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# Informed Consent

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### INTRODUCTION

In health care—at least in the United States—competent patients have a legal right to refuse most medical treatment, even for frivolous reasons. *Informed consent* is based on the *principle of autonomy*, which holds that people have a right to make decisions for themselves.

*Informed* consent, as opposed to *simple* consent, means that a patient is provided with information about offered treatments and alternative treatments. For example, a patient should be told about likely side-effects, the probability that the treatment will be successful, and what is likely to happen if the treatment is rejected.

Informed consent is typically thought to be negative in orientation. If a patient is competent, then that patient may refuse medical treatment. The same principle does not imply that a patient has a right to choose treatment or to insist on a treatment that health-care professionals consider harmful or not helpful.

A decisionally capable adult patient may refuse a treatment, even if doing so would mean a sure and quick death, and even if the treatment is easy to provide, effective, and with few side-effects. So the welfare of a patient takes second place when it comes to autonomously refusing treatment. Yet patient welfare does not take second place when it comes to choosing treatment. That is, a patient is not thought of as having a right to choose a treatment, to exercise his or her autonomy, when doing so would lead to harm. That is, consent is not extended to treatment that is harmful, ineffective, or beyond the range of standard practice.

A variety of court cases in the United States firmly establish the right to refuse treatment. In 1914, US Supreme Court Justice Cardozo, in *Schloendorff v. Society of*

*New York Hospital*, led the way with this claim: “Every human being of adult years and sound mind has a right to determine what shall be done with his own body...”

Informed consent, as a legal doctrine, is based in case law (i.e., judge-made law) and in constitutional law. This is significant, because as a constitutional right based in liberty and privacy, it is fundamentally important. It can be overridden only by a compelling state interest, for example, in the preservation of life and the protection of innocent third parties. Thus informed consent might not be required for those undergoing treatment for contagious diseases.

Treatment without consent has traditionally been considered a legal battery. Increasingly, however, courts have rejected the battery view and evaluate lack of informed consent as negligence. Negligence as opposed to battery is somewhat easier to defend against in a court of law. The legal theory of battery, or harmful touching, is generally reserved for cases in which the health-care provider renders treatment that is different from that to which the patient consented. The theory of negligence is applied to cases in which the provider does not furnish complete or adequate information to the patient. Court cases have made it relatively clear that health-care providers have an obligation to disclose adequate information about the diagnosis, nature, and purpose of the treatment, as well as risks and outcomes.

While it seems to be agreed (legally and morally) that informed consent is a crucial ingredient in medical practice, problems remain with interpreting the extent and nature of the information that should be provided to a patient. Also, problems remain with determining who is capable of decision making. A capable patient must be able to communicate; understand his or her circumstances; reason about his or her medical circumstances; and (in some accounts) appreciate the fact that the medical circumstances will affect him or her.

Children do not, typically, have a right to informed consent. Instead, their parents are called upon to make medical decisions in their place. When children are old enough to reason carefully about their situation, it is recommended that they be allowed to “assent” to treatment. This, however, does not legally override parental decision making, except in the case of medical research.

Informed consent may be waived in difficult circumstances, for example, when there is a genuine emergency. Moreover, when information would significantly influence a patient’s health, the *therapeutic privilege* may be invoked, pursuant to which material information may be temporarily withheld from the patient for his or her own good. However, the therapeutic privilege should be used with caution. Also, informed consent is presumed for ordinary treatment after a patient implicitly or explicitly requests care. Some treatments may be required by law, for example, for tuberculosis or for mental illnesses when a patient is a danger to others.

*Proxy decision making* is required when a person lacks decisional capacity. Typically, such decisions involve “substituted judgment.” This is a decision by the proxy based on what the patient would want, given her or his values or previously stated preferences. For children and mentally challenged people, or for people who are not well known by proxies, decisions should be made in the “best interest” of the patient.

Informed consent is extended by *advance directives*, which involve “living wills” or the designation of proxy decision makers in a durable power of medical attorney. Advance directives are increasingly used to make clear a patient’s preferences when he or she is not competent to make a decision, typically in end-of-life situations.

## LEGAL CASES

### I. *Canterbury v. Spence*

#### INTRODUCTION

The case *Canterbury v. Spence* (1972) 464 F. 2d 772 is influential as the classic statement of the patient-oriented standard for informed consent. The majority rule regarding the standard for informed consent remains the *community of physicians standard*, according to which a physician is legally required to disclose to the patient the same information that a majority of other physicians would disclose in the same or similar circumstances. A significant minority rule is the *reasonable patient standard*, articulated in this case.

The *Canterbury* court related the facts as follows:

The record we review tells a depressing tale. A youth troubled only by back pain submitted to an operation without being informed of a risk of paralysis incidental thereto. A day after the operation he fell from his hospital bed after having been left without assistance while voiding. A few hours after the fall, the lower half of his body was paralyzed, and he had to be operated on again. Despite extensive medical care, he has never been what he was before. Instead of the back pain, even years later, he hobbled about on crutches, a victim of paralysis of the bowels and urinary incontinence. In a very real sense this lawsuit is an understandable search for reasons.

At the time of the events which gave rise to this litigation, appellant [Canterbury] was nineteen years of age, a clerk-typist employed by the Federal Bureau of Investigation. In December, 1958, he began to experience severe pain

between his shoulder blades. He consulted two general practitioners, but the medications they prescribed failed to eliminate the pain. Thereafter, appellant secured an appointment with Dr. Spence, who is a neurosurgeon.

Dr. Spence examined appellant in his office at some length but found nothing amiss. On Dr. Spence's advice, appellant was x-rayed, but the films did not identify any abnormality. Dr. Spence then recommended that appellant undergo a myelogram—a procedure in which dye is injected into the spinal column and traced to find evidence of disease or other disorder—at the Washington Hospital Center.

Appellant entered the hospital on February 4, 1959. The myelogram revealed a “filling defect” in the region of the fourth thoracic vertebra. Since a myelogram often does no more than pinpoint the location of an aberration, surgery may be necessary to discover the cause. Dr. Spence told appellant that he would have to undergo a laminectomy—the excision of the posterior arch of the vertebra—to correct what he suspected was a ruptured disc. Appellant did not raise any objection to the proposed operation nor did he probe into its exact nature....

Dr. Spence performed the laminectomy on February 11 at the Washington Hospital Center.... [Canterbury's mother] traveled to Washington, arriving on that date but after the operation was over, and signed a consent form at the hospital. The laminectomy revealed several anomalies: a spinal cord that was swollen and unable to pulsate, an accumulation of large tortuous and dilated veins, and a complete absence of epidural fat which normally surrounds the spine. A thin hypodermic needle was inserted into the spinal cord to aspirate any cysts which might have been present, but no fluid emerged. In suturing the wound, Dr. Spence attempted to relieve the pressure on the spinal cord by enlarging the dura—the outer protective wall of the spinal cord—at the area of swelling.

For approximately the first day after the operation appellant recuperated normally, but then suffered a fall and an almost immediate setback. Since there is some conflict as to precisely when or why appellant fell, we reconstruct the events from the evidence most favorable to him. Dr. Spence left orders that appellant was to remain in bed during the process of voiding. These orders were changed to direct that voiding be done out of bed, and the jury could find that the change was made by hospital personnel. Just prior to the fall, appellant summoned a nurse and was given a receptacle for use in voiding, but was then left unattended. Appellant testified that during the course of the endeavor he slipped off the side of the bed, and that there was no one to assist him, or side rail to prevent the fall.

Hours later, appellant began to complain that he could not move his legs and that he was having trouble breathing; paralysis seems to have been virtually total from the waist down. Dr. Spence was notified on the night of February 12, and he

rushed to the hospital. Mrs. Canterbury signed another consent form and appellant was again taken into the operating room. The surgical wound was reopened and Dr. Spence created a gusset to allow the spinal cord greater room in which to pulsate.

Appellant's control over his muscles improved somewhat after the second operation but he was unable to void properly. As a result of this condition, he came under the care of a urologist while still in the hospital. In April, following a cystoscopic examination, appellant was operated on for removal of bladder stones, and in May was released from the hospital. He reentered the hospital the following August for a 10-day period, apparently because of his urologic problems. For several years after his discharge he was under the care of several specialists, and at all times was under the care of a urologist. At the time of the trial in April, 1968, appellant required crutches to walk, still suffered from urinal incontinence and paralysis of the bowels, and wore a penile clamp.

The patient filed an action for malpractice against Dr. Spence and the hospital where the surgery took place, including allegations of negligence in performance of the laminectomy and failure to obtain informed consent by failing to disclose the risk of paralysis from the surgery against Dr. Spence, and failure to give proper post-surgery care against the hospital. At the trial of the matter, the court granted the defendant's motion for a directed verdict for the defendants, which means that the court "directed" that the jury must find for the defendants.

Canterbury appealed. In its written opinion, the appellate court addressed the issue of the proper standard of disclosure for physicians:

... The majority of courts dealing with the problem have made the duty depend on whether it was the custom of physicians practicing in the community to make the particular disclosure to the patient. If so, the physician may be held liable for an unreasonable and injurious failure to divulge, but there can be no recovery unless the omission forsakes a practice prevalent in the profession ...

There are, in our view, formidable obstacles to acceptance of the notion that the physician's obligation to disclose is either germinated or limited by medical practice. To begin with, the reality of any discernible custom reflecting a professional consensus on communication of option and risk information to patients is open to serious doubt. We sense the danger that what in fact is no custom at all may be taken as an affirmative custom to maintain silence.... Nor can we ignore the fact that to bind the disclosure obligation to medical usage is to arrogate the decision on revelation to the physician alone. Respect for the patient's right of

self-determination on particular therapy demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves. [...]

... In our view, the patient's right of self-decision shapes the boundaries of the duty to reveal. That right can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The scope of the physician's communications to the patient, then, must be measured by the patient's need, and that need is the information material to the decision. Thus the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked. And to safeguard the patient's interest in achieving his own determination on treatment, the law must itself set the standard for adequate disclosure. [...]

From these considerations we derive the breadth of the disclosure of risks legally to be required. The scope of the standard is not subjective as to either the physician or the patient; it remains objective with due regard for the patient's informational needs and with suitable leeway for the physician's situation. In broad outline, we agree that "[a] risk is thus material when a reasonable person, in what the physician knows or should know to be the patient's position, would be likely to attach significance to the risk or cluster of risks in deciding whether or not to forego the proposed therapy."

The appellate court held that based upon the reasonable patient standard, there was sufficient evidence for the jury to decide the issue of informed consent, and also that there was sufficient evidence of medical negligence. As a result, the directed verdict was reversed, and a new trial was ordered.

#### CASE DISCUSSION

The court in *Canterbury* criticized the community of physicians standard on several bases. First, the court indicated that there may be no discernible standard of disclosure in many cases. Second, the standard may lead to minimizing disclosure standards as a means of reducing liability. Third, the court emphasized the fact that the concept of informed consent by its terms refers to the informational needs of the patient, not the conduct of the physician.

A "reasonable patient" standard is usually considered to be an objective standard. As the court in *Canterbury* stated, it is "not subjective as to either the physician or the patient; it remains objective with due regard for the patient's informational needs and with suitable leeway for the physician's situation." If a case is litigated, the

“finder of fact,” a jury in most cases, determines what a reasonable patient would want to know.

#### QUESTIONS

1. Which is preferable, the community of physicians standard or the reasonable patient standard? Why?
2. How is a physician to determine what information a “reasonable” patient would want to know?
3. Is it fair to require a physician to ascertain what a “reasonable patient” would want to know?
4. Is it preferable for a jury of individuals who likely have no medical knowledge to determine what a reasonable patient would want to know, or for the physician to do so?
5. The reasonable patient standard seems to reflect the deontological principle of respect for persons. That is, the autonomy of the patient is considered more important than the custom and practice of physicians. Could a consequentialist justify the adoption of the reasonable patient standard as well? How?
6. Could the reasonable patient standard be justified on the basis of the ethics of care, and/or particularist theory? How?

## II. *Jandre v. Bullis*

#### INTRODUCTION

The Wisconsin case *Jandre v. Bullis* (2012) 813 N.W. 2d 627 involved the issue of a physician’s duty under the doctrine of informed consent to inform a patient of alternative diagnoses and tests, even though the physician makes a different final diagnosis. The court related the facts of the case as follows:

On June 13, 2003, Jandre was at work and driving to a job site when he drank some coffee and it came out through his nose. He was drooling, his speech was slurred, his face drooped on the left side, he was unsteady, dizzy and his legs felt weak. His co-workers took him to the St. Joseph’s Hospital West Bend emergency

room. Jandre told the emergency room nurse his complaints, and his co-workers reported their observations of Jandre's symptoms. The nurse noted in Jandre's chart that he complained of left facial weakness, slurred speech and dizziness that lasted approximately twenty-plus minutes. The nurse noted that she observed that the left side of Jandre's face drooped.

Jandre was evaluated at the emergency room by Dr. Bullis. Dr. Bullis read Jandre's chart, including the nurse's notes, took a medical, social and family history from Jandre and performed a physical examination. Dr. Bullis testified that she observed left-side facial weakness and mild slurred speech. She made a differential diagnosis—which she testified was a “list” of what she was “evaluating the patient for”—of some kind of stroke or Bell's palsy. [...]

[However,] Dr. Bullis did not tell Jandre that he had an atypical presentation of Bell's palsy or that his symptoms were also consistent with a stroke. Although Dr. Bullis testified that she told Jandre what Bell's palsy was and explained it was not a stroke, Jandre's medical records document only that Dr. Bullis told him he had Bell's palsy and explained that final diagnosis. Jandre denied that Dr. Bullis mentioned the possibility that he was suffering from a stroke, either hemorrhagic or ischemic. Further, Jandre claimed that Dr. Bullis did not explain what a TIA or RIND were or that they could be warning signs of future stroke, which could result in death or disability. Jandre testified that Dr. Bullis did not tell him that there was a test called a carotid ultrasound that he could take to rule out ischemic stroke.

Eleven days later, on June 24, 2003, Jandre suffered a massive stroke. A carotid ultrasound performed at St. Luke's Hospital revealed that Jandre's right internal carotid artery was ninety-five per cent blocked. Two expert witnesses, both Jandre's treating physicians, testified at trial that if they had been called on June 13, 2003, the day of the emergency room examination, they would have ordered a carotid ultrasound. Both physicians testified that on June 13, 2003, Jandre had experienced a TIA or RIND and had a carotid ultrasound been done that day, it would have revealed a ninety-five per cent blockage in the right internal carotid artery. They testified that the blockage could have been treated by surgery, which would have significantly reduced the likelihood of Jandre suffering a stroke eleven days later.

On June 14, 2004, the Jandres filed suit against Dr. Bullis, PIC and the Fund, alleging that Dr. Bullis negligently: (1) diagnosed Jandre's condition and (2) failed to disclose information necessary for Jandre to make an informed decision with respect to his treatment.... The case proceeded to trial in February 2008, on both the negligent diagnosis claim and the informed consent claim. The jury found that



Dr. Bullis was not negligent in her diagnosis but was negligent with regard to her duty of informed consent.

On appeal the defendants argued that requiring physicians to disclose information regarding other treatments and diagnoses that the physician does not think are relevant would be unduly burdensome. The court of appeals rejected the argument:

Finally, we reject PIC's attempt to persuade us that requiring physicians to inform patients of tests like the carotid ultrasound puts physicians in an impossible position because it "require[s] doctors to provide information about diagnostic tools and treatments for any possible condition from which the defendant may suffer at some point in the future." ... We are not holding that Dr. Bullis had to provide information about any possible condition or that she had to provide information about conditions Jandre might suffer at some point in the future. Rather, we conclude that Dr. Bullis was required to inform Jandre about a test to rule out a condition she thought he was possibly suffering from, and which she did not rule out. [...]

Because WIS. STAT. § 448.30 requires a physician to inform a patient of "all alternate, viable medical modes of treatment, including diagnosis" that "a reasonable person in the patient's position want to know in order to make an intelligent decision with respect to the choices of treatment or diagnosis," ... and because a reasonable person in Jandre's position would want to know of the availability of a carotid ultrasound test to intelligently determine if he should follow the treatment recommendation made by Dr. Bullis, we conclude that the jury was properly asked to determine whether Dr. Bullis' failure to inform was negligent under § 448.30.

On appeal of the appellate court's affirmance of the result in the trial court, the Wisconsin Supreme Court held:

... we conclude that there was credible evidence in the record that would allow a reasonable jury to find Dr. Bullis negligent for failing to inform Jandre about an alternate, viable mode of treatment. There was testimony that using the carotid ultrasound was an accepted, alternative course of action that could have been employed in diagnosing Jandre's condition.

The Supreme Court thus upheld the jury verdict against Dr. Bullis for failing to inform Jandre of the alternative diagnosis and test for the condition.

## CASE DISCUSSION

In *Jandre v. Bullis*, the Wisconsin Court upheld the ascription of liability of the defendant physician for failing to disclose the fact that a viable method existed to determine if there was a different cause of the plaintiff's condition, even though the physician ultimately made a different diagnosis.

The Supreme Court's determination was based upon the state's statute regarding the obligation to obtain informed consent, Wis. Stat. section 448.30. The statute contained a reasonable patient standard. The Supreme Court held in *Jandre* that a reasonable patient would want to be apprised of the fact that there was another possible cause of his symptoms, and that there was a viable method to determine if the alternative cause was present in his case.

The *Jandre* case resulted in much controversy amongst health-care providers in Wisconsin. It was alleged that the holding was causing physicians, particularly physicians in emergency departments, to practice defensive medicine by explaining and prescribing multiple unnecessary tests relating to any other possible cause of a condition.

In direct response to the *Jandre* holding, in December 2013 Section 488.30 was amended in several material respects.<sup>1</sup> One significant change was that the reasonable *patient* standard was abandoned and a reasonable *physician* standard was adopted:

Any physician who treats a patient shall inform the patient about the availability of reasonable alternate medical modes of treatment and about the benefits and risks of these treatments. The reasonable physician standard is the standard for informing a patient under this section. The reasonable physician standard requires disclosure only of information that a reasonable physician in the same or a similar medical specialty would know and disclose under the circumstances.

Therefore, the emphasis of the new section is on the conduct of the physician, not the informational needs of the patient. If the physician discloses the same information as other providers, he or she has met the standard of care.

Further, in direct response to the holding in *Jandre*, the following provision was added to the specification of the types of disclosure the physician is not required to make: "(7) Information about alternate medical modes of treatment for any condition the physician has not included in his or her diagnosis at the time the physician informs the patient." The new version of Section 488.30 took effect in December 2013. If the new section had been in effect when the *Jandre* case was litigated, it is

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1 See Corneille Law Group, "Revised Informed Consent Statute Provides Greater Protection for Health Care Providers," <http://www.corneillelaw.com/2014/revised-informed-consent-statute-provides-greater-protection-for-healthcare-providers/>.

likely that the physician would not have been held liable for failing to disclose the possibility of a stroke and the availability of relevant diagnostic tests, as the physician had made a final diagnosis of Bell's palsy.

#### QUESTIONS

1. Did the amendments to the statute regarding informed consent go too far?
2. Would most patients want to be made aware of other possible treatments and diagnoses, even though the physician makes a final diagnosis that does not include them? Would you?
3. Carefully explain the difference between a reasonable patient standard and a reasonable physician standard. Which is preferable? Why?
4. How would a deontologist evaluate the old and new standards for informed consent? A consequentialist?

### III. *Gorab v. Zook*

#### INTRODUCTION

The court in *Gorab v. Zook* (1997) 943 P. 2d 423 applied the community of physicians standard for informed consent. The court related the facts of the case as follows:

In May 1987, petitioner, Lawrence N. Gorab, M.D. (Dr. Gorab), treated respondent, Daniel C. Zook (Mr. Zook), for prostatitis, a condition caused by the inflammation of the prostate gland. Dr. Gorab prescribed a sulfa antibiotic drug known commercially as Septra, which cured Mr. Zook's condition almost immediately. However, during the time he was taking the drug, Mr. Zook experienced fevers, chills, fatigue, and muscle aches. On June 1, 1987, several days after Mr. Zook stopped taking the drug, he experienced a spell resembling a grand mal seizure, which Mr. Zook alleges was caused by an adverse reaction to Septra.

The parties dispute certain facts in the case. For example, Dr. Gorab testified that when he prescribed Septra for Mr. Zook's prostatitis on the initial visit of May 15, 1987, he informed Mr. Zook of the "usual risks and precautions" of the drug, including the risk of fever, rash, headaches, nausea, kidney stones, and hepatitis. In contrast, Mr. Zook denies that Dr. Gorab informed him about any risks other than nausea and kidney stones. Both courts below found and the parties agree,

however, that Dr. Gorab did not warn Mr. Zook about the possibility of seizures from the use of Septra.

In addition, there is conflicting testimony regarding when Mr. Zook informed Dr. Gorab that he was experiencing adverse side effects from the drug. Mr. Zook claims that he and/or his wife told Dr. Gorab that he was experiencing flu-like symptoms some time between his initial visit on May 15, 1987, and his second visit on May 22. Mr. Zook further claims that he tried unsuccessfully to contact Dr. Gorab on May 23, 24, or 25, and that he told Dr. Gorab on May 26 that he had a body temperature of 102 degrees.

Dr. Gorab, on the other hand, claims that he noted a full respiratory infection during Mr. Zook's initial visit on May 15 and that he did not have contact with either Mr. Zook or his wife between May 15 and May 22. Additionally, Dr. Gorab asserts that his examination of Mr. Zook on May 22 indicated that he was handling the medication well and was not experiencing any adverse reactions. Dr. Gorab also denied that Mr. Zook contacted him between May 22 and May 25. Rather, Dr. Gorab claims that his next contact with Mr. Zook was on May 26, when he indicated he had various flu-like symptoms.

Mr. Zook filed this medical malpractice action, claiming that Dr. Gorab was negligent in failing to advise him to stop taking Septra after he began having an adverse reaction. Mr. Zook also argued at trial that Dr. Gorab had not properly obtained his informed consent before administering the Septra because he had not informed Mr. Zook of the possibility of seizures. Mr. Zook's informed consent claim also alluded to Dr. Gorab's failure to inform him of the possible risks of continuing to take Septra after Dr. Gorab learned of Mr. Zook's flu-like symptoms. [...]

Here, it is undisputed that, prior to prescribing Septra, Dr. Gorab did not disclose to Mr. Zook the risk of seizure as an adverse side effect. It is also undisputed that Mr. Zook suffered a seizure, which he contends resulted from his use of Septra. Mr. Zook therefore established a *prima facie* case of lack of informed consent and the burden shifted to Dr. Gorab to demonstrate that under the circumstances, his failure to warn complied with applicable medical standards.

Dr. Gorab met his burden by presenting the expert testimony of Dr. Augspurger, who testified that seizures suffered as a result of taking Septra are extremely rare and, as such, a reasonable urologist would not need to inform patients of that possibility. Thus, Dr. Augspurger testified that Dr. Gorab's disclosure, which did not include a warning about seizures, conformed sufficiently to the medical community's standard of care.

Under the burden shifting framework set forth above, Mr. Zook was then required to rebut Dr. Augspurger's testimony with expert testimony of his own,

thereby creating a disputed factual question for the jury to resolve. The record reveals, however, that Mr. Zook failed to present any testimony from a medical expert that the warning given by Dr. Gorab when he prescribed Septra did not comport with the applicable standard of care in the medical community.

The Supreme Court of Colorado held that since Mr. Zook provided no expert testimony that Dr. Gorab's failure to disclose the risk of seizure associated with the drug violated the community standard, Dr. Gorab must prevail on the claim of failure to obtain informed consent.

#### CASE DISCUSSION

The community standard, pursuant to which a physician needs to disclose the same information that other physicians disclose in the same or similar circumstances, is the majority view in US courts. In effect, the community standard equates the failure to obtain informed consent with any other type of medical malpractice, which is also subject to the community standard.

Benefits of the community standard include the fact that physicians should be aware of the practice of other physicians in the same or similar circumstances, and hence it is reasonable to consider physicians to be on notice of such practices. Further, physicians have the requisite training and experience to fully appreciate the significance of particular benefits and risks of particular treatment, as well as reasonable alternative treatments. The major flaw in the standard is that it fails to take into central account the informational needs of the patient.

#### QUESTIONS

1. Doesn't the community standard presuppose that there are clear standards regarding disclosure in relation to most treatments? What if there are not clear standards in regard to certain treatments?
2. In the *Gorab* case the dispositive issue for the Colorado Supreme Court was the absence of expert opinion to the effect that Dr. Gorab failed to disclose the risk of seizure. Does the fact that Mr. Zook apparently believed the failure to disclose the risk seem significant to you?
3. Is it possible or even likely that what physicians consider to be material risks may differ from the opinions of patients who have no medical training or experience? If so, is the community of physicians standard of questionable relevance to the interests of patients?

4. Provide justifications for the community of physicians standard for informed consent on the basis of consequentialist and deontological theory, respectively.

## CASE STUDIES

### IV. Emergency-Room Deliberation after a Critical Motorcycle Accident

#### INTRODUCTION

Emergency-room treatment is an exception to informed consent unless there is an available and suitable substitute decision maker or if the patient makes his or her wishes known to the staff in a decisionally capable way. In theory, this seems straightforward. In practice, doubt can arise in various ways. For example, it may be difficult to determine whether the patient is capable. Also, what seems like a clear expression of a patient's wishes may turn out to be questionable. Determining a patient's capability and his actual desire is at the heart of this tragic case.

#### CASE PRESENTATION

Johnny Avalon, a 22-year-old man living alone in a large California city, crashed while riding his motorcycle. Although traveling fairly slowly on a back street, he was not wearing his helmet; his head hit the street after he was thrown from his motorcycle. He was taken to the emergency room of a large county hospital. He had no identification, so the staff did not know his name, age, or address. His severe head injuries indicated that he would probably die soon regardless of treatment, but with quickly initiated treatment he might survive with significant handicaps. A full recovery was considered more or less out of the question.

The emergency-room staff discovered a small note, handwritten in pencil, in Mr. Avalon's pocket. It said: "Don't keep me alive." The staff speculated about whether the note was a blanket rejection of treatment by Mr. Avalon. Maybe it indicated that he wanted to commit suicide by being thrown from his motorcycle. Mr. Avalon was unconscious, and since little was known about him, no surrogate decision maker could be quickly located. Given the likely poor outcomes with treatment, including a life of paralysis, some of the staff members thought it was best to assume that he did not want treatment and therefore that treatment should not be initiated. Others on the staff talked about what the likely long-term costs would be, in financial terms and in terms of resources that might be best used by other patients. This view was part of the thinking of at least one of the staff members who thought that treatment should not be initiated. Another staff member worried that those who did not want

to initiate treatment might be improperly reacting to what they took to be a motorcycle-gang leather jacket that Mr. Avalon was wearing. His long beard added to the feeling that he was a gang member.

The sentiment against treatment was rejected by the surgeon in charge. She initiated aggressive treatment. After surgery, Mr. Avalon was put on life support. He died two days later, before his out-of-state mother and father were located.

#### CASE DISCUSSION

The main issue in the case is the right to informed consent. But other issues are also raised. One is the appropriate use of scarce and expensive medical resources. The other is possible discrimination based upon prejudice against young motorcycle riders and/or motorcycle gang members.

We can quickly reject any emergency-room decision not to treat due to cost considerations. This is not morally or legally appropriate. Questions of cost vs. benefit of medical treatment may be appropriate in some contexts, such as in political decision making, but should play no role in the treatment deliberations of emergency-care staff members. Simply put, that is not their job. Also, when two or more patients compete for the same scarce resources, such as available surgery-room space, a decision must be made about who receives the resource. This might best be done on a first come, first served basis, but issues of probable survival may be appropriate, so the staff should base treatment on the best interests of the patients.

Secondly, there is no room for discrimination against a class of people in health-care decisions. Discriminatory decisions fly in the face of the commitment of health-care providers. While it is generally appropriate to consider the perspective of all the parties that are involved, this does not mean that a morally or legally inappropriate point of view should be allowed to decide the issue. In this case the views of those who discriminate against motorcycle riders should play no role.

This leaves the issue of informed consent. Before we explore that issue, we consider whether any required information is missing.

We are not told about the exact nature of the patient's injuries or the kind of surgery performed. We are told that the injuries are very serious, that even with good treatment Mr. Avalon is likely to die, and that if he lives he will almost certainly face severe, but largely unspecified, handicaps.

Aside from medical information, this case is notable for the nearly complete lack of information. It is not that the case presentation is too abbreviated; it is rather that the emergency-room staff has so little information. They do not know Mr. Avalon's age, who his parents are, or where he comes from. What they do know is that he has a note in his pocket saying "Don't keep me alive."

We know that there is an emergency exception to informed consent. In this case, no one consented to Mr. Avalon's treatment, not even a surrogate. Typically, the emergency exception does not apply when the patient is able to consent to treatment, which is not true in the situation we are considering. The emergency exception does not apply if an appropriate surrogate is available, also not the case in this situation. But if an emergency patient has a valid and acceptable living will that rejects treatment, that could count as an appropriate expression of the patient's rejection of treatment. However, a simple note is far from a living will.

An emergency, almost by definition, takes away the ability to deliberate over consent. For example, in a non-emergency situation a medical staff may be unsure about a patient's capacity to consent to offered treatment. A specialist, perhaps a bioethicist or a psychiatrist, might be consulted to help determine capacity. However, there is no time for that in emergencies, so when in doubt about a patient's capacity, treatment might be undertaken under the emergency exception. Also, there might be questions about a surrogate—for example, whether the surrogate is the right person to make decisions for a patient. The staff might believe that the surrogate has some animosity toward the patient, thus excluding him or her from being a proper surrogate. Or else a surrogate's power of attorney might be unclear or from another state. A staff might believe that someone claiming to be the patient's wife might in fact not be. In all of these situations, there is no time to investigate problems, as there often is in more routine medicine. Again, this is part of the reason for the emergency exception. Typically, when in doubt, life-saving treatment without consent may be appropriate under the emergency exception.

Keeping in mind the lack of time to investigate doubts, is there enough doubt in this case to invoke the emergency exception? For example, is the note a clear expression of Mr. Avalon's wishes not to be treated? While the note might seem to be a clear statement, with greater reflection it is thoroughly inadequate. First of all, it is not signed or dated. Mr. Avalon may have found the note and put it in his pocket. Or the note may have some significance that is not apparent. Maybe it means that Mr. Avalon wants to be on drugs and compares that to some sort of non-living state. Maybe it is a reminder to himself to buy a rock song on the Internet with a similar name. Furthermore, we do not know Johnny's age. If he is under 18 he should not, under emergency circumstances, be considered capable of making an informed-consent decision. The medical team is making a life-or-death decision, and the note is not adequate evidence to overcome the emergency exception to informed consent.

Suppose the note was clearer. Suppose it explained exactly his circumstances, for example, that he intentionally crashed his motorcycle, that he was 22 years old, and that that he rejected all medical treatment because he wanted to die. Suppose the



note was signed and had the signature of a witness. Given the clarity of the note, would this invalidate the emergency exception?

Once again, the emergency nature of the situation means that there is no time to explore the note. It could be that the writer of the note was not capable of making a decision, perhaps due to drugs or a mental illness. Perhaps the writer was under 18 and simply lied about being 22.

We do not mean to raise unlikely scenarios; what we want to emphasize is that doubts about informed consent in emergency situations may properly allow treatment under the emergency exception. This might also be true if the patient was conscious and aggressively rejected treatment. But it might be unknown whether the patient was acting under the influence of the recently suffered trauma or was suffering from mental illness, etc.

In this case, the note is too easy to fault as evidence of a rejection of treatment.

#### QUESTIONS

1. Suppose that Mr. Avalon regains consciousness just before intubation and asks to be allowed to die. Should treatment be stopped?
2. Suppose the treatment is successful in that Mr. Avalon's life is saved but he is completely paralyzed from the neck down. Suppose that it is subsequently determined that Mr. Avalon is over 21 and has written a note rejecting treatment. Would this information indicate that the wrong decision was made?
3. Suppose that after the emergency treatment, it is determined that Mr. Avalon is capable of making decisions. Let us say that withdrawal of his ventilator would mean almost sure death. Would he then have a right to reject such life-sustaining treatment?

## V. Protection for a "Decisionally Incapable" Patient

#### INTRODUCTION

This is a case about a patient rejecting the care that is thought to be best by her health-care team. In our presentation and analysis, we use a format that involves exploring what might happen under two different scenarios. This is done to underscore the fact that different decisions lead to different consequences.

## CASE PRESENTATION AND DISCUSSION

Mrs. Jill Kenmore, an 84-year-old former elementary school teacher, lived alone at home. Her husband had died 12 years before, and Mrs. Kenmore was estranged from her three adult children. She lived in the northeast of the United States, while her children lived in western Canada. She had Chronic Obstructive Pulmonary Disease (COPD) and was diabetic. She was overweight, at 5'2" and 230 lbs. She lacked full mobility, yet she could walk slowly using a walker. She frequently stayed in bed for several days at a time. A neighbor often brought her food, usually snack food and items such as peanuts that she could eat without leaving her bed.

Mrs. Kenmore was forgetful and had trouble thinking through complex issues. For example, she had an opportunity to move to a smaller unit in her apartment house, at a significantly reduced rent. She wanted to save money and also thought a smaller apartment would be easier for her to maintain. Nevertheless, she could not decide whether to move because she was confused about the details of a new lease and about how she would move her furniture. Her indecisiveness caused her to lose the smaller apartment, which she afterwards regretted.

During a 16-month period, at three different times Mrs. Kenmore had body sores that became infected. She presented at the hospital and was treated and released each time. The length between hospital emergency department visits became shorter. Just a month after the previous visit, she presented again and this time was hospitalized. The infected areas were more widespread and presented a significant risk of death if she did not respond to treatment by way of antibiotics. The apparent cause of frequent infections was her extended periods in bed and lack of proper hygiene.

If she was released to her home, even with home-care visits, the health-care team believed she would face a high likelihood of death from frequent infections. She did seem agitated by the hospital stay, and the team believed she might not seek medical help if she became infected again. Based on all their information about Mrs. Kenmore, they thought that she should be placed in a nursing home. They asked Mrs. Kenmore to agree to placement, and she adamantly refused, saying that she would rather die than spend a single day in a nursing home. She told them that five years ago she had stayed for six weeks in a nursing home after knee replacement surgery and found it intolerable, like being in prison, she said. The health-care team tried to convince her that she would get good care in a cheerful environment at a local nursing home, but she refused to listen and became somewhat belligerent, raising her voice and using foul language.

Mrs. Kenmore's decision was considered unacceptable by the health-care team. They explored their options. The following were considered:

1. The first option considered was to discharge Mrs. Kenmore. The best argument for discharging Mrs. Kenmore was that she was capable of rejecting offered treatment. If she was not capable, then discharging Mrs. Kenmore to a dangerous situation would have been considered harmful, and thereby in violation of a health-care provider's ethical obligations. While discharging her would, in all probability, lead to future trips to the emergency department, since she was capable of making her own decisions, then she should be discharged. That left the main question: Is Mrs. Kenmore decisionally capable of rejecting nursing-home care?
2. The second option considered was to be more persistent, or maybe more aggressive, in talking her into moving to a nursing home. The health-care team discussed the situation and concluded that they might be able to talk Mrs. Kenmore into going to a nursing home if they promised her that she would only be going there for a few days in order to stabilize her condition. Once she was at the home, they thought it would be difficult for Mrs. Kenmore to leave, so she might stay of her own accord, or they might then seek to have her declared incompetent by a court. One member of the team objected to this approach, saying it amounted to deceit. Besides, Mrs. Kenmore's attitude toward a nursing home was based on her past experience and was not unreasonable. The other members of the team took this objection seriously but worried about the harmful situation that Mrs. Kenmore would face if she returned home.
3. The third option was to call for an ethics consultation. One member of the health-care team thought that since the issue involved informed consent and beneficence, someone who specializes in bioethics should be consulted. Mrs. Kenmore faced death if she went home, but she rejected nursing care, as is her apparent right unless she lacked decisional capacity. An ethics consultation could help to sort out these issues, or it might help, the team member thought, to talk Mrs. Kenmore into accepting nursing-home care. The other team members thought that the issues were clear cut and that they did not need support from an ethicist. The team member who wanted help could not understand this attitude and thought that she might call a consultant herself, as she knew was her right in the hospital, but she feared negative repercussions from the other team members.
4. The final option was to seek a court order to have Mrs. Kenmore committed to the nursing home. Some members of the team thought that seeking a

court order was the best way to go. They could consult legal counsel and get an opinion, and if counsel thought a judge might find Mrs. Kenmore incompetent, the problem would be resolved. Others thought that this was a decision of last resort. Furthermore, they did not trust that judges would make the best decision.

After a good deal of discussion, the health-care team narrowed down the options to two. We will explore what might have happened if a particular option had been selected. This, of course, is meant to explore the ethics of the options, and does not necessarily reflect what actually happened.

*Option 1.* The first option we examine is seeking a court order declaring Mrs. Kenmore incompetent. In this scenario, the team consulted the hospital attorney, who thought there was a good possibility a local judge would declare Mrs. Kenmore incompetent. Since she had no family, the court would probably appoint a guardian, and the guardian would probably have Mrs. Kenmore placed in a nursing home. The lawyer requested information about why the team thought that Mrs. Kenmore was incompetent.

The best reason to believe that Mrs. Kenmore was incompetent is that she was forgetful. However, she consistently rejected nursing care, so it is unlikely that a judge would think that her forgetfulness was enough to declare her incompetent.

She did not seem to appreciate the problems she would face if she went home. Lack of appreciation seemed like the most probable way of believing her to be incompetent. She might have underestimated her ability to care for herself, given the recurrence of her problems with infections. Or she might not have fully realized how deadly infections can be.

Mrs. Kenmore did have trouble reasoning through issues. Recall that she could not think through the complexities of moving to a new apartment. But keep in mind that the courts tend not to require a high level of reasoning skill. In this case, Mrs. Kenmore seemed to understand that she might die without nursing care but clearly stated that based on her past experience with a nursing home, she would rather die than go to one.

The hospital lawyer presented the case to a local judge, with the various arguments we explored about Mrs. Kenmore's incompetency. The judge thought it was a weak case. He reprimanded the hospital lawyer, citing the case of *Lane v. Candura* (see Chapter 3, Case #1). In that case, Mrs. Candura had gangrene, faced a more immediate threat than Mrs. Kenmore did, and seemed even less capable than Mrs. Kenmore. She was found to be competent. The judge chided the health-care team for attempting to deny Mrs. Kenmore her right to informed consent.

Given the judge's ruling, Mrs. Kenmore was discharged from the hospital. During the next twelve months she returned twice to the hospital emergency department. Each time the team tried to talk her into going to a nursing home, and she adamantly refused. A month after a successful treatment, she developed a new infection that quickly spread throughout her system, and she died two days later.

Did the health-care team do the right thing in going to a judge to have Mrs. Kenmore declared incompetent? The team members seemed to think so, but Mrs. Kenmore had a moral and legal right to reject nursing care. She clearly expressed her view that the nursing home was thoroughly unacceptable to her based on her past experience. Unfortunately, she died a year later, but this does not mean that she should have been denied her right to reject nursing-home care.

*Option 2.* We now consider the outcome under the option of attempting to talk Mrs. Kenmore into a nursing-home stay.

In this scenario, the hospital lawyer informed the team that it was highly unlikely that a local judge would agree that Mrs. Kenmore was incompetent. Furthermore, the lawyer said he would not bring this to a judge. He carefully explained that Mrs. Kenmore had a moral and legal right to reject such care.

The team decided to talk Mrs. Kenmore into staying at a nursing-care facility for a short period. They told her that this would only be for a few days, and that they would then help her to return to her home. They also told her that she needed this stay to stabilize her health, which was not fully true. They thought that she would stay permanently when she realized it wasn't as bad as she thought. Also, they would try to have employees of the home keep up the pressure on her once she was in the home.

Mrs. Kenmore agreed, feeling that a few days would not matter that much, given that hospital life was not good either. She believed she needed further stabilization, even though this was incorrect. Actually, she would have been released from the hospital in another day or two, given her current progress.

Mrs. Kenmore willingly went to the nursing home. Unfortunately, she died four days later after taking a bad fall. She was not happy at the home and barely talked with anyone.

Mrs. Kenmore expressed negative views about nursing care, but it is also true that the nursing home would probably have been better able to ensure that Mrs. Kenmore did not have recurring problems with infections. Older people, especially those who have mobility problems, face a risk of falling, and often falls are devastating. The team probably understood that people in new surroundings face a greater change of falling, but also understood that Mrs. Kenmore needed care that she couldn't get at home. All in all, it would seem that Mrs. Kenmore's death after a few days at the

nursing home is not in itself conclusive evidence that the team did something that was morally wrong by deceiving her into accepting nursing-home care. However, the fact that Mrs. Kenmore died might be a corroboration of the seriousness of her distaste for nursing-home living.

In fact, the health-care team did deceive Mrs. Kenmore. They may have had good intentions, thinking that her life would be prolonged by staying in a nursing home. That was a reasonable belief. Nevertheless, morally and legally a person has a right to informed consent. Informed consent involves the provision of truthful and relatively complete information. Deception does not, at least typically, play a proper role in the informed-consent process. Most bioethicists would probably agree that the health-care team did the wrong thing by deceiving Mrs. Kenmore. A minority view might be that the attempt to do good for Mrs. Kenmore morally legitimizes the level of deception that was involved. A deontologist would be more likely to believe that the deception was wrong than would a consequentialist.

Let's assume that both choices the health-care team finally debated were not thought to be proper. What would have been a better approach? We first examine the option of simply discharging Mrs. Kenmore from the hospital.

*Option 3.* This may have been a reasonable action. But keep in mind that the health-care team was convinced that Mrs. Kenmore would do better in a nursing home and that she faced a significant risk of developing life-threatening infections if she returned to her home. It would have been reasonable and morally proper to continue to try to talk Mrs. Kenmore into going to a nursing home. The team might have enlisted help in talking with her; perhaps a respected person from the clergy, a bioethicist, a psychologist, a psychiatrist, or a social worker could have helped. Perhaps her estranged children could have been involved as well. This may be the approach that a care ethicist would be most likely to recommend.

*Option 4.* Another choice we did not previously evaluate is calling for an ethics consultation. Since the health-care team was convinced that Mrs. Kenmore would do better in a nursing home, simply discharging her might not have been the best course, morally speaking. Moral issues are complex in this case, given Mrs. Kenmore's rights, her use of hospital resources, and the harm she was likely to face if she went home. A consultation might have helped to resolve such complexities. It would also have been reasonable and morally proper to enlist help with talking to Mrs. Kenmore about going to a nursing home. An ethics consultant might suggest getting help from someone that Mrs. Kenmore trusted.

In conclusion, the best approach may have been to talk Mrs. Kenmore into nursing care, using influence without using deception. If convincing Mrs. Kenmore proved to be unsuccessful, her decision should stand.

## QUESTIONS

1. Did Mrs. Kenmore act rationally by refusing to go to the nursing home?
2. If she did not act rationally, does that mean she was incapable of making a decision?
3. Was the deception of Mrs. Kenmore morally acceptable? Is deceiving ever morally acceptable? If so, under what kind of circumstances?
4. Is it morally appropriate to try to influence a patient? Under what conditions is influence unacceptable?
5. Does the fact that Mrs. Kenmore died in the nursing home suggest that in the future, pressure should not be put on capable patients to move to a nursing home against their wishes?

## VI. Patient Coerced into Additional Physical Therapy

### INTRODUCTION

Informed consent is a right, but that right can be denied in a variety of ways. Pressure on a patient is involved in this case. Is that pressure a legitimate tool to ensure needed therapy, or is it morally offensive?

### CASE PRESENTATION

After cancer surgery involving the removal of muscles in her neck and shoulders, Mrs. Flower, a 59-year-old secretary, was scheduled for 15 weeks of physical therapy (PT). Initial progress was significant, but after the eighth week, Mrs. Flower's progress became less evident, even negligible, to her. She started to believe that the therapy was not worth the pain and effort. Her physical therapist, Mr. Sam Plant, 43 years old and practicing for 15 years, adamantly disagreed. Fifteen weeks were likely to provide the best results for a future without significant movement impediment. He told Mrs. Flower that clinical research supported his view, and that she would face a long life with unneeded impairment by omitting a few weeks of additional therapy. Mrs. Flower agreed to give it two more weeks. During that two-week period, Mr. Plant constantly insisted that Mrs. Flower should continue therapy to its end. He ridiculed Mrs. Flower for her lack of foresight and indeed her foolishness if she refused. He also talked in an aggressive way, almost yelling. Mrs. Flower eventually

agreed to continue the therapy, and Mr. Plant continued to similarly pressure her to make sure she would keep her appointments.

#### CASE DISCUSSION

This case involves several conflicts of values. Mr. Plant apparently puts a high value on PT. Mrs. Flower seems to as well, given that she willingly participated for eight weeks. But she probably also values her own decision making, time, and effort. Mr. Plant is seemingly willing to compromise her ability to make an informed decision. We take Mr. Plant's actions to be a violation of informed consent. This compromise seems to involve a conflict between the welfare of Mrs. Plant and her autonomy. There may also be a conflict between Mr. Plant's actions and professional ethics. The aggressive treatment by Mr. Plant is probably a violation of a moral rule against coercion.

We are not given full information about the extent of Mrs. Flower's disability or about the likelihood and extent of further progress after the eight-week period except that the progress was less evident to Mrs. Flower. Mr. Plant mentioned evidence of the effectiveness of additional therapy, but we are not given details about that evidence. We are not told exactly what Mr. Plant said to Mrs. Flower, but we are told that it was aggressive. We are not told who Mr. Plant is working for and whether he might have a financial conflict of interest. If he were to suffer financial loss, directly or indirectly, this would be an additional conflict in the case. We also do not know whether Mrs. Flower is paying for the PT out of pocket or whether it is covered, in whole or in part, by health insurance. If she is paying some portion out of pocket, this would be an additional burden on her of PT.

Considered from a Kantian perspective, much of the missing information is probably unimportant. This is because consequences, for example, the extra good done by the additional PT, would not be of prime importance for a Kantian deontologist. A Kantian deontologist is likely to take a strong stand on informed consent and to reject undue interference with a patient's choice by way of coercive actions. Since Mr. Plant's behavior was "aggressive," it can easily be considered coercive. It is likely that from this deontological point of view, Mr. Plant's actions would be considered unethical even if the results of continued therapy were to be highly significant.

Still, the coercion was apparently done for Mrs. Flower's good, so the therapist's actions may be interpreted as beneficent. He probably believed that additional therapy was worth the additional cost. He talked about clinical studies, but we are not told what gains Mrs. Flower might have expected from additional sessions.

In effect, Mr. Plant was attempting to add to the costs Mrs. Flower would face if she stopped therapy. She had to face the fact her actions would negatively affect



Mr. Plant. He would be displeased with her; most people probably have a negative view about making another person unhappy. A deontologist would probably reject the extra cost placed on Mrs. Flower, the unhappiness Mr. Plant might experience, as well as the sense of humiliation or foolishness that she would be likely to feel if she stopped therapy. Even without these costs to Mrs. Flower, a deontologist would believe that overly aggressive attempts to influence a patient's decision are not morally appropriate.

We turn to utilitarian considerations. By the nature of utilitarian theory, the lack of information is serious. Utilitarians must determine the benefit and burdens, happiness and unhappiness, caused by an action. A utilitarian might believe that the value of therapy is best measured from a patient's perspective. After all, it is Mrs. Flower who would live with the benefits or burdens of continuing therapy. For this reason a utilitarian might believe that respecting a patient's choice is justified except in the face of easily predictable negative consequences.

Despite the fact that the consequences might best be evaluated from the point of view of the patient, a utilitarian is more likely than a deontologist to be concerned that the patient was improperly weighing present costs of additional weeks of therapy against many years of gains. Therefore, a utilitarian might decide that Mr. Plant was acting properly, in other words, that more good than harm was being done by Mr. Plant's actions. To reach this conclusion, a utilitarian would have to deal with the uncertainties of the gains and losses in this case.

We should quickly add that the effects of coercion by the PT are also difficult to predict. We might recall the case of *Shine v. Varga*, concerning a young woman with asthma who was forced into treatment, and then several years later died, arguably due to her subsequent fear of treatment. A utilitarian faces a number of unknowns, which can lead to problems with arriving at a moral decision.

A rule utilitarian is likely to object to coercive behavior in medicine because it tends to undermine mutual respect between health-care professional and patients and may encourage people to avoid needed health care. Harsh talk has no real role in medical care. In this case, Mr. Plant could have made his points without aggressive verbal behavior. It is legitimate for a health-care provider to try to influence a patient to do what is deemed in the patient's best interests, but ridicule and overly aggressive action are uncalled for. There is no clear and universal point at which influence crosses the line and become morally unacceptable, but in this case, it certainly appears that Mr. Plant's aggressive behavior went beyond acceptable influence.

A principlist would see this case as a conflict between the value of patient autonomy and beneficence. However, informed consent occupies a prime place in the theory. In this case, the good done by way of expected gain in mobility is not clearly

established. We conclude that a principlist is likely to reject Mr. Plant's behavior as unethical.

A care ethicist might view this case as stemming from the lack of respect given to a patient by a male health-care professional, or even a health-care system historically constructed and dominated by males. Mr. Plant might have been considerably less aggressive with a 59-year-old male. Instead, in this case, Mr. Plant could have negotiated with Mrs. Flower, something generally supported by care ethicists. For example, he could have offered to make the experience less difficult, say by playing her favorite music in the background, or by taking breaks, or even by applying physical pressure more gently.

Overall, it seems best to leave the decision up to Mrs. Flower and to assign the burden of providing accurate, respectful, and clear information to her therapist because that is his job, his role in providing health care. He has a license to practice that does not give him permission to coerce patients, but does, we assume, assign him the job of providing information.

In our opinion, most practicing physical therapists would reject the actions of Mr. Plant. Instead they would provide good information, perhaps the data relating to the clinical research referenced by Mr. Plant, offer ways to make PT less burdensome, and allow Mrs. Flower to make an informed decision. This view is supported by the American Physical Therapy *Code of Ethics for the Physical Therapist*.<sup>1</sup> The first principle of the Code is: "Physical therapists shall respect the inherent dignity and rights of all individuals."

#### QUESTIONS

1. What would you have done if you were Mrs. Flower?
2. Do you believe that Mr. Plant's actions were coercive? If so, should they be an exception to the moral rule against coercion?
3. Does it matter, in terms of a moral analysis, that Mr. Plant is a male and Mrs. Flower is a female?
4. Various theories could be used to evaluate the moral appropriateness of Mr. Plant's actions. Which theories are most likely to conclude that he did the right thing?

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1 [https://www.apta.org/uploadedFiles/APTAorg/About\\_Us/Policies/HOD/Ethics/CodeofEthics.pdf](https://www.apta.org/uploadedFiles/APTAorg/About_Us/Policies/HOD/Ethics/CodeofEthics.pdf).

5. From a moral point of view, what is the best defense of Mr. Plant's actions?
6. Did Mr. Plant violate Mrs. Flower's right to informed consent?
7. We deliberately ignored several conflicts in this case, such as the possible conflict of interest that Mr. Plant might have faced. Also, we did not fully explore the extent of possible gains to Mrs. Flower with increased therapy. Would such considerations affect your decision about this case?

## VII. Unwanted Procedure during Surgery

### INTRODUCTION

Our chapter introduction covered the basics of informed consent. However, some difficult issues arise that we did not cover. This is an advantage to studying cases, which are often complex and can show nuances about the demands of informed consent. In this case, the issue covered involves informed consent during surgery, when a patient is incapable of making an informed decision.

### CASE PRESENTATION

Ms. Sally Violet is a 21-year-old woman who has faced a series of difficult medical interventions for a variety of problems. Breast cancer (under control after surgery), kidney failure, pulmonary obstruction, diabetes, and liver disease are her main problems. Due to her circumstances, she is not likely to live for more than 10 more years. However, she is beginning to resist medical intervention. Her oncologist felt that her lung disease required surgery. Her parents, with whom she lives, talked her into this major surgery. She reluctantly agreed, but in return received a promise from her parents that they would not pressure her into any other intervention. This surgery, she insisted, would be the last intrusive procedure she would undergo. "It isn't worth it anymore," she said. Her doctors, including her surgeon, Dr. Stoer, know about Sally's attitude, and believe that her viewpoint is unfortunate.

Sally underwent surgery, but during the surgery Dr. Stoer unexpectedly discovered what appeared to be a malignant growth. Malignant or not, it needed to be removed because it could become life threatening. Given that Sally might reject another surgery, Dr. Stoer decided to seek permission from Sally's parents to remove the tumor, rather than waiting until Sally woke up and recovered. Although the tumor was potentially malignant, there was no urgent need to resect it at that time. In fact, the standard procedure would have been to close, give limited radiation, and

then resect or debulk the tumor. Sally's parents agreed to the extension of the surgery, as Dr. Stoer predicted they would.

Now, after the surgery, Sally feels betrayed. She believes that she might have a battery claim against Dr. Stoer because he fully understood that she did not want any additional procedures. Given that Sally is dependent on her parents financially and as caretakers, she does not think she will go forward with a lawsuit, but wishes she could. She does not blame her parents, because she understands their desire for her to live. But a professional, she says, should know better than to deny a person informed consent.

#### CASE DISCUSSION

We begin by addressing a common misunderstanding. It might be thought that if an additional procedure is required during surgery, then informed consent to the new procedure is not needed. This is not true, unless the new procedure involves a medical emergency. In Sally's case, we are told that this is not a medical emergency, and in fact the standard procedure would be to do the resection in an additional surgery. It is true that during surgery a surrogate may give permission if an additional procedure is needed. However, this case is about whether a surrogate's decision is morally appropriate.

It might be thought that Sally's rejection of additional interventions is unreasonable and that she is not capable of making an informed decision. Such assumptions are contrary to the intention of informed consent. Informed consent is partly based on the claim that a patient is the one who should decide about accepting interventions. Sally's decision is reasonable if she is competent and if it is based on her own stable value system, provided, of course, that she suffers no debilitating external or internal coercion. In this case, there is no indication that Sally is incapable of making an informed decision. We grant that there may be information we are not provided that would indicate a lack of capacity before her surgery, but given the information we have, she seems to be reacting in a reasonable way to her dire medical circumstances.

Sally's surgeon made the assumption that Sally would reject further surgery, and so he wanted to perform an additional procedure that Sally did not previously consent to. He denied Sally the opportunity to make a decision based on the particulars of the surgery, its benefits, its burdens, and what would occur without the procedure. With good information, Sally might have changed her mind about another intervention, which of course she has a right to do. In general, informed consent requires physicians to revisit decisions when the medical conditions change substantially, particularly when those changes are unexpected.

The surgeon made a serious mistake by failing to talk in advance about the possibility of the need for interventions beyond the planned one. Given this mistake to get consent for unexpected procedures, the surgeon may think that he was not given a clear directive by Sally. Her desire for no further intervention might not have included an extension of the surgery, given that she was already prepped and opened. We do not know whether she would have consented to additional procedures because there was no prior discussion of them.

Let us assume the following additional information: After the surgery, Dr. Stoer talked with a surgical resident about the issue. The resident thought that it was an open and shut case. After all, there was no urgency and the patient might have received better treatment if removing the tumor had been delayed. Dr. Stoer said that he understood, but he added that the resident was not taking into account the patient's preferences about another intervention. She would probably have rejected future surgery. He had the opportunity to give care, even if not optimal care. He claimed he had to balance the improbability of a second surgery against the clear good of resection before closing. The resident accepted the explanation.

Dr. Stoer is reasoning from the point of view of beneficence, a utilitarian position. However, he has a professional and legal obligation to ensure a proper informed consent process. This was not done. And his utilitarian reasoning was not well thought through. Recall that utilitarians ought to take into account all future contingencies, so we believe that even from a utilitarian perspective, Dr. Stoer did the wrong thing.

The surgeon did get consent from Sally's parents. However, a surrogate speaks for an incapable patient, in the interests of the patient. (Sally was temporally incapable due to the anesthesia.) A surrogate cannot negate the recently clearly expressed and well-known directives of the patient, and here the surgeon attempted to subvert Sally's decision making, which is morally inappropriate under the circumstances of this case.

Parents are not under the same obligation, legally and morally, to pursue informed consent as are health-care professionals. Parents face burdens from their children's diseases and benefits from effective therapies. Given the costs and gains of treatment and their hopes for their children, parents may legitimately put pressure on them. The same would hold true for spouses, when their partners face an illness. Although we say this strongly, we do recognize that some bioethicists would disagree. The real question involves the appropriateness of applying pressure in particular cases. If a parent forced a child into more expected suffering than benefit, such pressure would appear to be wrong, unless the additional suffering of the parents was great enough to offset the harm suffered by the patient. This is controversial, and some bioethicists would reject considering the parents' suffering. Sally herself judged

that the suffering from additional interventions, given the life she is leading, was not worth it. Her parents should, at the least, have taken her view carefully into account.

In this case it is not completely clear whether Sally would have rejected the extension. At least it was not clear to the parents at the time the surgeon asked for permission. Given this uncertainty, we think it is difficult to blame the parents for their decision, since they were trying to protect their interests as well as their daughter's. The physician chose to keep the patient under anesthesia, and it was the physician who set up the improper structure for the choice.

A care ethicist might object to the physician's decision based on the power structure in place. From this perspective, the appropriate path would have been to negotiate with the patient about additional procedures, preferably before the surgery. Given the failure to discuss additional procedures prior to the surgery, negotiation should have occurred after the surgeon closed without performing the additional procedure.

In the case as presented, the extension of the surgery was not urgent. But let's suppose instead that during the surgery Dr. Stoer had found a problem that *was* urgent. If not attended to, Sally would likely have died soon after or even during the surgery. The problem, let us assume, was partly a result of the surgery but was not caused by negligence on the part of the surgeon.

If such a problem had arisen during surgery, the surgeon should have corrected the problem. Whether or not the parents had given permission, in this life-and-death situation the surgeon should have proceeded to rectify the problem. If the parents had been asked and had objected to the new procedure, the surgeon would not have had time to try to convince them or to investigate the cause of their rejection. Given time constraints, it would have been best to proceed with the life-saving measure. Such intervention would be covered by the emergency exception.

The surgeon would probably not be found legally liable by a jury under battery or negligence for ignoring Sally's well-known desire not to have additional interventions. This is difficult to determine, however, in advance of the adjudication of a lawsuit. Although Sally's claim may seem clear, "additional intervention" may not mean a second procedure during a surgery. The surgeon probably needed permission, legally speaking, to do the second procedure, but the surgeon did get permission from Sally's parents. In most states, a lawsuit would not go forward as battery, in all likelihood, but as negligence. Given that Sally benefited medically from the intervention, as seems to be the case, it is unlikely that the surgeon would be liable even if Sally went ahead with a lawsuit. However, if the case went forward as a battery claim, Sally might or might not be successful in a lawsuit.

## QUESTIONS

1. In our case analysis we claimed that Dr. Stoer did the wrong thing even from a utilitarian perspective and that a utilitarian would have to take more into account than he did. Do you agree? Why or why not?
2. Is Sally's rejection of treatment reasonable? (To answer this question you might want to check out the meaning of *reasonable*.)
3. Do you agree that parents are not under the same obligations as physicians in terms of respecting the wishes of a patient? Why or why not?
4. Do you believe that the extra procedure in the surgery was an additional intervention?
5. Do you believe that Dr. Stoer should have been sued for negligence?
6. Which moral theory is most likely to support the actions of Dr. Stoer?

## VIII. Elderly Man Denied Informed Consent

### INTRODUCTION

It is understandable that children want to protect their aging parents. This might include keeping from them bad news about a devastating medical diagnosis. Sometimes a person faces nearly sure death, so being informed seems as though it cannot be helpful. Nevertheless, this may deny rights to an elderly person, pitting deontological considerations against seemingly benevolent concerns. The circumstances of the case we will examine are not especially unusual, making any judgment about its moral legitimacy all the more important.

### CASE PRESENTATION

Mr. Delrey had bone cancer. He was 92 years old and was otherwise in good health and alert. He was fully capable of making decisions. His 60-year-old daughter, with whom he lived, believed that he should not be told that his condition was terminal but instead that he should be kept as comfortable as possible in his final days, without aggressive, potentially life-prolonging therapy. Mr. Delrey's physician agreed that palliative care was an appropriate course for Mr. Delrey. He decided not to inform Mr. Delrey about medical alternatives or that he had terminal cancer. Although he

soon suffered significant pain, the pain was largely resolved within a few weeks due to palliative treatment. He died in a relatively peaceful way four months later.

#### CASE DISCUSSION

We are not told about Mr. Delrey's attitudes toward death and dying, if any. This might be important in terms of determining the legitimacy of the physician's denial of information to Mr. Delrey. A patient is not obligated to participate in the informed-consent process and may indeed relegate decision making to others or to the health-care team. Since we are not told about prior wishes, we will assume that he has not expressed his desires about death and dying.

Many people do not want to face a long dying process involving pain and suffering and instead opt for palliative care. Some opt for physician-assisted suicide, as practiced in states such as Oregon. But this sentiment is not universal. Some people want to live as long as possible; some want to experience special events, to have time to make arrangements, to see old friends and relatives, and so on.

Mr. Delrey's daughter probably had her father's best interest in mind. It is also possible—but this we do not know—that his daughter had an interest in his early death. She might have found it difficult to live with her father, or she might have stood to experience financial gain from his death. For our analysis, we assume good will on her part; however, the physician should not make this assumption. An inquiry into her motivations might have been in order because a conflict of interest on her part might have meant that she was not conveying her father's preferences.

The goal of keeping Mr. Delrey as comfortable as possible seemed to be a good one. However, aggressive therapy might have kept him alive for extra weeks or extra months. Mr. Delrey's age alone should not have been a reason to keep him from making decisions about his own care. Allowing the daughter to make decisions for her capable father was not morally or legally appropriate. In this case consequentialist considerations give way to a patient's rights.

Mr. Delrey's daughter was not the only one to negate Mr. Delrey's rights; his physician did so too. A daughter, however, is not under the same moral and legal obligations as a physician. Physicians have an obligation to provide a patient the right to an informed choice. Nothing in this case indicates that Mr. Delrey opted out of the informed-consent process, so the physician's actions were not morally acceptable.

Even though we believe that the daughter did not do the right thing, we are reluctant to place heavy moral blame on her, as she was probably trying to protect her father in an understandable way. The major blame rests with the physician.

The physician might have feared a lawsuit if he had not followed Mr. Delrey's daughter's instructions. A lawsuit seems to have been unlikely, but possible, if the



physician had informed Mr. Delrey against the wishes of the daughter. But in fact a lawsuit is still possible, perhaps by other family members, since the physician did not inform Mr. Delrey. Given Mr. Delrey's age and condition, he was unlikely to sue. Despite physicians' fears of lawsuits, they should not act according to that fear. The morally and legally appropriate thing to do in this case seems to have been to inform Mr. Delrey. Clearly, doing the morally right thing is often difficult.

#### QUESTIONS

1. Suppose that Mr. Delrey had previously told his daughter that he would not want to die in pain, and would seek palliative care when faced with a painful death. Would this statement justify the actions of the physician and Mr. Delrey's daughter?
2. Do you agree that the actions of the physician were unethical?
3. What would a care ethicist say about the daughter's actions?
4. How would a principlist evaluate this case?
5. Does the therapeutic privilege apply to this case?
6. Suppose the daughter claimed that not telling her father was in line with his religious or cultural beliefs—would that make it ethically permissible to withhold information? (This may be true of various cultural groups, including some Native Americans.)

## IX. HIV Patient: Confidentiality Hampering Informed Consent

#### INTRODUCTION

This case is about achieving optimal results by finding paths around obstacles to a good resolution. It follows the actions of a bioethicist who eventually reaches a decision that can be supported by many of those involved. Moral dilemmas in which there is a conflict of values involve a loss of value if one or the other of the conflicting values is supported. Finding a solution that resolves the conflict often provides the best result. In this way none of the originally conflicting values are sacrificed. This is the outcome of the current instructive case about an HIV patient who wants confidentiality.

## CASE PRESENTATION AND DISCUSSION

Tom Sherrington, a 28-year-old male with HIV, requested that none of his family members or friends be told about his health status. This was acceptable to the health-care staff until Tom became acutely ill, often going in and out of consciousness. The team worried about needing additional interventions if Tom became unable to communicate consent. Getting fully adequate consent from family members, for example his mother or father, might or might not require that the surrogate be provided details of Tom's disease. Such information would, against Tom's wishes, compromise confidentiality. If he reached a point where confidentiality became an issue, the team would have to face the possible dilemma of acting without fully informed consent from a proxy, or, in effect, becoming Tom's proxy.

A resident, Dr. Sheila Stanford, decided that the best approach would be to get Tom's permission to ask a family member for consent, if needed. Tom was able to communicate, just barely. His voice was extremely weak, but he could be understood. Dr. Stanford repeatedly asked Tom whether his family could be told about his illness. He repeatedly denied the request.

It might appear that Dr. Stanford did an adequate job of trying to get Tom's permission to inform a family member. She repeatedly asked Tom whether notifying a family member would be acceptable to him. He repeatedly rejected it.

Part of a bioethicist's job is to find ways around problems. The ideal would be to get Tom's freely offered consent to provide information to his surrogate. Although Dr. Stanford spent time with Tom and did ask the question repeatedly, she might not have provided Tom with enough information about why they needed permission, and there might have been alternatives to telling the family that were not covered.

Upset that they didn't get any further on the issue of designating a proxy, the team decided to call for a bioethics consult. Dr. Harry Sutton, who holds a PhD degree in philosophy, responded to the call. Dr. Sutton then interviewed Tom, even though he was told about the results of previous communication with him.

By the time of the interview, Tom's condition was more serious and he could no longer verbally communicate, partly due to his tracheotomy. At first Dr. Sutton thought that Tom was unaware of his surroundings and almost decided that an interview would not be productive. Even if Tom awoke and responded, his responses might not represent his true wishes, due to medications and the disease process.

But soon Tom responded. Dr. Sutton decided that Tom might be able to engage meaningfully in an interview, though he was somewhat skeptical. Dr. Sutton first explained who he was, why he was there, and asked Tom if he felt OK. Tom nodded "yes." Dr. Sutton asked several other questions, such as whether he wanted to

continue talking, all of which Tom responded to in the same way, with a positive head movement.

The bioethicist worried that Tom might be responding to all questions in the same way, so Dr. Sutton next asked a question that Tom responded to negatively, better indicating that Tom did understand. Still, he might have been responding in instinctive ways, without understanding. For this reason Dr. Sutton thought it might be premature to ask about his family. Instead, he asked whether Tom understood the importance of a proxy decision maker and the need to disclose information that might identify the source of his illness. The resident had omitted this from her interview with Tom.

After being reasonably sure that Tom understood the importance of proxy decision making and the possible need to divulge information about his illness, Dr. Sutton decided to ask Tom if it would be OK to inform his family if the need arose. Tom gave a negative response.

It might seem that further questions would not have been helpful. But in such cases there may be other alternatives; good bioethics involves finding ways out of dilemmas, if such ways exist. If there was some way to get Tom's approval for notifying someone outside the family, that might lead to a successful resolution of the issue.

Dr. Sutton asked Tom whether anyone within the family could be informed about his condition. He was surprised when Tom gave an affirmative answer. This also made Dr. Sutton suspicious that Tom might not understand what he was indicating. Regardless, he continued by going down the list of family members. Tom rejected all except a cousin, Alice, a history professor in a nearby university, someone who was thought of as a sort of renegade by the rest of the family. He positively responded to questions about providing her information about his HIV status, should that need arise.

It may be tempting to conclude that the solution had been found, but it is important to keep in mind that Tom was ill and was communicating only in a binary way, with "yes" or "no." With limited communication, misunderstanding is surely possible, maybe likely. Also, Tom was under heavy medication and might not really understand what he was communicating. So Dr. Sutton decided to ask more questions.

Dr. Sutton asked Tom whether it was all right to tell Alice that he had HIV, if the need to do so arose. Tom accepted that. Dr. Sutton asked whether there was anyone else in the family who might be similarly informed. Tom indicated that there was not. Dr. Sutton also questioned Tom about friends. Tom again gave a negative response. Dr. Sutton continued the interview until he was convinced that Tom's

willingness to use Alice as a surrogate was his preference. He subsequently informed the health-care team that Alice could serve as Tom's proxy but that she should be informed about Tom's condition only if that were required in the informed-consent process.

It may or may not be the case that Alice, or someone else in a similar circumstance, would tell other family members. There is no guarantee she wouldn't. Maybe Alice, since she was considered a renegade, would be less likely to tell than some others, but there was no guarantee. Dr. Sutton could only do his best. He had to rely on the patient's judgment about Alice and disclosure of information to her. Dr. Sutton advised the health-care team that Alice should be warned about telling others; that, he thought, was the best that could be done in this circumstance.

This case was successfully resolved by Dr. Sutton. His experience with informed-consent discussions in difficult circumstances, part of a consultant's job in a large hospital, allowed him to break the apparent impasse.

Although Dr. Sutton dissolved the dilemma, circumstances might have been different. If Tom consistently insisted that he did not want anyone told, Dr. Sutton would have had to inform the health-care team that Tom did not want anyone to know about his HIV status. In the event that Tom was no longer capable, the health-care team could provide other relevant information about the problem that needed treatment, say pneumonia.

Dr. Sutton would need to have checked to be sure that he understood his state's law about disclosing information relating to a patient's HIV status. If the law prohibits such disclosure, then the informed-consent process with a surrogate should not include that information, but could include other information, for example, that Tom had pneumonia. (It turns out that in Tom's state, the law does not prohibit disclosure under such circumstances.)

#### QUESTIONS

1. Would it have been morally appropriate to end questioning after the resident questioned Tom?
2. Two weeks after Dr. Sutton made his suggestions to the health-care team, the case concerning Tom was presented to the bioethics faculty of the hospital. This was a routine review to help avoid mistakes in the future and to provide mutual instruction. During the review, Dr. Sutton observed that he thought Tom might have approved of informing Alice due to fatigue. After all, he was very ill and had been asked many questions. On questioning by his peers, Dr. Sutton observed that he thought the chance that Tom did not provide a considered acceptance

of Alice was at least 1 in 10. One of Dr. Sutton's colleagues gently reprimanded him, saying that Dr. Sutton was "rolling dice" with Tom's right to confidentiality. Dr. Sutton was visibly upset with his colleague, and in a relatively rude way said that he got the best resolution possible. Do you agree with Dr. Sutton or with his colleague? That is, did Dr. Sutton "play dice" with Tom's rights, or did he get the best possible resolution? Fully explain your answer.

3. Did Dr. Sutton push the questioning too far?
4. In the case analysis, we mentioned the value of finding ways to avoid dilemmas. What was the dilemma in this case?