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From the Editor

Towards Defining Paternalism in Medicine

The theme editor introduces an issue focusing on paternalism in medical decision making.

It is 1804. A physician peers over the rims of his spectacles at his patient. She says, "Doctor, I don't want to die. Please tell me what to do." He replies, "Mrs. Smith, we will treat your illness with these leeches, which will cleanse your blood of the disease. That, combined with cold water dousing each night, will cure you."

In Southern California 2 hundred years later, a cancer patient says, "Doctor, I don't want to die. I've heard about a new experimental treatment being tested at Stanford, and I want to enroll in their study. If that doesn't work, then I want to get my nutritionist and a herbalist involved."

The history of medicine has witnessed a gradual erosion of the physician's time-honored role as all-knowing healer. Whether physicians were experts in their fields, self-taught folk healers, or complete quacks, the doctor's words, for generations, were accepted as correct, complete, final, and to be obeyed. Indeed, the language of the 1847 *Code of Medical Ethics* of the American Medical Association, titled "Obligations of Patients to Their Physicians", endorsed this paradigm.

The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them. A failure in one particular may render an otherwise judicious treatment dangerous, and even fatal¹.

The patient was treated like a child; innocent, unschooled, and too simple to know how to take care of himself or herself. This wise father-simple child relationship led to an inherently paternalistic model of the physician- patient relationship.

But while science and technology have filled medical books with more and more treatment options and diseases are better understood, the instantaneous dissemination of news around the world has simultaneously rendered the public hyper-aware of the new capabilities of medicine. As a result, patients have shifted from approaching physicians with hope and faith to approaching them with high expectations—of precision, of speed, of a virtual superstore of treatment options.

Patients have taken the reins of health care with both hands. They come to doctor's offices armed with reams of printouts from health Web sites. They specifically request medicines or treatments advertised in popular magazines, on television, and on the Internet. In response to this type of informed (though sometimes misinformed) patient, many physicians have come to grant a greater level of autonomy or shared decision making to all the patients in their practices.

A turning point in the shift from physician paternalism to respect for patient autonomy was the requirement for the patient's informed consent to treatment. The concept of informed consent did not exist in writings on Egyptian, Greek, or Roman medicine. Indeed, the phrase "informed consent" was not used until the 1950s. The notion of "consent to treatment" was a consequence of the Nuremberg Trials that later became enshrined in the research and treatment codes of democratic nations.

Today, as any medical student or resident can tell you, most procedures in a hospital are preceded by explanations and discussions at the patient's bedside that make clear all the risks and benefits of the procedure. The consent conversation must be conducted by an MD, and the patient must be able to understand what he or she is being asked to agree to.

Reflecting the importance of informed consent in modern health care, an opinion from the current AMA *Code of Ethics*, on "Fundamental Elements of the Patient-Physician Relationship" states: "The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment"².

Society's awareness of this change in approach to the patient has altered the connotation of the word 'paternalism' and, hence, popular perception of the physician who acts in a paternalistic manner. Paternalism in a physician is often described in a negative context, indicating inappropriately archaic behavior.

The dramatic changes in the role and perception of paternalism in medicine have complicated the medical field that residents and medical students are trying to navigate. Students at the University of California, Irvine, are taught the "Five E's" of effective patient-centered communication from day 1 of medical school (engage, empathize, educate, enlist, and extend). Concepts such as the five E's illustrate a shift in power to the patient and the requirement that the physician adapt to that patient. While medical training can theoretically teach such adaptability through example, ensuring that programs turn out nonpaternalistic physicians is something of a challenge. The older generation of physicians training younger residents and students comes from a time when paternalism was the norm in good medical practice. Physicians of today must acknowledge this changing tide while exerting enough authority to ensure that patients suffer no harm and receive the best medical care possible.

This issue of *Virtual Mentor* gives us perspectives from various points along the long and tortuous continuum from absolute patient autonomy to outright physician paternalism. We seek to illustrate the range of possibilities for shared decision making and how each situation should dictate the exact combination of patient and physician input.

We present 3 hypothetical clinical cases for comment, including the dilemma of a physician caught between her obligation to help her patient and her reservations about recurrent abortions, the case of a patient who tries to make a deal with his doctor to delay medical treatment for the sake of convenience, and, finally, a situation in which parents wish to convince their child's physician to accept their treatment decision.

The Policy Forum questions whether resorting to quasi-legal statements of patients' "rights" is the most effective means for securing patient autonomy. The Medicine and Society articles conjecture that unfettered patient autonomy is not necessarily a good thing, and that patients who desire full autonomy may be missing out on the education and perspective that are valuable components of a physician office visit. The complex case of a patient who is incompetent is explored in the Health Law section.

We hope that this discussion of physician and patient decision making will inform our readers and provoke discussion among practicing physicians, residents, and medical students. We welcome and encourage comments and questions.

The learning objectives for this issue are:

1. Understand what makes a medical decision or action paternalistic.
2. Understand the range of possibilities for shared decision making by patient and physician.
3. Recognize situations that call for the physician to take a dominant role in decision making.
4. Understand the requirements for true autonomous decision making.

Sincerely, Monya De

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Case and Commentary

Paternalism, Commentary 1

Anne Drapkin Lyerly, MD

Case

Lisa Morgan arrives in the office of Dr. Karen Anderson, her obstetrician/gynecologist. Dr. Anderson, who is going over her schedule for the day, hopes that Lisa is not pregnant again. Less than 2 years ago, Dr. Anderson had performed a therapeutic abortion for Lisa, who is now 20 years old and unmarried. The doctor's concerns are confirmed when her medical assistant, Elena, informs Dr. Anderson that Lisa is in the office seeking another abortion.

From the beginning of the office visit, Dr. Anderson is frustrated with the interaction. Lisa seems to be taking the situation lightly. Perhaps she is embarrassed, but her behavior is complicating a situation that is already uncomfortable for the doctor. Dr. Anderson intensely dislikes performing abortions but will do one when she thinks it is best for her patient, as with Lisa's first one. Dr. Anderson, who has a daughter about Lisa's age, does not want Lisa to regard abortion as a form of birth control.

Before agreeing to perform an abortion, Dr. Anderson brings up the topic of birth control. At the time of Lisa's first pregnancy, she had not been using any contraception. This time, she had been using birth control pills prescribed by Dr. Anderson, but she was forgetful, missing scheduled pills frequently by her own admission. Dr. Anderson suggests a longer-acting form of birth control, such as Depo-Provera (by injection) or an intrauterine device. Lisa cringes at the thought of shots, even as infrequently as 4 times a year, and says she knows women who have had bad cramping and even infections from IUDs. She wants to stay on the pill.

Dr. Anderson tries to persuade Lisa, saying that she is likely to forget her pills again, just as she did during the past few weeks. Dr. Anderson feels as though she is repeating the same words over and over again, and she insists, somewhat angrily now, upon Depo-Provera. Lisa still shakes her head vigorously, saying that she prefers pills to shots.

Dr. Anderson says, "Wait here, Lisa, I'll be back in a minute," and abruptly leaves the room to regain her composure. She vents to her assistant Elena, saying "I'm not making any headway with this girl. What else can I do? I don't want her to just choose another clinic, but I don't think using abortion as a form of birth control is healthy for this girl. I've got to try to educate my patients."

Commentary 1

In this scenario, Karen Anderson, an obstetrician/gynecologist, struggles about whether to perform an abortion for her patient, Lisa Morgan. Because Lisa has had an abortion in the past, seems to be "taking the situation lightly," and elects not to change her method of contraception, Dr. Anderson is uncomfortable about performing the procedure for Lisa again.

Like many dilemmas regarding abortion, this scenario has several layers of moral complexity. At first glance, the issue at stake is whether Dr. Anderson's potential refusal to perform the abortion constitutes unjustified paternalism or if it instead represents justified concern for her patient's well-being. Closer inspection, however, suggests that the essence of the dilemma stems from the physician's personal moral unease about this patient's reasons for requesting termination of pregnancy.

First, let us consider the question of paternalism. Paternalism has been defined as the "intentional overriding of 1 person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose preferences or actions are overridden."¹ In this scenario, Dr. Anderson contemplates refusing to perform an abortion for what she perceives to be Lisa's "own good"—an action that satisfies the definition of paternalism. She doesn't want to send the wrong message by reinforcing a supposition that abortion is a "healthy" method of contraception. According to this reasoning, refusing to provide an abortion would send a stronger message that abortion is not a healthy method of contraception.

Dr. Anderson's attempted beneficence indicates unjustified paternalism for at least 2 reasons. First, if her goal is to ensure that Lisa is better educated about safe and reliable contraception, refusing to perform an abortion is hardly the means to do so. Although she has offered the patient alternative forms of contraception such as Depo-Provera and the IUD, she certainly has not exhausted the possibilities, such as transdermal contraception, the contraceptive ring, or the diaphragm.

Even if Lisa continues to elect oral contraception, Dr. Anderson could advise her further on how to increase compliance (ie, taking the pills after another daily activity, such as brushing her teeth or removing contact lenses). Finally, her discussion should include counseling about the risks associated with pregnancy termination so that Lisa can consider these in the context of her own short- and long-term reproductive decision making. Lisa is a sexually active adult and should be educated not by example (or unjustified paternalistic decision making on the part of her physician) but by clear, articulate verbal exchange.

Admittedly, the patient as described does not appear to be optimally receptive to counseling, which brings us to the second flaw in the physician's rationale for paternalistic behavior. Even if further attempts at communication fail, Dr. Anderson would not be justified in refusing to provide the abortion for the patient's "own good." As a physician, she is not in a position to know better than Lisa what would be in Lisa's best interest. It is likely that Lisa, like many women considering abortion, will not disclose all of the considerations that led her to seek an abortion—particularly in light of what seems to be a judgmental and emotionally charged reaction on the part of her physician. One scholar in the field of abortion research reflected on a woman who:

...had three abortions in two years, but chose to keep using the rhythm method. I recall feeling puzzled by her insistence on an obviously ineffective method. A year later she came into my private office for psychotherapy; she wanted help in leaving her battering husband. It was he who had forbidden her to use any other form of birth control.²

Women's stories are complex, contextualized, and often unavailable to the individuals who perform their abortions. Assuming we can make conclusions about our patients' best interests during a short clinic visit—particularly decisions about reproduction—is at best presumptuous, at worst an arrogant and maleficent way to attend to patients as they work through difficult reproductive decision making.

Let us move, however, beyond the question of paternalism to what I perceive is at the heart of Dr. Anderson's dilemma: an apparent conflict between her values and those of her patient. Suppose that Dr. Anderson does in fact have a relatively detailed understanding of the patient's reasons for undergoing an abortion and that these reasons seem unethical to her. Perhaps she thinks that Lisa is approaching the decision to terminate her pregnancy with the wrong moral stance, and she (Dr. Anderson) simply does not want to be complicit in an act that to her is ethically problematic. How can Dr. Anderson resolve this dilemma?

On the one hand, a physician may, except in emergencies, choose whom to serve.³ Thus, Dr. Anderson is not obligated ethically to provide an abortion for Lisa and could refer this patient to another provider for these services. Closer analysis suggests, though, that continuing to provide care—even an abortion—for Lisa, would actually be an ethically preferable decision.

One reason that continuing to care for Lisa would be ethically preferable is that, despite Dr. Anderson's initial analysis, Lisa may in fact have reasons for pregnancy termination that the physician could understand to be morally acceptable. Moreover, even if Lisa's reasons for pregnancy termination seem shallow or patently wrong to Dr. Anderson, she cannot know her patient well enough to judge whether her action is morally acceptable in the context of Lisa's life. As philosopher Maggie Little has eloquently argued,

Deciding when it is morally decent to end a pregnancy, it turns out, is an admixture of settling impersonally or universally authoritative moral requirements, and of discovering and arbitrating—sometimes after agonizing deliberation, sometimes in a decision no less deep for its immediacy—one's own commitments, identity, and defining virtues.⁴

Note that Dr. Anderson's commitments, identity, and defining virtues are different from Lisa's, and recognizing that difference is critical to her appreciating an acceptable discrepancy between her own ethical decision making in a similar situation and that of her patient.

Secondly, as a physician who has decided to provide abortions, it is important for Dr. Anderson to consider her services in light of the history of abortion in the United States. Restricted access to abortion has historically been a serious public health problem for women. While a detailed discussion of this is beyond the scope of this commentary, studies indicate that before the legalization of abortion in 1973, 17 percent of pregnancy-related deaths were the result of illegal abortion. Presently, the risk of death from abortion is significantly less than the risk of death associated with carrying a pregnancy to term.⁵ Dr. Anderson may find her role in improving access to abortion by providing abortion services in a private, safe, and nonjudgmental clinical setting.

Physicians who are involved with patient decision making about reproduction interface with some of the most private, personal, and important decisions of an individual's life. Facilitating patients' own reasoned and reflective decisions about reproduction will almost always promote the best interests of our patients in particular and the health of women in general.

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Case and Commentary

Paternalism, Commentary 2

Barbara Katz Rothman, PhD

Case

Lisa Morgan arrives in the office of Dr. Karen Anderson, her obstetrician/gynecologist. Dr. Anderson, who is going over her schedule for the day, hopes that Lisa is not pregnant again. Less than 2 years ago, Dr. Anderson had performed a therapeutic abortion for Lisa, who is now 20 years old and unmarried. The doctor's concerns are confirmed when her medical assistant, Elena, informs Dr. Anderson that Lisa is in the office seeking another abortion.

From the beginning of the office visit, Dr. Anderson is frustrated with the interaction. Lisa seems to be taking the situation lightly. Perhaps she is embarrassed, but her behavior is complicating a situation that is already uncomfortable for the doctor. Dr. Anderson intensely dislikes performing abortions but will do one when she thinks it is best for her patient, as with Lisa's first one. Dr. Anderson, who has a daughter about Lisa's age, does not want Lisa to regard abortion as a form of birth control.

Before agreeing to perform an abortion, Dr. Anderson brings up the topic of birth control. At the time of Lisa's first pregnancy, she had not been using any contraception. This time, she had been using birth control pills prescribed by Dr. Anderson, but she was forgetful, missing scheduled pills frequently by her own admission. Dr. Anderson suggests a longer-acting form of birth control, such as Depo-Provera (by injection) or an intrauterine device. Lisa cringes at the thought of shots, even as infrequently as 4 times a year, and says she knows women who have had bad cramping and even infections from IUDs. She wants to stay on the pill.

Dr. Anderson tries to persuade Lisa, saying that she is likely to forget her pills again, just as she did during the past few weeks. Dr. Anderson feels as though she is repeating the same words over and over again, and she insists, somewhat angrily now, upon Depo-Provera. Lisa still shakes her head vigorously, saying that she prefers pills to shots.

Dr. Anderson says, "Wait here, Lisa, I'll be back in a minute," and abruptly leaves the room to regain her composure. She vents to her assistant Elena, saying "I'm not making any headway with this girl. What else can I do? I don't want her to just choose another clinic, but I don't think using abortion as a form of birth control is healthy for this girl. I've got to try to educate my patients."

Commentary 2

Abortion seems to be unique among procedures doctors perform, in that physicians' personal distaste for performing them is considered reason enough not to do them. A physician who, for example, really hates to attend the births of children with Down syndrome, cannot tell her patients, "You really must have prenatal diagnosis and abort if Down syndrome is diagnosed, because I hate to do those births." Or, less morally

fraught, a doctor who finds setting bones distasteful, just does not like to do it, cannot say to a patient: "You really must stop skiing because I hate to set bones." But a physician who "intensely dislikes performing abortions" is allowed to have that influence her practice and even her patient's treatment.

Karen dislikes performing abortions: no reason is given. No reason has to be given, it seems, if it is abortion. Its "unlike-ability" is taken for granted.

Ms Morgan is a sexually active, fertile woman who has experienced her second pregnancy in less than 2 years. At the time of her first pregnancy, she was not using any contraception and is now somewhat erratically taking birth control pills. Unless there was a long unexplained period of sexual abstinence between the last pregnancy and this one, she has apparently been fairly successful in her contraception. A 20-year-old, demonstrably fertile woman who does not conceive for almost 2 years is almost by definition fairly effective in her contraception.

We now are faced with a conflict between what Karen feels comfortable doing and what Ms Morgan feels she needs to have done. We are being asked to think of Karen as maternal: she has a daughter Ms Morgan's age, we are informed, and she tells her assistant that she is worried about the girl's health and needs to "educate" her patients.

What if we were to provide Karen with convincing data that barrier contraception and early abortions every 2 or so years are physically safer for Ms Morgan than Depo-Provera or than an IUD? Would that ease Karen's discomfort? Would she so educate her patients? If so, then we can ask whether Karen is behaving paternalistically. Paternalism is not just about power: it is the power of the parent, a power used in the perceived best interests of the other. If I force a child to have a vaccine, even though he or she really hates having the shot, I am doing so in the best interests of the child, doing something I believe he or she will "thank me for later." That, I believe, is what marks a particular use of power as "paternalistic."

I think that is not the case here though: it is not the safety of early abortion for her patients that troubles Karen but the act of abortion itself. It is, then, rather disingenuous for her to say that using abortion as a form of birth control is not healthy for this girl or for us to be asking whether this is paternalistic behavior on her part. Karen does not like, intensely does not like, to perform abortions, and she does not want her patients to have them. She would like Ms Morgan, and presumably her other patients, to do whatever it is they have to do to avoid putting Karen in the difficult position of having to do something she dislikes doing.

I regard that as inappropriate and unprofessional and an attempt at abusing her power; I do not think it rises to a standard of paternalism.

Barbara Katz Rothman, PhD is professor of sociology, City University of New York. Her first book was *In Labor: Women And Power In The Birthplace*. More recently, she published *The Book Of Life*, an ethical guide to issues involved with the human gene map, race, and normality.

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When the Physician's Medical Judgment is Rejected, Commentary 1

Kirsten G. Engel, MD

Case

Ian Douglas is a 53-year-old businessman who works long hours and is enjoying a successful and lucrative career. He has been smoking on and off for 25 years. He knows it's a bad habit that could destroy his lungs, but he just can't quite kick it. Lately, Mr. Douglas has been feeling tired, and every so often when he is really busy at work or when he exercises, he has chest pains. He has trouble breathing when he climbs a flight of stairs. He doesn't think his wife has noticed that this has been happening for about 6 months. The other week Mr. Douglas and his wife, Lynn, sat down to talk to their teenage son, Alec, who was failing 2 of his classes. Mr. Douglas blew up at Alec and started yelling at him for being so irresponsible. The chest pains started again and crept up the side of his neck. He had to stop mid-lecture and lie down. That's when Lynn said that, if she had to drive him to his internist herself, he was going to see a doctor.

When he went to see Dr. Coral, Mr. Douglas explained that he was having chest pains that lasted no longer than 5 minutes, which were always relieved by rest. He told Dr. Coral how he'd been having the symptoms for a while, but they didn't seem to be getting any better or any worse. Dr. Coral got an EKG in the office, which was normal, and had him undergo a stress test. Mr. Douglas had to stop the test on the treadmill early because he started feeling fatigued and having mild chest pains. Dr. Coral explained to him that the tests showed some ischemia and marked ST changes on his EKG. He told Mr. Douglas that he needed to make an appointment for an angiogram in the next day or 2 to better evaluate his coronary arteries.

Mr. Douglas made the appointment for the angiogram but didn't tell his wife. There was no reason to make her worry. Now he is recovering in the procedure room in his paper gown waiting for Dr. Coral to come back with the results from the angiogram. Mr. Douglas looks down at his gut and sighs.

"I really gotta start listening to Lynn when she tells me to go to the gym. I must be pushing 240 now," he thinks to himself. Dr. Coral enters the room with a serious look on his face.

"Mr. Douglas, I have both good and bad news for you," he pauses. "The angiogram shows that your 3 main coronary arteries are all severely blocked. The good news is that we caught this before you had a major heart attack."

Mr. Douglas lets out a sigh and waits to hear the rest.

"The bad news is that I am recommending you have triple bypass surgery as soon as possible."

Mr. Douglas gasps, "What do you mean triple bypass? Don't you think that's jumping the gun, I just have a little heart problem, right?"

Dr. Coral shakes head, "No, Mr. Douglas, quite frankly, you are at risk of having a serious heart attack. There is no question that this surgery is necessary, and I would like it to happen as soon as possible."

"Now, look, I understand I've got to do something about this. I'll quit smoking, and I'll go the gym, but I'm not having open heart surgery for these little chest pains."

"Mr. Douglas, I understand that you believe your symptoms don't warrant major surgery, but your heart is working overtime right now. It is just a matter of time before it gives out. You have to start eating better, and going to a gym, and you have to stop smoking, but you also have to have surgery. Period."

"Doc, I have a major deal that has to go through at work over the next several months. How about I start taking care of myself, and you let me get this deal signed, and then we'll talk about the surgery?"

Dr. Coral shakes his head. What can he tell this patient to make him understand that he might not make it to finish the business deal if he doesn't have surgery?

Commentary 1

Mr. Douglas's response evokes both distress and frustration. From a physician's perspective, this man is lucky to be alive, and surgery is his best and only opportunity to prevent an imminent catastrophic event. So, how should Dr. Coral respond to the patient's seemingly irrational resistance to a lifesaving intervention? The physician must strike a difficult balance in this situation: demonstrating respect for the patient's personal wishes and values, while preventing harm to the patient. This scenario introduces little doubt about the right decision for this patient. Instead, it raises 2 important questions about how the physician should approach this interaction. First, what should the physician say or do to help the patient make a decision in favor of the surgery? Secondly, is it possible that the physician could ever accept a treatment refusal from this patient?

As background to the first question, it is appropriate to consider briefly why the physician should want the patient to be part of the decision-making process. In this case, it seems obvious that the patient needs the surgery, so why not just tell the patient that and leave no alternative? Efforts to share decision making with patients are important because they acknowledge patients' rights to hold views, to make choices, and to take actions based on personal values and beliefs.¹ In sharing the decision making process with a patient, the physician actively engages the patient and supports his or her efforts to make a decision that is consistent with his or her individual values. Such collaborative or patient-centered decision making is not only ethically sound, but also leads to improved patient health outcomes.²

Patient participation in decision making depends on intact decision-making capacity (DMC); in other words, an assessment that the patient is capable of making a decision. DMC is based on 4 guidelines: the patient is able (1) to understand the information about the condition and the choices available; (2) to make a judgment about the information in keeping with his or her personal values and beliefs; (3) to understand the potential outcomes or consequences of different choices; and (4) to freely communicate his or her wishes.^{1, 2, 3} Mental status changes, psychiatric disease, or cognitive deficits frequently interfere with patients' DMC in an obvious and dramatic fashion. Even in the absence of such diseases or conditions, however, a patient's ability to make a decision may be impaired by more subtle factors. Mr. Douglas is a successful businessman who demonstrates no sign of cognitive difficulties or mental illness; however, his capacity to make a "good" health decision is clearly impaired. By keeping in mind the 4 elements of DMC, it is possible to gain greater insight into Mr. Douglas's responses and what the physician may be able to do to help facilitate his decision-making process.

As we think about how to respond to Mr. Douglas, we first need to ask ourselves, whether he understands the information that the physician has told him about his condition and the choices available to him. Although Dr. Coral's report is quite clear from a physician's perspective, we are not so sure if Mr. Douglas really understands what he has been told. One way to uncover misinterpretation or lack of comprehension is simply to ask Mr. Douglas to state his understanding of the problem and the management choices. In addition, it might be helpful to review in more detail the significance of the extent of disease (all 3 main vessels) and degree of stenosis (almost 100 percent blocked). Since Mr. Douglas seems to think that lifestyle modifications are still an alternative to the surgery, it would also be beneficial to clarify the important differences between the effectiveness of these interventions for treatment and prevention purposes, respectively.

Yet, a lack of information and understanding may not be the only issue involved in Mr. Douglas's resistance to the surgery. It would also be important for his physician to elicit the reasons behind his ambivalence. Mr. Douglas alludes to pressing business obligations as a reason to delay surgery. Is this really the reason, or is he simply afraid of having surgery? Or does he not want to have the surgery because he will have to tell his wife and is afraid of upsetting her? It is important to realize that the surgery may represent an undesirable loss of control for the patient and, thereby, cause him to accept higher risks with regard to his future health.⁴ By directly acknowledging and addressing the patient's concerns, the physician may facilitate a decision for the surgery. The physician should also encourage the patient to think about analogous health choices that may clarify his thinking. For example, would the patient continue walking on a broken leg when surgery was recommended? In some situations, family members may be allies who will also help to remind patients of how their current choices are inconsistent with previous experiences or decisions.

As one thinks about how to formulate a response to a resistant or ambivalent patient, such as Mr. Douglas, it is also important to consider the last 2 DMC guidelines: does the patient understand the potential outcomes or consequences of his choices and can he freely express his wishes? In such situations, it is critically important to use clear and unambiguous language in order to avoid misinterpretation. Specifically, Mr. Douglas should be told that his condition is life-threatening and that he will die without this surgery. If the situation is handled correctly, it is possible to fully disclose the seriousness of an illness without alienating the patient or precipitating detrimental stress or feelings of hopelessness.³ In addition, the physician should be sensitive to external forces or pressures that may be influencing the patient and interfering with his ability to express his true wishes. This may be particularly relevant for elderly patients who are heavily dependent on others and concerned that certain choices will increase the burden on family members.

If a physician feels that a patient is not able to fulfill 1 or more of the elements of DMC then his or her ability to make that decision should be brought into question and surrogate decision makers should be sought. For more serious decisions, the standards for DMC should be higher than for less important decisions or those with less significant outcome differences among the choices.⁵ But what does one do if the patient demonstrates the highest level of DMC and is still making a bad choice? Could a physician ever accept a choice such as Mr.

Douglas's refusal of surgery? Such a circumstance would require a physician to violate the obligation to prevent patient harm and, therefore, would demand consultation with an ethics committee. In this situation, the physician should remain compassionate and respectful, while reviewing the expected outcomes of the patient's choice and providing strong and consistent advice that opposes this decision.

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When the Physician's Medical Judgment is Rejected, Commentary 2

Robert E. Cranston, MD

Case

Ian Douglas is a 53-year-old businessman who works long hours and is enjoying a successful and lucrative career. He has been smoking on and off for 25 years. He knows it's a bad habit that could destroy his lungs, but he just can't quite kick it. Lately, Mr. Douglas has been feeling tired, and every so often when he is really busy at work or when he exercises, he has chest pains. He has trouble breathing when he climbs a flight of stairs. He doesn't think his wife has noticed that this has been happening for about 6 months. The other week Mr. Douglas and his wife, Lynn, sat down to talk to their teenage son, Alec, who was failing 2 of his classes. Mr. Douglas blew up at Alec and started yelling at him for being so irresponsible. The chest pains started again and crept up the side of his neck. He had to stop mid-lecture and lie down. That's when Lynn said that, if she had to drive him to his internist herself, he was going to see a doctor.

When he went to see Dr. Coral, Mr. Douglas explained that he was having chest pains that lasted no longer than 5 minutes, which were always relieved by rest. He told Dr. Coral how he'd been having the symptoms for a while, but they didn't seem to be getting any better or any worse. Dr. Coral got an EKG in the office, which was normal, and had him undergo a stress test. Mr. Douglas had to stop the test on the treadmill early because he started feeling fatigued and having mild chest pains. Dr. Coral explained to him that the tests showed some ischemia and marked ST changes on his EKG. He told Mr. Douglas that he needed to make an appointment for an angiogram in the next day or 2 to better evaluate his coronary arteries.

Mr. Douglas made the appointment for the angiogram but didn't tell his wife. There was no reason to make her worry. Now he is recovering in the procedure room in his paper gown waiting for Dr. Coral to come back with the results from the angiogram. Mr. Douglas looks down at his gut and sighs.

"I really gotta start listening to Lynn when she tells me to go to the gym. I must be pushing 240 now," he thinks to himself. Dr. Coral enters the room with a serious look on his face.

"Mr. Douglas, I have both good and bad news for you," he pauses. "The angiogram shows that your 3 main coronary arteries are all severely blocked. The good news is that we caught this before you had a major heart attack."

Mr. Douglas lets out a sigh and waits to hear the rest.

"The bad news is that I am recommending you have triple bypass surgery as soon as possible."

Mr. Douglas gasps, "What do you mean triple bypass? Don't you think that's jumping the gun, I just have a little heart problem, right?"

Dr. Coral shakes head, "No, Mr. Douglas, quite frankly, you are at risk of having a serious heart attack. There is no question that this surgery is necessary, and I would like it to happen as soon as possible."

"Now, look, I understand I've got to do something about this. I'll quit smoking, and I'll go the gym, but I'm not having open heart surgery for these little chest pains."

"Mr. Douglas, I understand that you believe your symptoms don't warrant major surgery, but your heart is working overtime right now. It is just a matter of time before it gives out. You have to start eating better, and going to a gym, and you have to stop smoking, but you also have to have surgery. Period."

"Doc, I have a major deal that has to go through at work over the next several months. How about I start taking care of myself, and you let me get this deal signed, and then we'll talk about the surgery?"

Dr. Coral shakes his head. What can he tell this patient to make him understand that he might not make it to finish the business deal if he doesn't have surgery?

Commentary 2

When a patient behaves dangerously, the physician should first try to determine if the patient is aware of the dangers, and whether the patient has decisional capacity in dealing with this danger. (Competency, per se, technically refers to a legal judgment, while decisional capacity is determined by a physician at the bedside.) In this case it is quite likely that Mr. Douglas does have decisional capacity. His behavior, nonetheless, is so questionable that a thorough history evaluating all factors that might be causing this poor decision making should be explored. How well does Dr. Coral know the patient? Has Mr. Douglas had any recent financial setbacks? Is his company in dire straits? Has his relationship with his wife changed? Is he depressed? What other psycho-social variables are present? Does Dr. Coral need to obtain immediate psychiatric consultation?

If each of these factors is explored and no obvious reason for his behavior is found, then we may be dealing with either a misunderstanding of the critical severity of the coronary artery disease or, more likely, denial. The interventions Mr. Douglas is suggesting are quite unlikely to correct his emergent condition. If Dr. Coral is convinced that his patient comprehends the facts of the situation, then he needs to deal more directly with the denial. Denial can at times serve a useful purpose, but in this setting would appear to be maladaptive. Dr. Coral would need to consider how to break through Mr. Douglas's denial.

We take great pains to obtain informed consent prior to undertaking potentially harmful procedures or medical therapies. We should do the same with informed refusal. Dr. Coral needs to make certain that his patient is fully informed regarding risks of not having a procedure done—the likely consequences, the lack of efficacy of the patient's proposed interventions, and the lack of other efficacious interventions. It is ethically necessary to make certain these are explored. Additionally, from a liability perspective, if he is unable to persuade Mr. Douglas to proceed with the bypass surgery, Dr. Coral might be well-advised to have the patient sign an Against Medical Advice document. At a minimum, Dr. Coral should meticulously document the extent and content of their discussion. Videotaping the discussion might prove necessary later if Mr. Douglas experiences a bad outcome and he or his estate accuses Dr. Coral of being negligent in fully apprising him of the dangers associated with his decision. Taking this step might also impress upon the patient of the seriousness of the situation.

A pure autonomy position would dictate that after Dr. Coral has explained this to Mr. Douglas, he should refrain from any form of coercion, allowing the patient to make his own decision. In issues of minor importance, taste, or simple preference, this might be appropriate. However, in this case, the potential outcome from an inappropriate decision is so critical that Dr. Coral has a fiduciary obligation to attempt to persuade Mr. Douglas not to act in a dangerous manner, and the line between persuasion and coercion may not be crystal clear. While most psychiatrists would not likely find his behavior worthy of involuntary hospital admission—as an imminent danger to himself or others—no one would argue that his plans were wise. When a patient's decisions are so poorly conceived, any conscientious doctor is compelled to attempt to dissuade the patient from foolish action. Coercion is unethical, but there is certainly a place for energetic persuasion in scenarios such as this.

Under federal HIPAA regulations, the doctor is not legally allowed to discuss Mr. Douglas's medical history with anyone unless the patient permits him to. Since Mr. Douglas didn't tell his wife he was having the heart catheterization, one would doubt that Mr. Douglas would be open to having the doctor discuss these new findings with her. However, Dr. Coral could certainly ask him directly, as opposed to assuming that permission would be denied. If Mr. Douglas refuses, then Dr. Coral might ask if the patient has any other confidant(s) that he could bring into the discussion. It may be that even though he won't tell his wife, he might be willing to share with his pastor, his brother, or his best friend. Dr. Coral should try to find an ally in persuading his patient to act more safely.

This also raises a question of certainty in prognostication. Medicine is an inexact science. While Dr. Coral is convinced of the immediate danger of delaying the bypass, he may be incorrect. Unlike mathematics, biological variability plays a major role in determining outcomes in medicine, and medical judgments regarding prognostication may vary. Dr. Coral might exploit this lack of certainty in prognostication to persuade his patient to see another doctor for a second opinion. If Mr. Douglas hears the same concerns strongly from 2 physicians it might change his mind. If this avenue is pursued, it would be imperative that the second opinion be obtained expeditiously, to minimize risk to Mr. Douglas.

If all else fails, and Dr. Coral is convinced that by postponing intervention Mr. Douglas is gravely endangering himself, he could choose to break confidentiality. HIPAA says it is illegal to inform anyone else of the contents of a patient-physician discussion, but if Mr. Douglas dies due to his postponement of the procedure, this will be small comfort for Dr. Coral and no comfort for Mr. Douglas's family. Is there a time when confidentiality should be breached in favor of saving a life? Historically, the answer has been "No." The Hippocratic Oath spells out the importance of confidentiality in patient-physician relations. On the other hand, the oath is rather short, and doesn't cover all eventualities. In the *Tarasoff* decision, the state of California was in the wrong for not breaking confidence. The court held that the state-employed psychologist had an obligation to break the patient's confidence in order to prevent injury to Tatiana Tarasoff. If the psychologist had exercised appropriate responsibility in warning her, she might still be alive today. In Mr. Douglas's case, exercising appropriate responsibility in warning Mrs. Douglas of her husband's dangerous decision might save his life and prevent Mrs. Douglas from becoming a widow and their children from becoming fatherless.

In conclusion, this vignette raises issues of decisionality (competency in a broad, but not legal, sense), autonomy, coercion vs persuasion, and confidentiality. One would hope that if Dr. Coral cannot resolve this difficult conundrum, he will seek out other resources available to him—wise friends, spiritual counselors, an ethics consult, or legal advisors—who will assist him in preventing the patient's untimely death.

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Case and Commentary

Finding the Balance in Shared Decision Making, Commentary 1

Ellen Painter Dollar

Case

Mr. and Mrs. Delgado had been closely involved in the treatment decisions and medical care of their 11-year-old son, Tony, since he was diagnosed with acute lymphocytic leukemia (ALL) at age 10. Both parents are teachers. During Tony's initial hospitalization, they alternated missing work; one's class would have a substitute teacher, then the other's would. One parent was always by Tony's side. The Delgados studied ALL so as to understand Tony's symptoms, their physiologic causes, and the blood levels that indicated how well Tony's treatment was working. They insisted on seeing all lab reports and discussing them with Tony's oncologist, Dr. Carmichael.

Dr. Carmichael supported the Delgados' endeavors from the beginning. He believed in educating his patients (or their parents) about whatever type of leukemia affected them, explaining his actions and decisions in as much detail as his listeners could absorb. Because either Mr. or Mrs. Delgado was always at the hospital, the Delgados' participation had never caused delay in Dr. Carmichael's decision making.

Tony had been in remission for 5 months when Mrs. Delgado took him to Dr. Carmichael, saying that he had a fever and flu-like symptoms. The history corroborated Mrs. Delgado's flu diagnosis, and Dr. Carmichael got a CBC and smear and ordered a peripheral blood culture, all of which were normal. Because of the viral flu explanation for Tony's fever, Dr. Carmichael suggested no antibiotic treatment and no hospitalization at the present. The Delgados disagreed, fearing that Tony's fever and fatigue signaled the return of an acute flare-up in the ALL. Dr. Carmichael cited recent pediatric hematology and oncology literature in support of his treatment decision. He advised that they watch Tony for the next few days and, if his flu resolved, wait until the next routine blood test in about 6 weeks before taking any further action. He had seen many children like Tony, he told the Delgados, and, in his judgment, the more time they spent at home living normal lives, the better.

During the discussion, the Delgados mentioned that both had used all their available personal time off during Tony's prior hospitalizations and would have to have someone else stay at home with him. They thought he would be better off in the hospital under professional care. Again Dr. Carmichael offered his medical judgment on the issue, mentioning that hospitalization carried an increased risk of other infections as well as psychological trauma for Tony. The Delgados said they didn't care much about other patients or "the literature." Tony was their son, and they wanted the best care for him. They believed the best care was hospital care. After working so well together for almost 2 years, Dr. Carmichael and the Delgados seemed to be at an impasse.

Commentary 1

I am the mother of a 4-year-old girl with a chronic disorder called osteogenesis imperfecta, or OI, a genetic disorder that causes affected people to have fragile bones. Like Tony, my daughter has frequent medical treatments and hospitalizations. Like the Delgados, my husband and I educate ourselves as much as possible about our daughter's condition by connecting with other families living with the disorder, reading current medical literature, and discussing matters in depth with our daughter's physicians. I see several reasons why the Delgados might disagree with Dr. Carmichael's "wait and see" approach to Tony's flu.

The Fear Factor

The Delgados are likely terrified by Tony's current symptoms. This case study doesn't tell us how Tony was originally diagnosed with ALL, but it's probable that initially, when he didn't feel well, his parents wrote it off as something harmless for some time before discovering that their son actually had a life-threatening illness. Seeing their child once again listless, feverish, and not "himself" may have awakened powerful feelings of helplessness and a determination not to let their guard down this time.

No matter how well-versed parents are in medical literature, no matter how convinced they are of the value of consulting research-based evidence before making decisions, there is a limit on the power of medical literature to allay parental fears and overcome parental intuition.

An example: I belong to an e-mail listserv of parents raising children with OI. Most parents who are expecting a baby known prenatally to have OI ask for a cesarean delivery, and many parents whose babies with OI were born vaginally are convinced that the delivery increased the number of fractures and amount of pain their babies had at birth. A recent study of delivery methods for infants with OI, however, shows that cesarean sections are not necessarily safer for babies with OI than vaginal delivery. While aware of the recent study, many of the parents I communicate with (who are largely very well-educated about OI and interested in medical literature) say that no study can overcome their intuitive conviction that uterine contractions and passage through a narrow birth canal are too risky for a fragile baby. When it comes to their child's safety and pain, they are unwilling to trust a medical study over their own gut feelings. I imagine the Delgados feel likewise.

The anxiety that the Delgados carry from day to day, knowing that their child has a grave illness that could resurface at any time, goes far beyond the normal worries that all parents have. Tony's flu increases the anxiety considerably. Not only are his parents worried that this illness signals a flare-up of his ALL, they are also worried about keeping their employers happy, and finding someone they trust to care for Tony while he is home recovering. The stress they are under no doubt colors their abilities to hear and accept Dr. Carmichael's medical judgment, no matter how well-reasoned it is.

How can the Delgados and Dr. Carmichael reach an agreement?

Dr. Carmichael is making valid recommendations for how to cope with Tony's flu. It would be irresponsible of him to hospitalize Tony against his better medical judgment, given his feelings that home is the healthiest place for Tony, both physically and emotionally. However, there are several things he can do that might reopen communication with the Delgados and help them problem solve as a team.

1. *Empathize.* Sharing more medical facts and research evidence won't help resolve this situation. If Dr. Carmichael acknowledges the emotions that affect the Delgados' decisions—their fear, fatigue, and anxiety—they might be more receptive to talking about alternatives to

hospitalization. Feeling understood and "heard" may help them remember that the doctor is their ally, someone who also has Tony's best interests at heart.

2. *Honor the parents' fears and intuition.* Dr. Carmichael suggested waiting until Tony's next routine appointment in 6 weeks before doing anything else. Instead, he could offer to see Tony again in a much shorter time, perhaps a week or so. This offer would help the Delgados feel that their fears about Tony's illness are not being brushed aside. They would feel more confident that something important won't be missed while Tony is recovering at home or during the 6 weeks until the next appointment.
3. *Help address their employment dilemma.* Dr. Carmichael can offer to write a letter to the Delgados' employers explaining why they need additional days off to care for Tony at home. He, or someone in his office, could refer them to a hospital social worker or the equivalent to talk about arranging home care for Tony if they absolutely cannot stay home to care with him. He could simply ask if they have any friends or family who might be able to stay with Tony for a few days. While it is not Dr. Carmichael's responsibility to solve the Delgados' employment problem, simply by acknowledging that the problem exists, asking a few questions, and offering a few suggestions, he might help them take a step back from the problem and think creatively about ways to solve it.

Ellen Painter Dollar is a freelance writer and a mother with a personal interest in the health care system. She is the author of *Growing Up with OI: A Guide for Children*. Ms Dollar and her 4-year-old daughter have Type I OI.

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Case and Commentary

Finding the Balance in Shared Decision Making, Commentary 2

Daniel A. Beals, MD

Case

Mr. and Mrs. Delgado had been closely involved in the treatment decisions and medical care of their 11-year-old son, Tony, since he was diagnosed with acute lymphocytic leukemia (ALL) at age 10. Both parents are teachers. During Tony's initial hospitalization, they alternated missing work; one's class would have a substitute teacher, then the other's would. One parent was always by Tony's side. The Delgados studied ALL so as to understand Tony's symptoms, their physiologic causes, and the blood levels that indicated how well Tony's treatment was working. They insisted on seeing all lab reports and discussing them with Tony's oncologist, Dr. Carmichael.

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During the discussion, the Delgados mentioned that both had used all their available personal time off during Tony's prior hospitalizations and would have to have someone else stay at home with him. They thought he would be better off in the hospital under professional care. Again Dr. Carmichael offered his medical judgment on the issue, mentioning that hospitalization carried an increased risk of other infections as well as psychological trauma for Tony. The Delgados said they didn't care much about other patients or "the literature." Tony was their son, and they wanted the best care for him. They believed the best care was hospital care. After working so well together for almost 2 years, Dr. Carmichael and the Delgados seemed to be at an impasse.

Commentary 2

Can a physician be compelled to provide care he or she thinks is unnecessary? Does the patient-physician relationship obligate the participants to anything more or less than strict scientifically based therapy? Can a spiritual approach influence the resolution of this problem? These questions are the crux of this bioethical dilemma.

Let us deal with the first question. Should a physician offer or render care that is not indicated or necessary? The American Medical Association *Code of Medical Ethics* answers this question succinctly in Opinion 8.20 on Invalid Medical Treatment. It states that treatments with no medical indication should not be used. It goes on to say that even in treatments that are medically indicated, if the treatment is regulated (such as precertification for hospital admission) the physician should abide by those regulations. Opinion 2.19, Unnecessary Services, states that physicians should not provide services they know are unnecessary.^{1, 2} In this case, Dr. Carmichael has performed a workup to assess whether there is an indication for specific therapies such as antibiotics or in-hospital observation. Finding none, he is being ethically responsible in the therapy he does recommend, namely observation at home and scheduled follow-up lab tests. Even if he were willing to treat the patient with antibiotics and hospitalization, he would likely have to "game the system" to acquire precertification. This would be dishonest and wasteful of medical resources, not to mention legally fraudulent.

How Close a Relationship?

The second question is not so easily answered. The case scenario intimates a close patient-physician relationship between Dr. Carmichael and the Delgados. Dr. Carmichael has done much to empower the Delgado parents to participate in care and decision making. A problem is now encountered when that high level of participation results in a disagreement about care and may threaten the entire relationship built up over 2 years. We must remember the Delgados' perspective in this issue. Parents of pediatric cancer survivors will typically have increased anxiety over even trivial medical problems. As a pediatric surgeon, I have examined my share of completely normal lymph nodes in patients who are in remission from lymphoma because the parents were sure it was a recurrence. Knowing that these parents have a distorted perspective³ is not enough. We have to deal with it in some way.

One way to address the problem would simply be to tell the parents they are overreacting. This would avoid unwarranted medical treatment but would not resolve the tension between patient and physician. Bernard Häring describes the patient-physician relationship as a tie that is a covenant of persons.⁴ This type of binding relationship does, I think, obligate the physician to treat not only the leukemia but also the parents' anxiety. If Dr. Carmichael can sympathetically listen to the Delgados' anxiety, he may be able to alleviate some of their fears and bring them to a point where they can release their perspective (to some extent at least) and follow the more detached medical advice of their doctor.

Maybe the doctor could help empower the parents in the treatment option that is appropriate. A daily telephone call from Dr. Carmichael and earlier follow-up of lab tests might ease the parents' anxiety and help them feel plugged in to the system even if they are at home. Perhaps the doctor could intervene at the school to allow some additional time off for 1 of the parents to watch their child.

Finally, how might a spiritual approach influence the resolution of this problem? Encouraging the parents to talk to someone in the realm of counseling or religion, someone they trust, might help to relieve their anxieties. If appropriate, expression of common faith (whether Christian or not) could serve to realign the parents' perspective to a bigger picture that would at least help them feel less isolated and out of control, although it might not resolve the conflict.

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On Distinguishing Justifiable from Unjustifiable Paternalism

Limiting the right of patients to make their own medical decisions can be justified only when a patient lacks the competence to do so or pose a threat to others.

Loretta Kopelman, PhD

Paternalism is the interference with people's liberties or autonomy "for their own good" or to "prevent their harm" irrespective of the preferences of the person whose liberty is being curtailed¹. A powerful way to understand the issues and controversies about paternalism in medicine is to consider the case of Dax Cowart, who was severely injured after a gas explosion caused second and third degree burns over 67 percent of his body². A 1974 film, shot 10 months after the accident, shows Cowart undergoing painful but life-saving treatments. The film mostly consists of Cowart's interviews with Robert White, a psychiatrist at the University of Texas at Galveston. Burn unit doctors told White that Cowart was irrational and depressed and needed to be declared incompetent so his mother could be appointed his legal guardian and authorize surgery on his hands.

Unlike doctors in the burn unit, the surgeons refused to operate unless Cowart gave informed consent or was declared legally incompetent and a court-appointed surrogate authorized surgery. Dr. White and another psychiatrist found Cowart to have the capacity to make his own medical decisions and refused to participate in the process to have him declared legally incompetent. Yet Cowart's doctors were still unwilling to honor Cowart's refusals of treatments. Eventually Cowart agreed to the surgery because, he said, he believed that it was the fastest route out of the hospital, where he could reestablish control over his life³.

The difficulty with paternalism for legally competent persons is that, first, someone's sincere belief about what is good for another person may be wrong. With the best intentions people may be mistaken about what harms or benefits others⁴. Doctors were wrong in assuming what values were most important to Cowart and in predicting that he would regain some vision and use of his hands, be able to dress himself, and attend to his personal needs. Second, limiting the liberty of competent persons offers insufficient respect for their autonomous actions or their ability to make decisions for themselves. People find it intrinsically valuable to plan their own lives and live as they wish⁵. Third, there is utility or instrumental value in letting people live as they wish because competent people generally are the best judges of what is best for them and because we learn from each other's successes and failures⁶. In deciding for ourselves, moreover, we develop our potential as autonomous persons, gain respect from others, and do not feel thwarted. Paternalism is generally considered an unwarranted interference with the liberties of people who can act autonomously because it undercuts what they want for themselves and their liberty to live out their lives as they wish as long as they do not interfere with others. Current laws and policies generally do not permit medical paternalism for legally competent persons.

Sometimes we are not sure whether persons are competent who, in our view, are about to harm themselves. In such cases, it seems appropriate, perhaps even a moral duty, to interfere to determine if the person is competent. For example, a seemingly competent person may want to fly from a 15th story window, eat poisonous mushrooms, or walk into a minefield. *Weak paternalism* permits interference with the liberty of others to determine whether they are competent or capable of making a rational choice [7-9]. Most people would argue that it is justifiable to interfere with persons about to harm themselves to determine if they have the capacity to look after their interests, understand the consequences of what they are doing, or act voluntarily. Weak paternalism honors the autonomous decisions of competent persons while also protecting people who may be acting nonautonomously or on insufficient information. Weak paternalism is especially important in medicine since it extends more protection to people who are impaired by such things as illness, ignorance, drugs, or fear.

When Cowart was first taken to the hospital, he demanded that the clinicians let him die. Since Cowart was disoriented and hallucinating, his doctors could justify treating Cowart over his objections, using this widely defended principle of *weak paternalism*. As the months went by and he became articulate, clear in his reasoning, and unwavering in his refusals of burdensome treatments, it became increasingly difficult for physicians to use the defense of weak paternalism.

Cowart is now a lawyer defending patients' rights. He insists that, while he is happy to be alive, he was not treated with respect, and his competent refusal should have been honored. He was more accurate in predicting the severe limitations with which he lives and claims that the result was not worth his suffering. Honoring a patient's competent refusal of a burdensome treatment does not constitute participation in a suicide, as some doctors feared. One would hope that Cowart's doctors would have recommended or even implored him to consider life-saving treatments or meet persons with disabilities who were living full and happy lives. Still, they crossed a legal and moral line in treating this highly competent man against his will without even a court hearing.

First-year medical students at the Brody School of Medicine watch the film about Cowart, *Please Let Me Die*, in our medical humanities course². It introduces them to issues of competency, informed consent, and paternalism. Most, if not all, students agree with the psychiatrists but struggle with the difficult choice faced by his doctors. Compassion seems to lead them in one direction and respect for liberty in another. There is no conflict between the need to protect sick people and to honor their self-determination when they authorize recommended treatments or hospitalizations. The problems arise when we cannot simultaneously do what we think is best for people and also respect their refusal of treatment or hospitalization, and solutions often depend on competency determinations.

Justifiable Paternalism

Paternalism is justifiable if someone lacks the capacity to look after his or her interests. Some form of protection is justified or even obligatory when people cannot make decisions for themselves, suffer incapacitating illnesses, show involuntary self-destructive behavior, or make choices so inappropriate to their own established life goals that we doubt their autonomy. Interference seems justified in the presence of people's nonautonomous, self-destructive behavior or when they resort to acts that are irrational, unreasonable, and uncharacteristic. Thus, paternalism (some prefer the less sexist word "parentalism") is sometimes a duty in medicine, and clinicians have to decide when they should act like good parents and help people who cannot look out for themselves.

For example, temporary involuntary commitment of a patient may ultimately enlarge that person's liberty⁸. Civil commitment laws for persons considered dangerous to themselves are paternalistic in the sense that they

interfere with the liberty or autonomy of such persons for their own good or to prevent harm. The justification for these laws is that people sometimes lack the capacity to act in their own interest. When people are very ill, they are "not themselves" and are not choosing autonomously. As a society, we can even adopt paternalistic laws for competent adults, such as requiring motorists to wear seatbelts, motorcyclists to wear helmets, prohibiting swimming in dangerous areas, and requiring parents to protect their children. Doctors, however, are private citizens and cannot restrain the liberties of others simply because they do not like competent patients' decisions.

Limiting the liberty of others can be justified if they lack capacity to make the relevant decision (paternalism), if they pose harm to others (the harm principle), or if their behavior is so bizarre that we should intervene to allow time to determine if their actions are autonomous and informed (weak paternalism). Interference with the liberty of adults requires a heavy burden of proof to show they are incapacitated, incompetent, or a threat to themselves or others. It requires proving that the probability and magnitude of the possible harm merits the interference and that the means used are effective and the least restrictive means available^{10,11}.

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In The Literature

Resurgent Paternalism

Meme Wang, MPH

Chervenak F, McCullough L. The threat of the new managed practice of medicine to patients' autonomy. *J Clin Ethics*. 1995;6(4):320-323.

Sulmasy D. Managed care and the new medical paternalism. *J Clin Ethics*. 1995;6(4):324-326.

Is it possible that managed care has added a new level of paternalism to the medical encounter? Frank Chervenak and Laurence B. McCullough assert in their article, "The Threat of the New Managed Practice to Patients' Autonomy," that managed practice fosters a "resurgent paternalism." They define the managed practice of medicine as the "attempts of payers and providers to reduce and control the variability and, therefore, the cost of medical care."¹

These attempts by managed care organizations to achieve economic efficiency involve 2 main strategies that threaten the autonomy of the patient, the authors claim. The first is to apply cost-efficiency and cost-benefit analyses to physicians' diagnosis and treatment recommendations. The second strategy is standardizing medical care through practice guidelines, while still maintaining quality. Daniel Sulmasy, in his article, "Managed Care and the New Medical Paternalism," further suggests that managed care organizations offer physicians economic incentives to discourage the utilization of health care services as an additional strategy to contain costs.²

Patients often have no idea of the potential threats to their autonomy that these strategies pose. When choosing coverage or seeking care under managed practice arrangements, patients are generally uninformed about financial incentives used to influence physicians' decisions to provide less care. Nor do all patients understand the nature of the cost-effective outcomes that managed care organizations define as valuable. They are also uninformed about the content of practice guidelines that withhold the use of certain diagnostic tools or treatments. Patients are denied not only tests and treatments, but also information that they might have deemed valuable in making their health care choices. They are deprived of the right to exercise their autonomy, and, moreover, they are unaware of this loss. This is the new medical paternalism.³

Chervenak and McCullough believe that all rational patients value information concerning their health because information underlies decisions and behaviors and involves what they call the "essential exercise of autonomy." They state, "in the absence of information needed to make fundamental human decisions, autonomy is undermined at its foundations."⁴ The authors contrast the "essential exercise of autonomy" with what they label the "nonessential exercise of autonomy." An example of a nonessential exercise of autonomy is allowing patients unlimited choice of physicians. The authors propose that restricting a patient's nonessential exercise of autonomy as a cost-cutting measure is allowable, such as when the patient's choice of physicians is limited to a reasonable number of "approved" physicians.

On the other hand, undermining the *essential* exercise of autonomy is intolerable from an ethical standpoint. It violates a core value of the profession—respect for patient autonomy. It disregards the patient as a person capable of making fundamental decisions. As a case in point, the authors discuss managed care practice guidelines that restrict the use of routine obstetric ultrasound screening.

Chervenak, director of obstetrics and maternal fetal medicine at a major New York hospital, and McCullough, a professor of medicine and ethics at Baylor College of Medicine in Houston, demonstrate the peril to patient autonomy under managed practice in their analysis of the Routine Antenatal Diagnostic Imaging Ultrasound Study (RADIUS). They contend that RADIUS has been applied to defend US practice guidelines that restrict routine obstetric ultrasounds.

RADIUS, a large randomized clinical trial, assessed the effectiveness of routine ultrasound screening for women who were at low risk for poor pregnancy outcomes. It concluded that routine use of obstetric ultrasound did not produce better perinatal outcomes than discretionary use by physician order. Investigators, furthermore, found that its routine practice would add more than \$500 million annually to the cost of health care in the United States. In the context of total quality management, a tool employed by managed care organizations to eliminate unnecessary steps in clinical treatment, these findings indicate that routine obstetric ultrasound screening adds no value, only cost, to the outcomes of obstetric management. It can, therefore, be eliminated from practice guidelines.

The authors acknowledge that the principle of beneficence can ethically support elimination of routine obstetric ultrasound screening from practice guidelines. This principle "obliges the physician to act in a way that produces a greater balance of goods over harms for the patient, as those goods and harms are understood from a rigorous clinical perspective."⁵ Based on the conclusion of the RADIUS trial, routine obstetric ultrasound screening does not produce a greater balance of goods over harms for the patient. Hence, beneficence supports eliminating its use on a routine basis. If eliminating the ultrasound diagnosis posed risk or harm to the patient in the name of cost savings, the physician's decision to withhold this treatment would dishonor his fiduciary role. Total quality management, therefore, aligns itself with the principle of beneficent care, allowing practice guidelines to eliminate routine obstetric ultrasound screening from treatment of low-risk patients and substitute less costly, equally beneficent care, as defined in terms of epidemiological outcomes, without breaching the integrity of the profession.

The authors maintain, however, that this conclusion is valid only if traditional epidemiological measures, such as perinatal morbidity and mortality, constitute the only relevant outcomes. Investigators have found that routine obstetric ultrasound screening detects fetal anomalies in 16.6 percent of the women before 24 weeks, compared to an abnormality detection rate of 4.9 percent in the group that does not receive routine ultrasound screening. This is a threefold difference in detection frequency of fetal anomalies, which suggests that routine screening can improve the well-being of pregnant women significantly. It provides information about the presence or absence of fetal anomalies that can help a woman decide whether to continue a pregnancy or take another course of action. Denying coverage for routine ultrasounds may be harmful if ultrasounds can reveal useful diagnostic data that women may need to exercise their constitutional right to decide whether to continue pregnancy.

Chervenak and McCullough argue, therefore, that managed practice can jeopardize patient autonomy with its single-minded pursuit of economic efficiency and emphasis on beneficent care. They conclude that, "cost considerations and beneficence can reinforce each other to create a resurgent paternalism as a basic, until now hidden, ethical feature of the new managed practice of medicine."⁶

The authors propose that respect for the essential exercise of autonomy should be given equal importance with beneficence in medical care as a solution to the new medical paternalism. Beneficence and autonomy-based criteria, taken together, should be determinants in defining outcomes of total quality management, ie quality, cost-efficient medical care. This is especially crucial when the essential exercise of autonomy is at risk. Autonomy-based criteria demand that practice guidelines incorporate steps, such as safe and noninvasive routine obstetric ultrasound screening, that contribute to quality, cost-effective medical care. Omitting routine obstetric ultrasounds to reduce costs is paternalistic and therefore, is ethically

unacceptable. Managed practice cannot ignore consideration of the essential exercise of autonomy without the risk of being paternalistic. Chervenak and McCullough's rationale also morally obligates physicians to advocate for guidelines that are based on the essential exercises of patient autonomy. They caution, however, that (1) respect for the essential exercise of autonomy is required only after the clinical quality of a procedure has been determined, and (2) not all seemingly essential exercises of autonomy are truly essential, such as the request for a third-trimester ultrasound to screen for growth retardation.⁷

Daniel Sulmasy develops Chervenak and McCullough's proposed solution in his article, "Managed Care and the New Paternalism," and suggests that patients be asked what they consider relevant knowledge in making decisions about health care services because what patients value is unknown in advance of the patient-physician encounter. He concedes that there is a great deal of waste in medical care, and it should, therefore, be rationed. The responsibility, however, of deciding what must be withheld from practice guidelines should not fall solely on physicians or administrators. Patients should be encouraged to participate together with physicians in an open and public dialogue to decide what should be rationed. He states that while guidelines deal with populations, "autonomy is exercised by individuals, not populations."⁸

Writing in the mid-1990s, these authors believe that managed care exerts a paternalistic force on health care. They agree that respect for the patients' essential exercise of autonomy is key to preserving the trust in the physician's fiduciary and advocacy roles for the patient, and consequently, the integrity of the profession.

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Disputing Parental Judgment in a Case of Dialysis

In cases where a parent is denying life-saving medical treatment, physician paternalism can step in to help provide the proper care to the patient.

Douglas Brosnan, JD

Rachel needs medical treatment for pyelonephritis. Currently, Rachel lives in a group home where she enjoys listening to music, looking at magazines, and socializing with the staff and other residents. She manages her own personal hygiene and engages in other activities of daily living. Rachel also holds down a job at a local publishing workshop where she collates, creates templates, and stuffs envelopes. She works independently, and her employer is very satisfied with her work. She is able to communicate her wants and needs as well as answer a telephone appropriately.

However, Rachel has never been judged competent to manage her personal or financial affairs or provide informed consent for any medical treatment. She is a 33-year-old woman with Down syndrome. Due to the diminished level of Rachel's mental functioning, her mother was appointed her legal guardian. Throughout her life, Rachel has required various degrees of medical attention, from treatment with antibiotics to surgery that required significant patient compliance during intensive rehabilitation.

Recently, a new medical issue has surfaced. As a result of her chronic pyelonephritis, Rachel's kidneys have begun to fail. She needs life-long hemodialysis in order to stave off uremia and ultimately death. This treatment requires that she undergo a minor surgical procedure for the creation of a permanent, high-flow arteriovenous fistula for hemodialysis access. Dialysis would then require Rachel's cooperation for long periods of time, sitting while blood is siphoned to the dialysis machine and returned to her body. Such treatments usually last approximately 3 hours and may be required as often as 3 times a week.

What is usually considered routine therapy for patients in renal failure is now the focus of a vehement dispute. This dispute arose when Rachel's mother refused to give consent for her daughter to receive this life-saving treatment. Based on concerns that her daughter would not be able to understand the need to sit still during the dialysis treatments or the need for the repetitive pain inflicted by sticking her with needles 3 times every week, Rachel's mother felt that hemodialysis would essentially result in emotional torture for her daughter. Rachel's hemodialysis director contested her mother's decision, and a guardian ad litem was appointed for Rachel by the court.

Rachel's need for dialysis is urgent. She retains an estimated 10 percent of her renal function and will certainly die within the next year if she is not dialyzed. With treatment, Rachel could enjoy 10 to 20 years of "quality life." Rachel's physicians, as well as the hemodialysis center director, all of whom have significant experience treating mentally handicapped patients, agree that Rachel is a good candidate for hemodialysis and would be able to comply with the treatment regimen.

Legal Analysis

The above facts are adapted from a case in which a state court of appeals refused to allow a guardian to withhold consent for life-saving hemodialysis of a ward¹. This case lies at the crossroads of medicine and the law, and it raises several critical questions about the law's response to paternalism in medicine.

Patient Autonomy vs Physician Paternalism

Over a century ago, U.S. law responded to the "problem" of physician-directed care. The law's first response was granting the right to refuse medical care. "There is implicit recognition in the law...that a person has a strong interest in being free from nonconsensual invasion of his bodily integrity. In short, the law recognizes the individual interest in preserving the inviolability of his person"². This right to bodily integrity extends to physicians attempting to implement medical therapy on a patient. In other words, patient rights include a right to refusal of treatment.

To ensure the right of bodily integrity as well as to combat paternalism in medicine, the law imposes a burden on the clinician to obtain informed consent. This requires physicians to "communicate material information" to their patients. Two standards have emerged for defining what information qualifies as material.

Traditionally, courts asked what a reasonable physician would have disclosed under the circumstances. With time, this "professional standard" came under criticism for its excessive paternalism and the effective immunity that it granted to defendants in medical malpractice cases.

As a result, almost half of the states have shifted to a "patient standard" of informed consent. Under the patient standard for defining materiality, many courts use an objective test, asking whether a reasonable person would regard the information as important³.

The combination of these 2 rights, informed consent and refusal of treatment, allows every competent adult "to forgo treatment, or even cure, if it entails what for him or her are intolerable consequences or risks, however unwise his sense of values may be in the eyes of the medical profession"⁴. Knowing exercise of this right requires knowledge of the available options and the risks attendant on each⁵.

Patients Who Are Declared Incompetent

Little controversy exists in the importance of the right to refuse medical treatment and to informed consent. However, these legal doctrines cease to operate as effective safeguards when faced with a patient who has been declared legally incompetent. As a preliminary matter, it is necessary to address the meaning of "competence." Generally, "competence" is defined as the "ability to understand problems and make decisions"⁶. If this case were brought before the court in the 1970s or earlier, the issue of competence probably would not even have arisen. Then, courts presumed "and, in many states, the law was, that institutionalization was equivalent to a finding of legal incompetency. By 1970, however, this notion of merging the concepts of institutionalization and incompetency had survived in only a handful of jurisdictions and had been specifically rejected in many others"⁷. Today, virtually every state has an explicit provision to the effect that institutionalization does not affect competency, much less create a presumption of incompetency. (The problems associated with the subjectivity in the law, as illustrated here by the changing legal lexicon, will be addressed later.)

Rachel, who has been declared incompetent, needs others to make decisions for her in order to successfully adapt and thrive. Her guardian made the decision that she would live in a group home, presumably

someone found Rachel the job at the publishing shop, and someone is making daily financial decisions on her behalf.

Rachel, however, is far from being in a vegetative state: she possesses the ability to communicate via speech and gestures, answers the telephone appropriately, and has actively cooperated with every dietary and medical intervention to date. These factors indicate that Rachel comprehends basic ideas and is able to communicate her wants; however, there is no record of her wishes in the probate court's record. In fact the only indication of her desires is the picture painted circumstantially—Rachel is generally a happy woman who enjoys her job. She also participates in outside activities that bring her joy. Rachel, according to the record, is not a morose, hapless person without desire to continue living.

To protect the limited capacity she does possess, the court engages in a "substituted judgment" inquiry. "Substituted judgment" (or an equivalent variant depending on the jurisdiction) is an exercise by which the court "does not decide what is necessarily the best decision but rather what decision would be made by the incompetent person [here, Rachel] if she were competent"⁸.

In making this determination, the jurist must first investigate factors specific to Rachel's particular situation including expressed preferences, religious convictions, any impact on her family, likelihood of adverse side effects from treatment, consequences of refusing treatment, and Rachel's present and future incompetence must be investigated. Then the jurist must consider countervailing state interests such as the preservation of life, protection of innocents, prevention of suicide, and the maintenance of the ethical integrity of the medical profession⁸. But does the "substituted judgment" inquiry really address the patient's desires while minimizing paternalism?

The substituted judgment inquiry is really a euphemism for judicial decision making because there is no meaningful way by which to prioritize these considerations. For example, are the state's interests more important than the patient-specific concerns? The courts have not addressed this question. In the 1993 case on which this analysis is based, the court made a futile attempt to address this concern, stating that factors relating to the patient's situation and preferences should be paramount. In effect, the court tried to have it both ways—essentially applying the substituted judgment test to determine what the individual *would* have wanted if she or he were competent; while simultaneously giving great weight to the preferences expressed by the incompetent patient. Ultimately the appellate court remanded this case to the probate court for further proceedings to determine Rachel's desires and her ability to understand the need for dialysis.

The judiciary is inherently ill equipped to manage medical decision making. First, by involving itself in cases of medical decision making, the court substitutes its judgment for sound medical judgment. Although guided by physician testimony, courts ultimately deprive the incompetent patients of the advantages afforded by the medical team's judgment, imposing a court's supervening decision. Just as there can be no question that a court is far better positioned to rule on statutory matters, there is no disputing that the health care team has superior knowledge and experience making medical decisions.

Generally, giving patients a voice in managing their health care decisions is good practice. However, when confronted with a patient who is legally incapable of partnering with the physician in making health care decisions, the question of who ultimately should make medical choices arises. The law proposes that legal guardians should step into the shoes of the patient and control the patient's treatment. However, as in Rachel's case, guardians, even when appointed by the court, do not always act in the best interest of the ward. The court acts as a safety net when there is conflict between the physician and the guardian. However, as explained earlier, a court is not the best forum to make such decisions. So, who should partner with the physician of a patient who is incompetent?

An obvious solution would be to consult with those who know the patient well and are knowledgeable about health care. Here, although Rachel's mother presumably knows Rachel well, she is not knowledgeable in medicine. Rather, it may be Rachel's longtime physician who knows Rachel best, has his patient's best interests in mind, and understands medicine. In fact, Rachel's physician even consulted with a hemodialysis expert to ensure that a patient with Down syndrome could handle such treatments. Here, medical paternalism, or at least physician advocacy, saved Rachel's life. Without the vehement objections from her physician as well as his faithful advocacy through the appellate process, Rachel's desires would not have been addressed and her life, prematurely and unnecessarily ended. In the case of incompetent patients, it makes sense not only to allow, but to encourage physician-directed decision making.

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Clinical Pearl

Indications for Bypass Surgery

Preventing coronary artery disease should be a top priority as the disease incidence increases with an aging population, but the condition can be managed with both medical and surgical treatments supported by lifestyle changes.

Jennifer Reenan, MD

The defining feature of coronary artery disease is a focal narrowing in the vascular endothelium, which impedes the flow of blood to the myocardium. Atherosclerotic plaque forms the principal lesion, which is composed of a necrotic center containing cell debris, cholesterol, and calcium. Outlining the necrotic center is a fibrous cap made of proliferated smooth muscle cells, connective tissue, and lipids.

Although there are many identifiable risk factors for atherosclerosis, none of them constitutes a known mechanism for the pathogenesis of coronary artery disease. The widely accepted "response to injury" theory proposes that the initial stimulus is an injury to the arterial endothelium. Damaged endothelial cells release various chemotactic factors and stimulate the deposition of fatty material. If the process is not reversed, mature fibrous plaques will obstruct the arterial lumen.

Angina Pectoris

Angina pectoris is the main clinical consequence of decreased blood flow in the coronary arteries. It is characterized by chest pain or pressure often described by patients as crushing or squeezing. One of the most important features of angina is that it is typically brought on by physical exertion.

The New York Heart Association (NYHA) has developed a functional classification system that is commonly used by physicians to assess the severity of angina ranging from Class I angina, which is brought on only with unusually strenuous activity, to Class IV, angina experienced while one is at rest.

There are several types of anginal syndromes. Stable angina describes a predictable pattern of anginal symptoms. Unstable angina is more worrisome as it may presage a myocardial infarction. Angina is classified as unstable when there is a change in either the frequency, duration, or severity of the attacks. Symptoms occurring at rest are also considered unstable and are particularly alarming. Prinzmetal's angina is a variant type of pain, typically occurring at night, which is suspected to occur as a result of transient coronary spasm.

Symptomless coronary heart disease does occur, especially in diabetic patients. Without the warning symptoms of angina, the first presentation of coronary heart disease may be a potentially deadly heart attack.

Diagnosis of Angina Pectoris

Patient history alone can lead quickly to a diagnosis of angina pectoris, and noninvasive testing options can confirm the diagnosis, preferably by means of a stress test. A resting electrocardiogram may be taken but is likely to be normal in the absence of pain and in patients with no previous history of myocardial infarction. Stress electrocardiography, recorded while the patient performs some sort of physical exercise, helps detect and evaluate the severity of myocardial ischemia. A detailed discussion on the wide variability in the sensitivity and specificity of exercise stress testing is available in the "ACC/AHA Guidelines For Exercise Testing," the American College of Cardiology/American Heart Association task force report on exercise stress testing¹.

The standard exercise stress test is considered low yield in certain patients including those with existing EKG abnormalities such as left bundle branch blocks or left ventricular hypertrophy. A nuclear stress test is an excellent alternative to the standard stress test. Thallium, a radioactive substance, is injected into the bloodstream during peak exercise and a gamma camera is used to visualize the heart and its blood supply. Pharmacologic stress tests utilizing dobutamine, adenosine, and dipyridamole are other alternatives and are suited for patients who are unable to exercise or who have deep venous thrombosis.

Cardiac catheterization is the gold standard test for the diagnosis of coronary artery disease and is used to determine whether medical or surgical therapy is more appropriate and to plan revascularization surgery². When the patient's history suggests congestive heart failure or when a revascularization procedure is being contemplated, an echocardiogram is appropriate².

Medical Management

Most cases of chronic stable angina in patients who are considered to be at low risk for myocardial infarct (ie, single- vessel disease not affecting the left main stem artery) can be managed without surgical intervention.

Drug therapy can reduce ischemic pain, minimize the frequency and severity of ischemic episodes, prevent serious complications (myocardial infarction), and improve the quality of life. For a good overview of the medical management of chronic stable angina, see an article published in the American Family Physician in January 2000². Important items in the drug therapy arsenal are:

- Nitrates,
- Beta-adrenergic blockers,
- Calcium channel blockers,
- Aspirin, and
- Lipid-lowering agents.

The management of unstable angina or angina at rest (Class IV) initially involves treatment with bed rest, intravenous heparin, and aspirin. When the patient is stable, cardiac catheterization is performed to assess the degree of stenosis and plan revascularization procedures.

Percutaneous Coronary Interventions

Percutaneous Coronary interventions (PCI) are invasive procedures during which a small balloon-tipped catheter is inserted into either a femoral or brachial artery and threaded up to the obstructing lesion in the coronary artery. When the balloon is inflated, the plaque is flattened against the endothelial wall, the artery is dilated, and blood flow to the myocardium is increased. Small wire stents can be inserted at the site to maintain dilation and prevent restenosis³.

Coronary Artery Bypass Surgery

More serious cases of coronary artery disease require coronary artery bypass graft surgery (CABG), a procedure designed to restore blood flow to the myocardium. Performed since the late 1960s, this is now one of the most common operations in the United States—up to 500,000 are done yearly.

Indications for Coronary Artery Bypass Graft Surgery

The 1999 Guidelines for CABG Surgery developed by the American College of Cardiology and the American Heart Association list the following 6 conditions as indications for CABG in patients with stable angina⁴:

1. Significant left main coronary artery stenosis.
2. Left main equivalent: significant (70 percent) stenosis of the proximal left anterior descending (LAD) and proximal left circumflex arteries.
3. Three-vessel disease.
4. Two-vessel disease with significant proximal LAD stenosis and either ejection fraction <0.50 or demonstrable ischemia on noninvasive testing.
5. One- or 2-vessel stenosis without significant proximal LAD stenosis, but with a large area of viable myocardium and high-risk criteria on noninvasive testing.
6. Disabling angina despite maximal noninvasive therapy, when surgery can be performed with acceptable risk.

During the procedure, the clogged coronary artery is "bypassed" by grafting a vessel (usually the patient's own saphenous vein or internal mammary artery) around the lesion. The surgery traditionally requires that the heart be stopped while the patient is connected to a heart-lung machine, which oxygenates and circulates the blood in place of the pumping heart. Innovations in surgical technique allow for minimally invasive bypass surgery and avoid the use of the heart-lung pump.

The chief anatomical indications for CABG are the presence of triple-vessel disease, severe left main stem artery stenosis, or left main equivalent disease (ie, 70 percent or greater stenosis of left anterior descending and proximal left circumflex artery)—particularly if left ventricular function is impaired. Overall, scientific studies have shown that CABG improves long-term survival in these high-risk patients, while also relieving their symptoms of angina⁴.

The benefits of CABG are not uncontested, however. For example, the Bypass Angioplasty Revascularization Investigation (BARI) was a large, randomized controlled trial which looked at mortality in patients with multivessel disease who were treated with either CABG or the less invasive PCI. No statistical difference in survival rates was found at either 5 or 10 years with a single exception. Diabetic patients had a statistically significant lower mortality with CABG at 10 years⁵. In the 1990s, larger meta-analyses comparing short term outcomes (1-3 years) of PCI versus CABG also found no significant difference in rates of death⁶. It is important to note that BARI is often criticized for its inclusion criteria. Sixty percent of patients in the trial had moderate 2-vessel disease. Such patients would not be expected to benefit from CABG to the same extent as those with more severe anatomical disease.

What, then, can we say about the benefits of invasive therapies such as PCI and CABG? Invasive therapy is generally not recommended for low-risk patients with single-vessel disease unless they suffer significantly from angina or have failed medical therapy.

Low-risk patients with single-vessel disease who are not achieving desired anginal relief with medical therapy will likely improve both symptoms and quality of life with PCI. CABG has not been shown to improve survival in low-risk patients with single-vessel disease except those with left main or left main equivalent disease³. Second, those patients at high risk for complications (due the anatomic severity of their disease) who undergo CABG, will see a reduction in their risk of death³. Also, in these high-risk patients, CABG delivers a more immediate improvement in quality of life when compared to PCI and requires fewer repeat procedures³.

For moderate risk patients (ie, 2-vessel disease), either invasive procedure may be used. Deciding between the procedures can be difficult and should be based on patient preference and risk factor analysis. However, a new meta- analysis study (which includes the BARI trial) prepared by physicians at Tufts-New England Medical Center suggests that CABG is associated with both decreased risk of mortality and greater symptom improvement at 5 years when compared to PCI. The researchers found a 1.9 percent absolute survival advantage favoring CABG at 5 years. Patients undergoing PCI were more likely to require repeat procedures and have more severe anginal symptoms compared to those who underwent bypass surgery⁷.

Clearly, prevention of atherosclerotic coronary artery disease should be a top priority, given the rising incidence of this disease as the population ages. Both medical and surgical approaches to the management of coronary artery disease need to be supported by lifestyle changes.

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Addressing Paternalism with Patients' Rights: Unintended Consequences

A bioethicist discusses how the need for patient autonomy and patients' rights can be fulfilled through strong patient-physician communication.

Felicia Cohn, PhD

Patients' rights statements, whether legislative proposals or institutional policies, are generally designed to protect and empower patients in the health care setting. They have arisen in response to paternalistic clinician behaviors, managed care disparities, and the technological imperative (ie, the belief that if we have the technology, we will use it). They seek to assure patient participation in and ultimate authority over decisions about medical care and to provide recourse if care does not go well.

This simplistic explanation of patients' rights suggests an appropriate emphasis on patient self-determination over conceptions of medical benefit with which the patient does not agree. Yet, the focus on rights language appears not to have produced a balance between the values of patient autonomy and physician beneficence; rather, rights language prioritizes autonomy over all other values, sometimes without adequate ethical justification. Patients' rights intended to enhance the patient-physician relationship can endanger the notion of relationship and reduce physicians to defensive technicians.

Rights Versus Relationships

The essence of the medical relationship is communication between patient and physician. By communicating, the patient and physician can determine together how best to treat the patient in accord with the patient's values and perception of his or her best medical interests, on the one hand, and the physician's professional knowledge, experience, and values, on the other. The American Medical Association describes the clinical encounter as the "embodiment" of medical practice and notes that it has "long been recognized that successful medical care requires an ongoing collaborative effort between patients and physicians"¹.

Yet, communication may be at the root of some of the problems in medicine that are triggering the call for explicit patients' rights. "What has been true for the evolution of mankind has been equally true for the progress of medicine: We have spared no effort to make better tools but we have paid little attention to learning how to communicate better with one another"². A seminal study of end-of-life care, the "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)", suggests a general failure in communication in the face of entrenched practice patterns. The study documents limited patient-physician communication occurring even after the implementation of measures to improve it^{3,4}.

The SUPPORT study demonstrated, for example, no change in the number of days patients remained in intensive care and no decrease in pain suffered, despite known patient wishes for less care and better pain management. If dialogue serves as the foundation of medical relationships, then:

Ideally, physicians should define their diagnostic and therapeutic goals in terms of the everyday life and function of individual patients. Unfortunately, that ideal is seldom met because of the difficulty of holding impersonal technical imperatives in check, and because doctors seem to be trained to focus on diseases almost to the exclusion of how sick persons actually live their lives in families and communities. In part the problem arises because physicians are trained from the first days of medical school to disregard the knowledge they bring with them of everyday life and human function as irrelevant to medicine. Another obstacle is that doctors are not trained to include in their decision making the kind of "soft" and often subjective information that is relevant to the everyday life and function of sick persons. Correction of these educational errors would do much to help change physician's priorities in patient care⁵.

Such a change in physician priorities might quiet the cries for patients' rights and would reflect long-standing statements of medical values expressed in codes of ethics.

Patient advocates, seeking a means of correcting the inadequacies described, turn to the lever of the law. If we required physicians to provide patients with a role in clinical decision making, then collaboration, not conflict, would result. The majority of explicit patients' rights in existing bills and policies appear to be responses to inadequate or inappropriate communication. Studies, for example, suggest that even in the most egregious of medical errors, the harmed patients or their families were most aggrieved, not by the unfavorable medical outcome itself, but by the lack of disclosure or explanation or by the simple failure to apologize^{6,7}. These sought-after rights really require only that patients be heard or allowed to have some measure of control over the information shared, eg, the right to refuse treatment, to lodge complaints, to maintain privacy and confidentiality.

Resorting to rights language as a solution for patient grievances, however, may be as much a problem as a solution. Rights language is notable for "its starkness and simplicity, its prodigality in bestowing the rights label, its legalistic character, its exaggerated absoluteness, its hyperindividualism, its insularity, and its silence with respect to personal, civic, and collective responsibilities"⁸. Rights are established to protect values that are fundamental to relationships, and when we are unable to establish those relationships, we turn to legislated solutions to enforce what is missing. Concepts of confidentiality, fairness, mutual respect, and compassion have long been part of the codes of medical practice. The need to develop policies and laws that speak to these values reflects not the need for rights but the lack of emphasis on the fundamental nature of the relationship in the context of health care. Legislating on these issues may ironically result in reducing the patient-physician encounter from a humanistic interaction to a legalistic contractual one, limiting rather than expanding expression of the very values the policies and laws were created to enhance.

Physician as Technician

Various metaphors and models exist to describe the role of the physician in a patient's life—such as parent, educator, counselor, priest, and negotiator^{9,10}. Each metaphor highlights particular core values upon which the ethical practice of medicine is founded. These values arise "from the moral traditions of medicine and nursing and from the ethical, religious, and legal traditions of our society" and include beneficence (promotion of the patient's well-being); respect for patient autonomy (claim to decision making in medical care, including the patient's claim to self-governance); integrity of health care professionals (fidelity to one's own conscientious moral and religious beliefs); and justice (equitable distribution of health care resources)¹¹. The parent-child or paternalistic model, for example, emphasizes beneficence and clinician integrity while the technician-consumer model emphasizes patient autonomy.

As patients' rights grow and the environment becomes more litigious, the technician metaphor may appear increasingly attractive. The technician-doctor, like the auto mechanic, assesses the problem, provides choices

among available options, and is obligated to provide the treatment the patient selects; whereas the paternalistic doctor limits choice by selecting what he or she believes is the best treatment for the patient. In the climate of patients' rights, either failing to offer all that is technically available or imposing 1 option over another may become grounds for legal action, particularly if the course of care does not go well.

In prioritizing patient autonomy above all other values, however, the technician model fails to adequately account for the physician's moral agency and other values important to the practice of medicine. Further, the conception of autonomy that has come to guide medical interactions does not accurately reflect the meaning and limits of self-governance. Respect for patient autonomy refers to patient self-governance (shared decision making) and appreciating individual preferences. It does *not* mean submitting to whatever the patient wants. Patients, as consumers, are permitted to base medical decisions on their own idiosyncrasies, preconceptions, and knowledge; but they cannot necessarily demand that health care professionals help them pursue those decisions, particularly when the physician perceives that the decision poses risk to the patient or to his or her own integrity.

Medical treatment is not simply a matter of self-determination but of a joint decision between patient and physician regarding what best reflects the patient's goals of care and the physician's judgment as to the most appropriate way of achieving those goals. Both patient and physician are stakeholders in the care process. The assertion of patients' rights may subvert the negotiation, providing a trump card for patient choice and setting aside medical judgment for the sake of "respecting patient autonomy." Far from demonstrating respect for a patient's values and preferences, the technician-doctor need not even understand what the patient believes; rather the physician simply agrees to do whatever the patient asks. No relationship develops, and when the physician wishes to refuse a patient's demand for nonbeneficial, futile, or otherwise medically inappropriate treatment, no context for mutual negotiation based on trust exists. "When self-determination runs amok"¹³ physicians may feel they are reduced to providing technical assistance to their patients.

Beyond the impact on the patient-physician relationship, the quest for rights to more and better health care, for increased control over medical information and decision making, and for legal means of redress for care gone wrong has obscured discussions about the goals of health care and priorities for use. A focus on paternalism and patients' rights highlights the difficult balance among patient autonomy, beneficence, and clinician integrity but masks the role of distributive justice¹⁴. Ultimately, considerations of justice may mean that society must constrain and prioritize the medical choices available to individuals—those a physician may offer and those a patient may seek—to promote more equitable distribution for all.

The call for rights finds strength in a culture that pushes the limits of medical technology to the point of denying the inevitability of death, pays too little attention to the prudent and fair access to and distribution of health care resources, seeks to assign blame for all nature of misfortune, and worries about increasing infringements on personal information. Until we address these characteristics, we cannot begin to make the really difficult choices: Whose health? Which diseases? What technology? Focusing on individual rights of either patients or physicians may distract us from these broader societal choices.

Yet, none of this discussion is intended to suggest that patients do not or should not have rights. Certainly patients must have a role in decisions about their health and lives. Unchecked physician paternalism rarely can be justified, but neither can unlimited patient autonomy. This discussion serves merely as a caution against the law of unintended consequences and a reminder that personal values do not exist in a vacuum. The difficult task of balancing autonomy and beneficence remains, but these are only 2 among a number of values that health care must demonstrate.

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Invoking Therapeutic Privilege

Physicians can ethically withhold information in situations where full disclosure of a diagnosis or treatment would cause great psychological harm to the patient.

Matthew Wynia, MD, MPH

The Patient

On a busy Tuesday morning, she arrives looking for help from a specialist in infectious diseases. She has already been to several other experts. First, she tried exterminators. Later she had turned to internists, dermatologists, and even a psychiatrist. None has been of help.

"Doctor," she says, "I have parasites." Insects cover her body, she reports, crawling in and out of her skin, infesting her intestines and appearing in her stool. Sometimes, she says, they are visible in her sputum. They itch. And she scratches, hard. Her hair has been torn out in clumps. "See what I have to do," she says. It is a statement, not a question. She vigorously demonstrates how she scrapes and digs to remove the bugs from her scalp.

They come in a variety of shapes and sizes. She has brought samples in plastic containers, Ziploc bags and Tupperware. She says some are small and red, some white and tube-like, others have round black heads on a stringy body. Many she finds on the ground or the floor of her shower, "after they've fallen off." For months she has showered several times each day in vain attempts to cleanse herself of her tenacious hitchhikers. The containers hold dirt, twigs, pieces of leaves, skin, blood, and water.

"And," she says, finishing her opening monologue, "if one more doctor tells me I'm crazy, I'm going to go postal!"

The H and P

"How long has this been going on?"

At least a year, probably more, she says. Examining her, it looks like it. Her skin is red and patchy, with scabs, scars, and open lesions virtually everywhere she can reach. Areas of skin that are readily accessible for scratching, such as her forearms, neck, scalp, and lower legs, have bloody and crusting sores, some of which appear to have developed mild superficial skin infections. She is anxious to show me her scalp, which has borne the worst of her exuberant scratching. Large patches of hair have been torn out, replaced by weeping scabs. Her skin is dry from over-washing, scratching, scraping, and using alcohol swabs in

attempts at disinfection. But there are no parasites. No creeping creatures, no mites, no fleas, no bites, no pustules with worms poking their nasty heads out. Her laboratory tests are normal. There are no parasites in her stool.

The Diagnosis

I know what she has.

She has delusional parasitosis. It is a psychiatric condition, unrelated to infectious diseases—except that patients who have it believe they are infested. Antibiotics and antiparasitic drugs have no role, unless the open sores she has created become infected.

Sometimes it is treatable with anti-psychotic medications. But many patients with delusions of parasitic infestations will refuse psychiatric care, believing that this won't help cure their infestation. She, for instance, cannot conceive of the possibility that she is not infested. And she has told me, as directly as possible, that if I consider her to have a psychiatric condition she does not want to hear it.

The Treatment Plan

So I tell her that I don't know for sure the exact cause of all of her symptoms, but that scratching her sores will not help. I say that I do not know of any antibiotic that will help either, but there are some medicines that might reduce her itching. Perhaps I can provide some skin cream to apply when she feels like scratching.

Finally, however, I must broach the tender subject. "Often situations like yours will improve over time," I say, "but in order to improve you will have to address the psychological stress that having this condition must be putting on you."

"Oh yes," she agrees. Tears form. The stress is tremendous. She is depressed and angry that she can't get better and that no one can tell her what is wrong. Would she be willing to see a psychiatrist that I would recommend? Yes.

The Doctor's Dilemma

I know the diagnosis—but I haven't told her. I will tell her psychiatrist instead. I invoke "therapeutic privilege."

Therapeutic privilege is an exemption from informed consent guidelines and is, most would say, a frank exercise of paternalism. The *AMA Code of Medical Ethics* says that physicians may withhold information about a patient's diagnosis or treatment when disclosing it would pose a serious psychological threat, so serious a threat as to be medically contraindicated. But, the *Code* opinion continues, this privilege is not to be used merely because a physician thinks the information, if disclosed, might cause the patient to forgo needed treatment. Competent patients retain the right to refuse treatment and must be given as much information as necessary to help them make informed decisions about consent or refusal.

Each individual use of therapeutic privilege, then, must be justified—based on danger and/or patient incompetence, not merely beneficence. The *Code* says I am not to use this paternalistic tool merely as a way to secure the patient's assent to treatment. Nor may I invoke it merely to avoid giving the patient bad news—telling her something she says she doesn't want to hear "from one more doctor."

How does using "therapeutic privilege" in this case differ from, say, withholding a patient's diagnosis of cancer until after she returns from her daughter's wedding in 2 weeks? I think it differs in several ways. First, I have accurately described my patient's symptoms to her and told her that antibiotics and antiparasitics will not help. I have also told her that a skin cream may reduce the itching and, most importantly, that I recommend she see a psychiatrist to help manage her condition and the stress it can cause. I have withheld from her only the medical name for her illness, a name that carries with it the stigma of psychiatric illness and hence a name she has said she does not want to hear. Insisting that my patient hear the name of her condition, at the likely cost of failing to ensure that she understands what she needs to do to help improve her situation, would be harmful. Indeed, some might refer to the unnecessary pain that forcibly inflicting such brute medical terms on her would cause as "iatrogenic suffering." That is, suffering not directly related to her disease but to the ham-handed way some patients are treated within the health care system.

But, you might say, the same argument could be made for using "malignant neoplasm" instead of "cancer." Isn't tricking patients with slippery "medicalese" something to shy away from? Here is another point to be considered. Because of my patient's delusion, her decision-making capability is not intact. While she is not legally incompetent, neither is she fully capable of making health care decisions. I cannot convince her that her symptoms and illness have the best chance of resolving under psychiatric care. Her illness itself prevents her from understanding that message. By contrast, my hypothetical cancer patient presumably does not have a mental illness. Soon enough she will find out that she has cancer (if, in fact, she does not already know) and realize that I have deceived her, if only for 2 weeks. She may be angry, or accepting, of this in retrospect, but she almost certainly will not accept my future comments as entirely trustworthy. Our relationship and, consequently, her care, will suffer to some degree unless and until I can regain her trust.

Returning to the concern expressed in the *Code of Medical Ethics*: am I withholding information merely to ensure that my patient does not refuse treatment? In my reading, the *Code's* main concern here is that physicians might withhold information about risks associated with a diagnostic test or treatment for fear that full disclosure of those risks would frighten the patient and cause him or her to refuse the intervention. But my goal here is not to convince the patient to undergo a risky diagnostic or therapeutic intervention to which she would not consent if she had adequate information.

In the end, even with the *Code of Ethics* for guidance, my decision to invoke therapeutic privilege was an exercise of clinical and ethical judgment. What do you think? In this case, did I judge wisely?

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Physician Autonomy, Paternalism, and Professionalism: Finding Our Voice Amid Conflicting Duties

Rules of managed health care and the demand for high physician productivity have harmed patients' ability to make informed, autonomous decisions.

Geoffrey C. Williams, MD, PhD, and Timothy E. Quill, MD

The American Board of Internal Medicine and other leading medical organizations recently articulated "A Physician Charter" based on 3 principles: (1) the primacy of patient welfare; (2) patient autonomy; and (3) social justice¹. The charter is intended to establish a system of core values for everyone working in the medical profession, and for physicians in particular. These 3 principles function as the proverbial 3-legged stool.

Overall, patients will be better served, and physicians will feel more satisfied with their work, if all 3 principles are fully integrated by medical professionals in support of the medical encounter.

The writers of the charter believe it is needed because changes in the health care delivery system and the conditions of medical practice in the industrialized world are tempting physicians to abandon their commitment to the primacy of patient welfare. Physicians are now subject to powerful adverse forces, which may contribute to their loss of voice in the medical encounter^{2,3,4}. This paper describes some of these forces, shows how they can undermine the patient-physician relationship, and explores these 3 principles of medical professionalism can help physicians regain their voice.

Challenges to Medical Decision Making

Medical practice is becoming more challenging because its evidence base and guidelines are in constant evolution. For example, the Centers for Disease Control and Prevention (CDC) has identified 12 risk factors for average adult patient that require more than 24 preventive services⁵. The CDC has made recommendations concerning which preventive services provide the greatest health benefit for the resources invested. Comparing health benefits across treatments for chronic diseases and preventive services, Woolf argues that we need a national evidence base that will inform policymakers about improvements in the population's health and that will also inform practitioners about health improvements expected for the individual patient⁶.

The practice of medicine is further complicated by new epidemics (eg, SARS, obesity), and new evidence regarding established treatments (eg, hormone replacement therapy) that change the standards of care. Physicians must actively participate in discussions about new epidemics and treatment standards to help patients interpret the distorted media coverage that surrounds them and understand how the information relates

to them. Patients also need physician help in interpreting the direct-to-consumer advertising of costly medications, fad diets, and "health" supplements.

Both physicians and patients are inundated with arbitrary treatment regulations and financial punishments for "out-of-system treatments." Physicians have added pressures from pharmaceutical industry inducements that encourage the use of expensive treatments of marginal efficacy. They are penalized for low productivity, which threatens their willingness to discuss complex patient problems, even those that are most likely to affect the patient's health². Patterns of physician reimbursement encourage procedure-oriented interventions and minimize counseling, in spite of the greater benefit of brief counseling for patient health^{5,6,7}. On their side of the encounter, patients may pay more for maintaining established relationships with out-of-system clinicians and are charged copayments for preventive treatments, which reduces their utilization of these proven, effective services⁸.

Undermining the Patient-Physician Relationship

As a result of all these complex, sometimes contradictory, often covert and self-interested inducements from third parties, physicians often are confronted with resistance when they explain their treatment decisions to patients. The case of antibiotic treatment for viral infections is a prime example. Antibiotics have not been shown to improve medical outcomes for otherwise healthy patients with early symptoms of upper respiratory infections. In fact, patients incur the risk of side effects (allergic reactions, GI disturbance, and cost) without the potential for benefit. From the social justice point of view, prescribing antibiotics for URIs in otherwise healthy people wastes resources and could contribute to resistant bacteria in the population. Yet, patients frequently request, and sometimes demand, these antibiotics and interpret physicians' withholding them as undermining their autonomy. Patients feel further dissatisfied if they have been charged a copayment for the visit without getting what they perceive to be an effective treatment in return.

In cases such as this, the value the patient places on having access to prescribed medication on demand appears to be in conflict with the physician's obligation to put patient welfare first and to consider social justice in allocation of medical resources. An approach that would enhance patient autonomy would require the physician to: (1) elicit the patients' concerns and perceptions about their illnesses and their medications, (2) provide the patient with information about the risk of side effects, and (3) explore and understand differences in his or her perceptions and values and those of the patient.

Unfortunately, pressure on the physician to be productive may limit the extent to which he is willing to have this in-depth discussion, especially when the discussion tends to be filled with conflict and is time-consuming. It is easier to write the prescription in the name of supporting "patient autonomy."

Patient Autonomy—Mistaken and Real

There are important difficulties with this simplistic notion of autonomy defined as the patient's right to make treatment decisions independently. First, without being reasonably informed about benefits and burdens, the patient cannot possibly be autonomous. An autonomous decision is one in which the decision maker has adequate information about his or her options, their probable outcomes, and the risks and benefits associated with each. Hence, a physician who allows a patient to dictate treatment decisions without adequate information has misunderstood autonomy as independence rather than as volition. Allowing the patient to make an uninformed decision in the name of patient autonomy actually violates all 3 elements of professionalism defined above.

How well are physicians doing in offering "informed" consent in the current environment? In a study that examined audiotapes of more than 3500 clinical decisions in 1000 patient-physician encounters, Braddock and colleagues rated how fully informed patients were about the decisions they were making². They found that only 9 percent of the decisions were fully informed, and none of the intermediate level decisions, such as accepting a prescribed medication, met criteria for being fully informed. Among the researchers' criteria were discussions of the nature of the decision, the patient's preferences, the treatment alternatives and uncertainties, and an assessment of the patient's understanding. Certainly, this method of assessing the informed decision-making process was rigorous, inasmuch as it required meeting all criteria in each category of decision making. However, the data are symptomatic of the difficulties physicians have in supporting the principles articulated in the Charter. Braddock concluded that informed decision making among his group of primary care physicians and surgeons was "often incomplete"⁹.

This decision making conflict could be resolved with external controls. For example, with the prescribing of antibiotics, a physician might say, "I would love to prescribe antibiotics for you, but the system will not allow it." This might, however, leave both sides feeling unsatisfied and manipulated. An alternative resolution would entail the physician's engaging the patient in an active discussion of the risks and benefits of the antibiotic, trying to inform the patient rather than simply controlling him or her. Patients who are engaged in active discussions and informed decision making have a chance to understand that their welfare may be mildly threatened rather than improved by inappropriately taking antibiotics. Since personal health and autonomy are basic, shared values, this frank discussion is more likely to result in the patients' internalizing the physician's message and stopping their pursuit of inappropriate prescriptions.

Enhancing Real Patient—and Physician—Autonomy

By avoiding the discussion and prescribing the antibiotic, the physician has undermined all 3 principles of patient welfare, social justice, and patient autonomy. By controlling the patient, and refusing to prescribe the antibiotic without an extensive, mutually informing discussion, the physician has undermined patient autonomy but may have supported patient welfare and social justice. Thus, it is only by using their knowledge, expertise, and communication skills in a mutually informative process that physicians can support all 3 principles of professional care—including promotion of patient autonomy.

In the 8 years since Quill and Brody published their study on the balance between physician power and patient choice¹⁰, a considerable amount of empirical work has been done to assess patient autonomy and discover methods of intervening to increase it¹¹. The effectiveness of an "enhanced autonomy intervention" by practitioners has been demonstrated in a randomized clinical trial of tobacco dependence treatment¹². The results indicate that patient autonomy is enhanced when practitioners make the effort to:

- elicit patient values,
- acknowledge patient affect,
- provide a clear rationale for cessation and use of medications,
- support patient initiations (ie, to support patient preference for the use of pharmacotherapy),
- and minimize external control.

These efforts more than doubled the 6-month prolonged abstinence from tobacco achieved by patients in community care. Patients in community care were provided self-help materials, contact and cost information on all active smoking cessation programs in the community, and encouraged to meet with their physicians about quitting. Patients in the intervention group were twice as likely to take medications for cessation and to use them for a longer period of time than those in community care. The enhanced autonomy intervention had this effect on abstinence whether the patient initially wanted to quit smoking or

not. Patient quality of life, assessed by measurements of depressive symptoms and vitality, was also enhanced in patients who stopped smoking. This study illustrates how an important health outcome is enhanced when medical intervention actively advocates for patient welfare and patient autonomy. Since tobacco companies disproportionately prey upon people of lower socioeconomic status and on those with mental illness, medical intervention also serves social justice.

An Active Voice, Not a Controlling Voice

Most medical encounters involve decisions that are far less clear-cut than the effectiveness of antibiotics in upper respiratory infections and treating patients for tobacco dependence. If physicians have difficulty fully informing patients about treatment options in cases where the evidence of benefits and harms is clear, doing so is likely to be more difficult in complicated circumstances, such as cases where the therapeutic recommendations have not been tested in a randomized controlled trial and are based on physician experience and judgment. Potential conflicts between physician and patient values are more likely to occur.

At the other end of the spectrum, some patients tend to rely too much on physician opinion. Several studies have identified that as many as two-thirds of patients prefer that the physician make the decisions¹³, probably because they believe they lack competence. It is easier for the physician to simply make the decision, but this leaves the patient uninformed about treatment options and unable to evaluate the physician's treatment decision and how it may conflict with the best interest of the patient.

All 3 principles of care direct physicians to inform patients about adverse external forces that can influence their recommendations. This includes disclosing anything that the physician would be embarrassed to have the patient discover later (eg, recruitment incentives for enrolling patients in clinical trials, personal profit from tests ordered, or reimbursement incentives from insurers for withholding expensive tests of marginal effectiveness). Respect for patient autonomy requires that physicians provide this information freely and explore its meaning and implications with the patient. Physicians must support patients' seeking second opinions when conflicts of interest exist that could influence the physicians' recommendations or when the patient chooses alternative sources of care and testing. Perhaps, a more time efficient way to address this issue might be to post physician conflict-of-interest statements in waiting rooms and examination rooms.

In the long run, well-informed patients are the most effective force for protecting the primacy of patient welfare, enhancing their autonomy, and avoiding social injustice. These core principles of care imply that physicians need an active voice in the relationship, using their expertise and experience to enhance patient welfare rather than keeping quiet in a misguided effort to protect independent patient decision making. The enhanced autonomy approach has been demonstrated to be more motivational for patients when practitioners maintain a clear active voice that is not controlling. Following an enhanced autonomy model of care will almost certainly result in physicians' voices being heard again in the practice of medicine.

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