through legislation and the courts). Therefore, while the process of obtaining "informed consent" from parents for treatment of their children is superficially very similar to the process of obtaining informed consent from an autonomous adult, the rationale behind the process is radically different. For this reason, the Committee on Bioethics of the American Academy of Pediatrics (1995) recently wrote:

"We now realize that the doctrine of "informed consent" has only limited direct application in pediatrics. Only patients who have appropriate decisional capacity and legal empowerment can give informed consent to medical care. In all other situations, parents or other surrogates provide informed permission for diagnosis and treatment of children with the assent of the child whenever appropriate." (emphasis in original)

Reconciling Law and Ethics: Competence and Decision-Making Capacity. In addition to the problems outlined above, informed consent in pediatrics is also complicated by differences between the requirements of law and the principles of ethics. As noted above, informed consent (in the legal sense) can only be given by someone who is competent (in the legal sense). In other words, informed consent is legally valid only for patients who have reached the age of legal majority (either 18 or 21 years, depending upon the jurisdiction).

For this reason, the President's Commission (referred to above) pointed out a very important distinction between competence and decision-making capacity. Competence, the Commission noted, is a legal term. Only a judge can decide that an individual is incompetent. With regard to medical decision-making, however, the question that matters most is not whether the patient is legally competent, but whether the patient has decision-making capacity. Furthermore, where-as competence is an "all or none" phenomena, decision-making capacity exists on a spectrum. This spectrum is defined by two  

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dimensions, or axes. On one axis is the developmental maturity of the patient; on the other is the consequences of the decision. On this theory, a 10-year-old may have sufficient decisional capacity to decide whether to undergo cosmetic surgery, whereas the child would not have sufficient capacity to decide whether to undergo a potentially life-saving appendectomy. Therefore, the preferences of the 10-year-old child should be given great weight in the former situation and little weight in the latter. While one could argue, from an ethical perspective, that some 20-year-olds do not have sufficient decisional capacity to refuse potentially life-saving therapy, anyone over the age of majority must be presumed to have decisional capacity unless there is very strong evidence to the contrary.

*Emancipated minor status.* Reconciliation of the legal requirements of informed consent with the ethical requirement to respect decisional capacity is often difficult. From a legal perspective, two approaches have been adopted in the law to bring these two into closer agreement. First, all states recognize some form of emancipated minor status. An emancipated minor has the same rights in making health care decisions as an individual who has reached the age of majority. Three categories of emancipation are recognized: 1) court-ordered emancipation (e.g., teenagers living apart from their parents who petition the court to be treated as though they have reached legal majority); 2) statutorily defined emancipation (e.g., married minors or minors who are parents); or 3) medical emancipation (e.g., minors seeking treatment for a specific medical condition such as a sexually transmitted disease).

*Mature minor doctrine.* The other approach, utilized in some jurisdictions, is the mature minor doctrine. This is more limited in scope than emancipation statutes and recognizes that, in many instances, minors may have sufficient maturity to make important decisions for themselves. Rather than affecting the global status of the individual, mature minor statutes are generally invoked for empowering minors to make particular decisions.

**Assent for Pediatric Patients.** The American Academy of Pediatrics has been even more progressive than the law in emphasizing the importance of involving children in decision-making to the fullest extent of their capacity. As noted previously, the Academy's Committee on Bioethics (1995) has promoted much more ex-tensive use of the concept of *assent*. The Committee noted that assent should include at least the following elements

1) Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
2) Telling the patient what he or she can expect with tests and treatment(s).
3) Making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy).
4) Soliciting an expression of the patient's willingness to accept the proposed care. Regarding this final point, "no one should solicit a patient's views without intending to weigh them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived."

The Committee noted that, as they develop, children "should become the primary guardians of personal health and the primary partners in medical decision-making, assuming responsibility from their parents." In emphasizing the importance of this being an interactive process, the Committee made clear that it was not recommending the development of new bureaucratic mechanisms, such as the use of "assent forms." Nevertheless, the Committee's endorsement of the concepts of parental permission and assent suggest changes in our approach to decision-making for children that are nothing short of radical.

**ANNOTATED BIBLIOGRAPHY**

http://www.asahq.org/wlm/Ethics.html

10/20/03
Informed Consent:
This paper by Gild is an excellent review of informed consent.


Informed Consent for Pediatrics:
These papers illustrate the development of thinking about informed consent in the pediatric population. As emphasized in the text, the paper from the Committee on Bioethics of the American Academy of Pediatrics represents the culmination of this line of reasoning.


The Problem of Undertreatment: Baby Doe:
Every anesthesiologist should know the story of Baby Doe and some of the consequences of this historic case. At a minimum, this should provide a background for understanding that parental refusal of potentially life-saving treatment must be overridden in at least some cases.


The Problems of Overreatment: Baby L and the Futility Debate:
If undertreatment was the problem of the 1980s, overtreatment is the problem of the 1990s. Below is the standard reference for the Baby L case (reference #4), as well as an overview of some of the current literature on the futility debate. The paper by Tomlinson and Czlonka is a nice description of the most current thinking on this topic.

2. Waisel DB, Truog RD. The cardiopulmonary resuscitation-not-indicated order: futility revisited. Ann...

**The Jehovah's Witness Patient:**
The management of the Jehovah's Witness patient should be very familiar territory for any anesthesiologist. These papers are standard excellent references on this topic from the anesthesia perspective.


**Case 1**

**The Child of a Jehovah's Witness**
A 7-year-old presents for resection of an abdominal tumor. The neoplasm is quite vascular, and extensive blood loss is anticipated. In the preoperative waiting area, the child's parents notify you that they are Jehovah's Witnesses and that they will not give permission for their child to receive blood or blood products.

1) What should you discuss with the family?

2) Would the situation be different if the patient were 17 years old? Why?

3) Should a court order for blood administration be obtained preoperatively? How would you accomplish this in your hospital?

4) What should be included in the documentation for informed consent for the anesthetic and surgery?

**Case 1, Instructor's Notes**
This is a "bread and butter" case for the pediatric anesthesiologist, and everyone who practices in the field should be very clear about how to handle cases like this. Unfortunately, many anesthesiologists have been taught that Jeho-va'h's Witnesses have the right to refuse blood transfusions, without learning the exceptions to this rule. While it is true that virtually any competent adult has the right to refuse even life-saving medical treatments, there are some exceptions. For example, some judges have ordered the mothers of small children to be transfused against their will, on the view that the mother does not have the right to abandon her children by refusing a life-saving treatment. In addition, legally incompetent minors are also excluded from the general rule, on the grounds that the refusal of blood by the parents is not congruent with the child's best interests.
As discussed above, however, there are inconsistencies between the law and ethics of informed consent. While the law holds that any unemancipated minor is legally incompetent, ethics would focus primarily upon the decisional capacity of the child. If, for example, the patient were a mature 17-year-old who was deeply committed to the beliefs of his/her religion, then the ethically "right" approach would be to honor the patient's refusal. This would be acceptable from a legal perspective, however, only if a judge made an exception based upon the mature minor doctrine.

At a practical level, how should the anesthesiologist proceed? The following is an outline of the process at the Children's Hospital in Boston (the correct procedure at other hospitals may vary, depending upon the opinions of the hospital's administration and legal counsel). When caring for any non-emancipated minor, the anesthesiologist needs to inform the patient's parents that, in the event that blood or blood products would be life-saving, a court order will be sought to administer these agents. This communication must be clearly documented in the chart. Since giving permission for the administration of blood products is contrary to the tenets of their faith, it is not necessary for the parents to give written consent for the administration of blood products. Nevertheless, they should understand that a court order will be sought if they decide to proceed with surgery and the administration of blood products becomes potentially life-saving.

If more than minimal blood loss is anticipated, should a court order for blood administration be obtained prospectively? The answer to this depends upon the local circumstances. In many cases, hospital legal counsel will have a relationship with the local judiciary such that a court order can be obtained very quickly. In this case, especially when the need for a life-saving transfusion is relatively unlikely, it is probably not necessary to obtain a prospective order. On the other hand, if there is a chance that the judge involved will not be familiar with the case law surrounding Jehovah's Witness patients, then waiting until the blood is needed could be a mistake. In any case, based upon the strong legal precedent for giving blood in these situations, no child should be allowed to die because of parental refusal to consent for the administration of blood products.

Against this background, however, anesthesiologists should make every effort to administer an anesthetic in accord with the parents' religious beliefs. This means that the anesthesiologist should be skilled in all of the techniques that are currently available to minimize the need for transfusions, including hemodilution, cell-saver technology and even hormonal therapy to stimulate the production of red blood cells. Jehovah's Witnesses vary in exactly which techniques they will accept (for example, there is controversy within the membership over whether cell saver techniques or the administration of albumin is acceptable), so the anesthesiologist should explore with the family the exact requirements of their beliefs. Again, however, while making all reasonable accommodation to avoid the need for a transfusion, no child of Jehovah's Witness parents should die for lack of transfused blood without the physicians seeking a court order to administer the blood against the parents' wishes.

Case 2

A Teenager Refuses Care

A 16-year-old presents to the preoperative waiting area for spinal fusion surgery. She is healthy except for progressive idiopathic scoliosis. Her parents have taken her to see an orthopedic surgeon, who recommended and scheduled surgery. While awaiting surgery over the past several weeks, she has become quite anxious. Her parents have repeatedly insisted, however, that she undergo this operation in order to prevent the cosmetic and physiologic abnormalities that will develop unless progression is halted. In the preoperative waiting area, she is visibly upset. She refuses to allow insertion of an
intravenous catheter, and she refuses to leave the waiting area and enter the operating room. When you ask her why she is refusing the surgery, she bases her decision upon a fear of needles and the thought of "being cut." At this time, you believe that the only way to induce anesthesia would be to forcibly hold her down and administer an IM or IV sedative like ketamine.

1) How should you proceed? What options do you have?

2) Should she be forcibly subdued?

3) Is it relevant that she is refusing surgery because she is afraid of needles and of "being cut?" What if she were refusing surgery out of a fear of death or intraoperative awareness?

4) What principles influence how you should proceed?

Case 2, Instructor's Notes

This is a difficult case, and there are few right answers. The only definite recommendation is that this adolescent should not be forcibly subdued, either physically or with sedatives, at this time. The case is not urgent, and the surgery should be deferred. This will allow time to involve other consultants (adolescent medicine specialists, psychiatrists, etc.) and to formulate a plan for the future.

Hopefully, this young woman can be persuaded to undergo the procedure willingly. If her reluctance is based primarily upon acute anxiety in the preoperative holding area, then she may benefit from a sedative like oral diazepam before coming to the hospital on her next visit. If the care team can be convinced that she is definitely committed to undergoing the surgery but is simply unable to control her emotions in the immediate preoperative period, then it may be possible to make a contract with her so that she understands that she will be forcibly restrained and sedated on the next occasion if she is unable to control herself. In this way, her more fundamental request (to undergo surgery) will be honored, even though her immediate request (to leave the hospital) will be overridden.

A more difficult question will arise if she persists in her refusal of surgery. This refusal is even further complicated by the "immature" reasons given for her refusal (fear of needles and of "being cut"). To see the matter more clearly, if she were five years younger, there would be little question about the appropriateness of proceeding against her will, while if she were 25 years older, overriding her refusal could be legal grounds for a charge of battery against the physicians. This is, therefore, a difficult decision that should be made only after extensive involvement from her primary and consulting physicians as well as her parents. The ultimate question is whether the benefits of the spinal surgery are sufficiently large and sufficiently probable to offset the potentially substantial harm of forcing her into surgery against her will. As noted in the text above, everyone involved should clearly understand that the choice is not "the parents' decision." The relevant question concerns what decision is in her best interest. While the parents can provide very helpful information toward answering this question, their views are certainly not determinative.

Case 3

http://www.asahq.org/wlm/Ethics.html 10/20/03
The Privacy of Teenagers

Recently, a 16-year-old young woman underwent elective surgery in your hospital. Several days later, she experienced a miscarriage. The Chief of Staff of the hospital demanded that the anesthesia department adopt a policy requiring all females of childbearing age to have a pregnancy test prior to any anesthetic or surgery.

1) What kind of policy would you create?

2) How would it be implemented?

3) What problems would you anticipate?

Case 3, Instructor's Notes

Anesthetic agents may pose risks to pregnant women. As described in the case, many hospitals therefore require a pregnancy test on any woman of childbearing age who needs anesthesia and surgery. From the discussions above, it should be apparent that policies of this type may create difficult dilemmas in the pediatric population.

The problems arise if the adolescent female does not want her parents to know that she is pregnant. In addition, in many states, adolescents have the legal right to keep this information private from their parents. When there is a policy to routinely do a urine test for pregnancy on all women of childbearing age, the anesthesiologist can be placed in an ethical and legal bind.

For example, if a pregnancy test is routinely sent on all adolescent females, then the result will be important to the decision about whether or not to go ahead with surgery. If the anesthesiologist believes the case should be postponed, and if the adolescent refuses to allow her parents to know the results of the pregnancy test, then the anesthesiologist may be in the awkward position of telling the patient's parents that the case is canceled without being able to tell them why.

Fortunately, this difficult conundrum is almost always avoidable by immediately involving pediatricians, gynecologists and social workers with expertise in adolescent issues, since they will usually convince the adolescent that the best course of action is for the patient to inform her parents of the test results and to work together in dealing with the pregnancy. Nevertheless, there is still the possibility that the adolescent will refuse to disclose this information to her parents.

Finally, an approach used by some institutions is to notify the adolescent before the day of surgery that routine pregnancy testing will be done preoperatively and that this information will be used to determine whether or not to proceed with elective surgery. This prenotification will allow adolescents who suspect they may be pregnant and who want to keep this information private the opportunity to deal with the situation in other ways, and not be unexpectedly confronted with the information on the day of surgery.

Special Teaching Method

http://www.asahq.org/wlm/Ethics.html
In most teaching hospitals, anesthesiologists interact primarily with a child's parents in obtaining consent for anesthesia. According to the principles discussed here, however, anesthesiologists should involve children in decision-making to the fullest extent of their capacity.

As an exercise, anesthesia residents should make a conscious effort for a week to "push the envelope" of involving children in the discussions about anesthesia and the process of informed consent. While it is certainly important for the anesthesiologist to remain appropriate and not to overstep the bounds of reasonable expectations by the child and the family, this exercise will almost certainly reveal that children are generally much more capable of participating in these discussions than we typically realize.

After a week or so, the trainees should get together again and discuss their experiences with consciously testing the limits of pediatric involvement in decision-making. Hopefully, the insights gained from this experiential exercise will lead to long-term changes in understanding and behavior.

INFORMED CONSENT FOR JEHOWAH'S WITNESSES

Imagine yourself as an anesthesiologist on the old time TV show "Password," and the phrase that appeared on your screen was Jehovah's Witness. There can be little doubt what the response in this word association game would be: refuses blood transfusion. While practicing anesthesiologists are well aware that members of the Jehovah's Witness faith routinely refuse blood transfusion in the perioperative setting, it behooves us to have a clear understanding of not only this religious sect's beliefs, but also the legal, ethical and medical implications of entering into the care of a Jehovah's Witness. In this regard, a number of important issues need to be addressed so that a practicing anesthesiologist can be knowledgeable in obtaining proper informed consent for the Jehovah's Witness in the perioperative period.

The Origin of the Religious Beliefs of Jehovah's Witnesses. It is imperative to recognize that the Jehovah's Witness religion is a fundamentalist Christian sect whose orthodoxy believes that eternal salvation is forfeited upon receiving a blood transfusion. The official church opinion appeared in the Watchtower in 1945 and was based on numerous biblical passages in both the Old and New Testaments describing the so-called "blood sin." It is important to emphasize that to Jehovah's Witnesses, the sanctity of blood is central to their faith and must be acknowledged and respected by anesthesiologists who are providing care.

Reviewing some of these biblical passages may help provide insight into this religious sect. Biblical references show not only that a Jehovah's Witness should not "take" blood, but also that the punishment is "being cut off from his people" (the loss of eternal life).

Every moving thing that liveth shall be meat for you; even as the green herb have I given you all things. But flesh with the life thereof, which is the blood thereof, shall ye not eat. (Genesis 9:3, 4)

Moreover, ye shall eat no manner of blood, whether it be of fowl or of beast in any of your dwellings. Whosoever soul it be that eateth any manner of blood, even that should shall be cut off from his people. (Leviticus 7:26, 27)

Indeed, to the Jehovah's Witness, the Bible states that transfusion is prohibited even in emergency situations. This passage refers to starving soldiers who have eaten forbidden food.

Behold the people sin against the Lord, in that they eat with the blood. (I Samuel 14:33)
Once a foundation for religious understanding has been laid, other topics related to transfusion can be considered. This includes component therapy, hormonal therapy, autologous blood transfusion, intraoperative blood conservation techniques and organ transplantation. Obtaining copies of the Watchtower and their numerous publications regarding the sanctity of blood is helpful and can provide further insight into the patient's religion.

**Legal Considerations.** At this time, all law regarding the care of the Jehovah's Witness is case rather than statutory law, and therefore each state may have different rulings about the care of these patients. It may be important, therefore, to review those particular cases for the state in which the anesthesiologist practices. Different cases may be reviewed within the context of the law and include the competent adult with no dependents undergoing an elective procedure, the competent adult with no dependents in the emergency situation, the competent adult with dependents, the incompetent patient in the emergency setting, the pregnant patient and minors in both the emergency and elective situations. As a gross generalization, competent, nonpregnant adults who are not sole providers may refuse blood products. On the other hand, the courts have had a tendency to intervene in favor of transfusions for patients who are parturients, minors, sole providers and other adults who are in emergency situations and unable to communicate or have not provided an advance directive. This is based in part on the idea that refusing life-sustaining treatment requires clear enunciation. As part of the informed consent process, it is important to review the advance medical directive/release that is often provided by the Jehovah's Witness to the anesthesiologist. (See Appendix).

**Ethical Considerations.** The principle of respect for autonomy holds that patients have a right to follow a "self-chosen plan." Physicians have an obligation to support that right. In this situation, the patient's right would be to determine whether to receive transfusions. On the other hand, particularly when a minor is involved, physicians have an obligation to respect the principle of beneficence or the requirement to promote that which is good. This principle can be interpreted as requiring the physician to give life-sustaining blood. Finally, the state has a paternalistic interest in preventing "suicide" and in ensuring that minors have an adult to care for them. This comes to the forefront with situations parturients, sole caregivers and minors.

It is obvious from a review of the legal cases cited that the principles of either respect for autonomy or beneficence enter into every case decision. The reader should determine what his or her state's rights and interests are in regard to the care of the Jehovah's Witness patient and how they balance with the individual patient's rights.

**Providing Care.** It is important to take into account the personal, moral and ethical beliefs of the anesthesiologist who is caring for the Jehovah's Witness patient. While the concept may be a difficult one for the novice to grasp, by entering into a covenant with a Jehovah's Witness patient, the anesthesiologist accepts the patient's belief that receiving a transfusion will prevent him or her from achieving eternal salvation. *In the eyes of Jehovah's Witnesses, physicians who allow them to die rather than receive blood transfusions practice the principle of beneficence and, in so doing, pay the ultimate respect to their religion. Each anesthesiologist needs to consider whether the constraints imposed by the Jehovah's Witness patient is acceptable to his or her ethical, moral and personal standards. If an anesthesiologist can not agree to a patient's desires, the anesthesiologist has both the right and obligation to withdraw from that patient's care. The anesthesiologist should then attempt to find a substitute caregiver.*

**Medical Alternatives to Blood Transfusions.** While the discussion centers on informed consent for the Jehovah's Witness patient, this cannot be properly entertained without a clear understanding of the medical alternatives to transfusion. As in any religion it should be pointed out that there are reform and
orthodox viewpoints and, therefore, each patient may make individual choices that differ from others of their same religion. The TABLE below outlines techniques and therapies that can be offered in the perioperative period to either conserve or prevent blood loss.

**TABLE. Perioperative Techniques and Therapies Acceptable to Jehovah's Witnesses**

**TECHNIQUE / THERAPY**

- Hypotensive anesthesia
- Crystalloid solution
- Induced hypothermia
- Synthetic colloid solutions
- Continuous arterial blood gas monitoring
- Dextran
- In-line blood reservoirs
- Desmopressin
- Microchemistry blood analysis
- Iron
- Extracorporeal circulation* (nonblood- primed)
- Perfluorocarbons
- Cell-saver systems
- Erythropoietin*
- Hemodilution*
- Human albumin*

*Potentially unacceptable to many Jehovah's Witnesses and therefore best discussed with the individual patient.

**ANNOTATED BIBLIOGRAPHY**

**Religious Beliefs:**

**Legal Aspects of Care:**

**Medical Aspects of Care:**


A complete discussion of the religious and anesthetic considerations for the Jehovah's Witness patient. Many of the legal cases are reviewed in detail.


**Case, Part 1**

*A Jehovah's Witness "Needs" Blood*

A 52-year-old female presents for a same-day admission abdominal hysterectomy. She has been followed for a number of years by her gynecologist who recognizes that she is a Jehovah's Witness. Her past medical history is only pertinent for anemia attributed to her uterine leiomyomas for which she has been referred to an internist for preoperative iron supplementation. As an outpatient, her hemoglobin levels range between 10-10.5 g/dl. A dictated preoperative history and physical by the gynecologist is present on the chart that documents the patient's religion as a Jehovah's Witness. On the day of admission, however, neither the patient nor the gynecologist inform the anesthesiologist performing the preoperative history and physical of the patient's religious beliefs. The hospital consent form does not
discuss the possible need for intraoperative transfusion. The anesthesiologist directly involved in her case is also unaware of her prior verbal refusal of blood transfusion. During the course of the general anesthetic, she loses 1500 cc of blood acutely. Despite normal hemodynamics, the surgeon requests the patient receive 2 units of packed red blood cells. The anesthesiologist agrees to transfuse. The remainder of the case proceeds without further complications. On postoperative day one, the patient and her husband are astonished and dismayed at the revelation that she has been transfused. An eventual malpractice lawsuit is filed.

1) What is your understanding of the Jehovah's Witness' objection to blood transfusion?

2) Is there a consensus of legal opinion regarding the rights of this competent patient?

3) Are there situations in which the patient's rights are outweighed by the rights or interests of others (e.g., the physicians, hospital or state)? If so, how would these pertain to this case?

4) Who is ultimately responsible for directing intraoperative transfusion: the surgeon or the anesthesiologist? What if the surgeon was to convey to the anesthesiologist the patient's religious objection but still insisted on the transfusion?

5) Who then is responsible for obtaining consent for transfusion?

6) If a patient does not sign a written consent, are the patient's religious objections considered null and void?

7) If the patient were a known Jehovah's Witness, what course should the anesthesiologist take in caring for this patient in the preoperative setting?

8) Is the anesthesiologist obliged to deliver care in this case? What about in an emergency case?

9) What were the medical alternatives to transfusion in this case?

Case, Part 1, Instructor's Notes

1) The objection to blood transfusions is based on the biblical interpretation that accepting a blood transfusion will cause them to forfeit eternal salvation. How does the fact that this objection arises from religious beliefs affect its weight?

2) Care of the Jehovah's Witness is based on case law rather than statutory law. While the courts have some responsibility to consider previous case law, distinctions in cases may cause different legal outcomes.

3) Situations in which the patient's rights conflict and may be outweighed by the rights and interests of others center on situations in which a third party is affected. These include parturients, sole providers and minors.

4 & 5) This is a complex issue that includes other substantive concerns such as patient-anesthesiologist relationship and the role of the consultant. Neither provider necessarily has overriding decision-making authority. Once the anesthesiologist obtains informed consent from the patient and agrees not to give a transfusion, the anesthesiologist is honor-bound to fulfill that promise. If the anesthesiologist first hears about the patient's religious beliefs during the anesthetic, he or she must try to ascertain if there is a
viable written directive from that patient. In the absence of that directive and direct conversation with the patient, the anesthesiologist should probably transfuse. Of course, the anesthesiologist would have been better off to have ascertained the patient's preferences about transfusion therapy before the operation. Participants of this case discussion should consider which cases anesthesiologists should obtain informed consent for blood transfusion and what information should be provided.

6) A signed consent is desirable because it can clearly define the patient's preferences and provide support in discussions with other caregivers if the patient is unable to communicate (e.g., under general anesthesia). A signed consent also provides legal support. Lack of a signed consent, however, does not make the patient's transfusion preferences null and void. An anesthesiologist can base refusal of therapy on a thorough discussion with the patient (although documentation of the discussion is preferred, even without the patient's signature).

7) The anesthesiologist should clarify and agree to the patient's preferences, ensure that the surgeon was aware of and amenable to the patient's desires and use perioperative alternatives to blood transfusions.

8) An anesthesiologist is not obligated to provide care in the nonemergent situation, but he or she should make attempts to find alternate care. In emergency cases, the anesthesiologist should provide care until arrangements for a replacement can be made.

9) See the table (page D-2) and the article by Benson KT. Anesth Analg. 1989; 69:647-656.

Case, Part 2

A Question of Law

During the evidentiary proceedings, the surgeon and patient admit during deposition that neither had informed the anesthesiologist of the patient's religious beliefs, and a written refusal of transfusion form was never signed. Nonetheless, the anesthesiologist is named in the lawsuit and is also cited for having transfused the patient despite normal heart rate and blood pressure.

1) Is lack of knowledge regarding this patient's religious objection to transfusion, despite a preoperative written surgical history recognizing her as a Jehovah's Witness, sufficient evidence of the anesthesiologist's innocence?

2) Should the relative lack of medical need for transfusion be allowed into evidence as part of the malpractice proceeding?

3) Are there grounds for filing battery charges against the physicians involved?

Case, Part 2, Instructor's Notes

1-4) These are questions for an individual court to decide, and as noted, these matters are based on case law so there are no definable statutes upon which to base this discussion. Whether an anesthesiologist needs to discuss blood transfusions with a patient preoperatively depends in part on the likelihood of the
patient needing a transfusion. Perhaps the anesthesiologist should have broached the issue 
preoperatively as part of sound medical care; however, whether this conversation is required as 
"standard of care" remains debatable.

If the anesthesiologist were truly unaware of the patient's objection to blood transfusion, then he or she 
would not be held accountable for administering blood, as no clear-cut verbal or written directive was 
provided. In the event that a directive to withhold blood transfusion was specified, then the 
anesthesiologist was obligated not to transfuse. However, in this situation, one has to consider whether 
the transfusion was medically indicated. If the transfusion was not medically indicated, then the 
anesthesiologist may be held liable for not practicing the standard of care for blood transfusion in any 
patient.

The fact that the patient is a Jehovah's Witness may or may not be relevant in any ensuing damages 
awarded. Legally, however, the plaintiff's attorney would have to show that damages occurred due to the 
transfusion.

**Special Teaching Method**

**Mock Trial**

A mock trial may be an educational and entertaining way to examine the complexity and reasoning of 
the case law for Jehovah's Witnesses. It is quite possible that original decisions may be overturned by 
the mock appellate court.

Suggested situations and cases:

1) The competent adult who has no dependents and is in an emergency situation

*In re Estate of Brooks*, 205 N.E., 2d. 435, (1965). The court ruled that transfusing without the patient's 
consent was in violation of her constitutional rights.

state's interest to sustain life.

2) The competent adult who has dependents and is in an emergency situation

*In re President and Directors of Georgetown College*, Inc., 331 F.2d 1000 D.C.cir., (1964). The court 
authorized transfusions to the mother of a 7-month-old child.

*Holmes v. Silver Cross Hospital of Joliet*, Illinois, 340 F.Supp. 125, (1972). The court ruled that the 
patient's civil rights were violated when the patient (a father of one) was transfused with blood following 
a motor vehicle accident.

3) The pregnant adult

*In the matter of the Application of Jamaica Hospital*, 491 N.Y.2d. 898, (1985). The court appointed a 
conservator to be able to transfuse a pregnant Jehovah's Witness in case she hemorrhaged from her

http://www.asahq.org/wlm/Ethics.html

10/20/03
esophageal varices.

4) The minor patient

_Sampson v. Taylor_ , 29 N.Y.2d, 900 (1972). The court ruled to permit transfusions for a 15-year-old boy's elective operation to repair significant facial disfigurement secondary to neurofibromatosis.

The court ruled that a 17-year-old patient was a "mature minor" and therefore capable of refusing transfusions as part of the therapy to achieve remission of leukemia.

**APPENDIX I**

**ADVANCE MEDICAL DIRECTIVE/RELEASE**

I, , make this advance directive as a formal statement of my wishes. These instructions reflect my resolute decision.

I direct that no blood transfusions (whole blood, red cells, white cells, platelets, or blood plasma) be given to me under any circumstances, even if physicians deem such necessary to preserve my life or health. I will accept nonblood volume expanders (such as dextran, saline or Ringer's solution, or hetastarch) and other nonblood management.

This legal directive is an exercise of my right to accept or to refuse medical treatment in accord with my deeply held values and convictions. I am one of Jehovah's Witnesses, and I make this directive out of obedience to commands in the Bible, such as: "Keep abstaining from blood." (Acts 15:28, 29). This is, and has been, my unwavering religious stand for years. I am years old.

I also know that there are various dangers associated with blood transfusions. So I have decided to avoid such dangers and, instead, to accept whatever risks may seem to be involved in my choice of alternative nonblood management.

I release physicians, anesthesiologists, and hospitals and their personnel from liability for any damages that might be caused by my refusal of blood, despite their otherwise competent care.

I authorize the person(s) named on the reverse to see that my instructions set forth in this directive are upheld and to answer any questions about my absolute refusal of blood.

Signature Date

Address Telephone

Witness

Witness